PROJECT ON DEATH IN AMERICA

JULY 1994 - DECEMBER 1997

The experience of dying has changed over the past several decades, with many more people enduring prolonged deaths as a consequence of chronic, progressive disease. Needless suffering—physical, emotional, existential, and spiritual—too often accompanies these deaths, for both dying persons and survivors. The mission of the Project on Death in America is to understand and transform the culture and experience of dying and bereavement through initiatives in research, scholarship, the humanities, and the arts, and to foster innovations in the provision of care, public education, professional education, and public policy.

Project on Death in America
Report of Activities
July 1994 – December 1997

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REPORT OF ACTIVITIES

JULY 1994 – DECEMBER 1997

The Project on Death in America is a program of the Open Society Institute, a private operating and grantmaking foundation that promotes the development of open societies around the world. OSI develops and implements a variety of U.S. and international programs in the areas of educational, social, and legal reform, and encourages public debate and policy alternatives in complex and often controversial fields. OSI is part of an informal network of 31 autonomous nonprofit foundations created by philanthropist George Soros in Central and Eastern Europe, Mongolia, South Africa, Haiti, Guatemala, and the United States.

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REFLECTIONS ON DEATH IN AMERICA

BY GEORGE SOROS

CHAIRMAN, OPEN SOCIETY INSTITUTE

George Soros

MY father died at home in 1963. He was terminally ill. Although he agreed to an operation, he didn't particularly want to survive it, because he was afraid that the combination of the illness and the operation would invade and destroy his autonomy as a human being. Unfortunately, that in fact is what happened. After the operation he had very little time left. I'm afraid I kind of wrote him off at that point. I was there when he died, yet I let him die alone. I could see him, but I wasn't at his bedside. The day after he died I went into the office. I didn't talk about my father's death. So I kind of denied his dying, I certainly didn't participate in it.

My mother's death was more recent. She had joined the Hemlock Society and had at hand the means of doing away with herself. I asked her if she needed my help; I offered it, although I wasn't particularly keen to do it. But I would have helped her because I felt that I owed it to her. At the point of decision, however, she did not want to take her own life, and I'm glad she didn't. Her decision gave the family a chance to rally around her and be there as she prepared to die. And this time we did maintain good contact right to the end.

She had this experience, which is described in Kubler-Ross, of walking up to the gates of heaven, and I was accompanying her. She told me she was worried that she might drag me with her. So I reassured her that I was firmly ensconced on this earth and she should not worry. Her dying was really a very positive experience for all of us because of the way she handled herself and the way the family, not just me but particularly my children, could participate in it.

These personal experiences with the deaths of my parents are two of the reasons I established the Project on Death in America to promote a better understanding of the experiences of dying and bereavement and by doing so help transform the culture surrounding death.

Through its Faculty Scholars Program and Grants Program, the project supports initiatives in research, scholarship, the humanities, and the arts, as well as innovations in the provision of care, public education, professional education, and public policy.

What do we want to transform and why? An explanation begins with a small matter, the name of our project. It took a considerable amount of discussion to rid ourselves of clever euphemisms and settle on a name that states our purpose directly, even starkly: the Project on Death in America.

In America, the land of the perpetually young, growing older is an embarrassment, and dying is a failure. Death has replaced sex as the taboo subject of our times. Only our preoccupation with violence breaks through this shroud of silence.

Even doctors, especially doctors, don't like to think about death. A federal pamphlet for physicians about treating people with HIV infection recommends making arrangements for the care of the children when the patient becomes sick, but says nothing about the need for long-term plans for when the patient dies. It is easier to find descriptions of the way people die and what can be done to ease their death in the medical textbooks of the turn-of-the-century than in today's voluminous literature on the treatment and cure of diseases.

"We have created a medical culture so intent on curing disease and prolonging life that it fails to provide support during one of life's most emphatic phases—death. Advances in high-technology interventions have deluded doctors and patients alike into believing that the inevitable can be delayed almost indefinitely."

This emphasis on treating disease, instead of providing care, has altered the practice of medicine. People live longer, surviving four or five illnesses before dying. But the health care bill grows with every illness. Our success has also brought other unintended consequences. We have created a medical culture that is so intent on curing disease and prolonging life that it fails to provide support during one of life's most emphatic phases—death. Advances in high-technology interventions have contributed to this weakness in our medical system, deluding doctors and patients alike into believing that the inevitable can be delayed almost indefinitely.

The reality of death and the perceptions of the participants—the dying person, the doctor, the family members—are separated by a wide gap. We need to bring the two into closer alignment. Doctors who are on a first-name basis with disease must re-acquaint themselves with the patient. They must recognize that, by focusing exclusively on conquering disease and prolonging life, they abandon the dying when, in their own words, there is nothing more to be done. They must come to terms with their own death in order to provide proper care for the dying.

Eighty percent of people die in hospitals, yet, for most people, hospitals are not a good place to die. Hospitals are set up to take care of acute illnesses, and dying is not an illness. It doesn't belong to an official medical category, it has no DRG that would permit reimbursement for the hospital and the physician. If you go to a hospital to die, the doctors have to find something wrong with you, something to treat, like pneumonia or dehydration, or they cannot admit you. They hook you up to tubes and machines and try to fix a condition that isn't fixable. The need to arrive at a reimbursable diagnosis changes the reality. The doctors and nurses are working to prolong life, instead of preparing a patient for death.

The ideal of a peaceful death is more likely to be achieved at home in familiar surroundings that are more conducive to the comfort and ritual of leave taking from family and friends. Only 20 percent of people die in their own home, in a nursing home, or in a hospice. Hospices offer the kind of palliative care that should be routine procedure in every institution that cares for the dying. Proper care includes the control of pain and other symptoms as well as attention to the psychological and spiritual needs of the patient.

But the hospice alternative, unfortunately, is not available to the majority of dying patients. Medicare coverage is limited. As a result, most hospice programs deliver care to the dying in their own home, restricting custodial services to only four hours a day. This requires the presence of a family member who doesn't work, who is physically able, and who is willing to assume the responsibilities for care the rest of the time.

The recommendations that follow from these observations are obvious. First and foremost, doctors, nurses, and other health professionals need better training in the care of the dying, especially in the relief of pain. Health professionals also need training in alleviating the psychological, emotional, and existential suffering that may accompany dying. Physical pain is what people fear most about dying. A dying person in pain cannot think about anything else, leaving no room for coming to terms with death, for reviewing one's life, putting one's affairs in order, for saying good-bye. Therefore, pain relief must come first. Doctors often under-medicate their dying patients for fear of turning them into drug addicts.

Second, hospitals must be required to develop and adopt a comprehensive DRG for terminal care. This single change would go a long ways toward removing the hypocrisy that now surrounds a hospital's treatment of the dying and freeing doctors and nurses to provide the kind of care that doesn't rely on technology—such as the simple act of paying attention to a dying person, holding their hand, listening, and comforting them.

Third, we must increase the availability of hospice services for terminally ill patients, removing restrictions on admittance and enhancing reimbursement regulations. We should consider laws that permit next of kin to decide to forgo life-sustaining medical interventions even when a patient's wishes are not known. The government may have to help family members financially so that they can take care of the dying at home by the least expensive means. These are only a few of the approaches to transforming the culture of dying that our project is exploring.

How much will all this cost? Can we afford to care for the dying properly? The number of people dying in the United States currently stands at 2.2 million annually. Increases in cancer and AIDS deaths and the aging of the baby boomers will cause this figure to climb faster than the population. Today 1 in 8 Americans is 65 years or older. In 30 to 40 years, 1 in 5 will be in that age group. The average life expectancy for those reaching age 65 is already 81 for men and 85 for women. The fear is that the care of the dying elderly will drain the national treasury. Like most fears, this one is based on a myth, the popular perception that elderly, terminally ill patients consume enormous amounts of resources shortly before they die.

It is true that nearly half of all medical expenses are incurred in the last six months of people's lives. But it is also true that medical expenditures in the last year of life are lower for people 80 years and older than for those in younger age groups. Aggressive, life-prolonging interventions, which may at times go against the patient's wishes, are much more expensive than proper care for the dying.

This brings me to that hotly debated subject, physician-assisted suicide and euthanasia. This is the one aspect of dying that is talked about everywhere—on television, in public forums, in newspaper headlines and serious journal articles, and in the courts. I believe in personal autonomy; I believe people should be allowed to determine their own end. But I also recognize that legalizing euthanasia could have unintended consequences, leading to all kinds of abuses. The issues need to be carefully weighed. Very few terminally ill patients would avail themselves of the opportunity even if euthanasia were legalized. After all, my mother refused my help, and I am glad she did. The Project on Death in America concerns itself with the vast majority of people who are not looking for physician-assisted suicide, and they have their work cut out for them.

As people come to terms with death, recognizing it as a fact of life, then the demand for physician-assisted suicide, as well as for unnecessary medical interventions, will drop. That is one way I hope our efforts will influence the culture of dying.

This essay was adapted from a speech at the College of Physicians and Surgeons of Columbia University in November 1994 soon after the establishment of the Project on Death in America.

Comfort Care
York, Pennsylvania

IMPROVING THE CARE OF THE DYING

BY KATHLEEN FOLEY, M.D.

DIRECTOR, PROJECT ON DEATH IN AMERICA

Kathleen Foley, M.D., with Marcia Angell, M.D., and Timothy Quill, M.D., at a conference on dying.

FROM July 1994 to December 1997, the Project on Death in America provided funding for programs and individuals to address, through research and model systems of care, the barriers modern society and medicine face in providing appropriate, compassionate care of the dying. Through our Grants Program and Faculty Scholars Program, we have focused attention on a wide range of initiatives that reflect the complex issues of our death culture. The grants and faculty scholars' programs described in this report show how much excellent work is being done—and how much more needs to be accomplished.

The activities of PDIA and its network of grantees and scholars, as well as the work of many other funders and organizations, are improving care for the terminally ill and their families and raising public awareness and discussion about death and dying. Death is no longer the taboo subject it was when George Soros established PDIA three years ago. People are beginning to think and talk about America's culture of dying, about how we die and how we want to die. Professional journals and the popular media are devoting increasing amounts of space to covering the issues surrounding dying and bereavement.

A focal point of much of the initial coverage was the medical, legal, and ethical debate over physician-assisted suicide. PDIA participated in this debate by calling attention to the larger issues that the movement for physician-assisted suicide both reflects and conceals. The project filed an amicus brief in two Supreme Court cases concerning physician-assisted suicide, arguing that the Court should not find a constitutional right to such assistance until we, as a society, have taken measures to assure that the terminally ill who consider suicide are not motivated by the failure of doctors to treat their pain or depression, or by economic fears.

In June 1997, the Supreme Court, rejecting arguments for a right to physician-assisted suicide, agreed with us and went even further to support, in essence, a right to palliative care. To make this right a reality, PDIA remains committed to improving medical care for the dying and reducing the enormous burdens placed on their caregivers. We must promote better communication between doctors and patients, establish humane guidelines for withdrawing or withholding treatment, and educate all physicians about the principles and practices of palliative care.

One of PDIA's first-year grants supported an exhibition, "Hospice: A Photographic Inquiry," which opened at the Corcoran Gallery of Art in Washington, DC, before embarking on a 15-city tour through the year 2000. Its images by five quite different photographers provide the media and the public with a more positive view of how we die. Hospice offers the kind of palliative care every dying person deserves. As Vicki Goldberg, writing about the exhibition in the *New York Times*, defined the hospice mission: "The goal of hospice is to manage physical pain for the terminally ill so that psychological and spiritual pain can be attended to and the business of life—love, anger, wounds, regrets, loss, matters unfinished and unsaid (and hitherto unsayable)—can be wrapped up as peacefully as possible."

Hospice or palliative care was the focus of a large number of the close to 2,000 requests for grants that the project received, as well as the 87 programs we selected for funding. Three hospice grants went to support the care of dying homeless men and women in special homes in Washington, DC, and Cleveland, Ohio. By creating respectful and loving communities and hospice care, these programs serve as models for end-of-life care for vulnerable populations. They demonstrate the need for better reimbursement programs to prevent the marginalization of the dying poor.

Two other issues that received a fair amount of support from PDIA were advance directives and bereavement counseling under a range of circumstances, including sudden and violent death. A study by the Center to Improve Care of the Dying showed that physicians often do not know about a patient's advance directive (not to be resuscitated, for example) or they do not adhere to the directive. We gave the center a grant to develop a broader process of advance care planning aimed at improving communication.

PDIA awarded a grant to Health Force: Women and Men Against AIDS, which helps grieving individuals write "Dear Death" letters as a way of coming to terms with their loss. PDIA also cosponsored two nationwide teleconferences on grief in relation to sudden loss and prolonged death organized by the Hospice Foundation of America.

Care of terminally ill children presents difficult problems to physicians, parents, and caregivers. In an example of community empowerment, a foster care program in Brooklyn, with support from PDIA, is establishing guidelines for hospice care for children with AIDS. One of our faculty scholars is studying how doctors make the decision to transition from curative care to palliative care when the dying patient is a child.

Thirty-eight faculty scholars were selected by PDIA from July 1994 to December 1997, forming a network of physicians and nurses who will lead the transformation of end-of-life care through their initiatives in clinical practice and research. Their programs focus on creating innovative models of care and developing new curricula. Each year, the faculty scholars confer at seminars on important end-of-life issues and disseminate the results of their own work.

In addition to its Grants Program and Faculty Scholars Program, PDIA launched a number of special initiatives to further its mission. Among these was the creation, in collaboration with other foundations, of Grantmakers Concerned with Care at the End of Life. This new coalition will increase foundation interest and support for programs working on dying and bereavement by organizing conferences and sharing information. Other special initiatives included the organization of conferences that would bring together people in the health care professions to establish standards for the care of the dying and priorities for teaching end-of-life care.

As this report of the project's work tries to show, the culture and care of the dying is a wide-ranging, complicated subject that requires broad public discussion—"death talk"—to achieve true improvement and real choice in the way we die.

GRANTS PROGRAM

Day of the Dead
San Francisco, CA

DURING the period covered by this report, the Grants Program of the Project on Death in America supported innovative approaches to understanding and changing the process of dying and bereavement. The program encouraged efforts in the following areas:

- Epidemiology, ethnography, and history of dying and bereavement in the United States
- Physical, emotional, spiritual, and existential components in dying and bereavement
- Contribution of the arts and humanities
- New service delivery models for the dying and their families and friends
- Educational programs for the public about death and dying
- Educational programs for the health care professions
- The shaping of governmental and institutional policy

Epidemiology, Ethnography, and History of Dying and Bereavement in the United States

The Project on Death in America supported research and analyses of the social forces, past and present, affecting the process of dying, especially as they provide the foundation for change: where and how death occurs, and under what social and medical conditions; the services that are delivered to dying persons and their families, at what expense, and under what types of legal and ethical guidelines; how different communities and different cultural, religious, and socio-economic groups respond to the process of dying and grieving; how health care professionals predict outcomes, including death and suffering, how the plan of care develops, and how it unfolds.

Barnard College

Columbia University
New York, NY
Lesley A. Sharp, Ph.D.

$16,300

Cross-cultural Dimensions of Death and Mourning in Relation to Organ Donation

Organ donation in the United States currently relies upon Universalist assumptions about death and often downplays cross-cultural differences in grief and mourning. Procurement professionals assume that donation eases or shortens the period of grief for a donor's surviving kin, who are comforted knowing that their loved one lives on in anonymous strangers. Yet preliminary research reveals that the donation process alters grieving and may in fact prolong and even intensify the period of mourning.

This anthropological project is investigating cross-cultural differences toward death and mourning among Hispanics, African Americans, and Anglos in Manhattan, comparing professional attitudes to lay beliefs, with the objective of suggesting future policy and training guidelines for procurement professionals.

Baystate Medical Center

Springfield, MA
Lewis M. Cohen, M.D.

$137,656

Dialysis Discontinuation: The Decision to Die and the Quality of Dying

Once kidney function in people with kidney disease falls below 10 percent of normal, dialysis therapy or transplantation is required to sustain life. Some patients with degenerative medical conditions and their families choose to discontinue dialysis. Unlike many cases in which life-sustaining systems are discontinued, a substantial number of dialysis patients are alert and capable of making their own medical decisions.

In this bioethical, psychiatric, and clinical study, approximately 100 patients with end-stage kidney disease will be observed and evaluated to explore their decision to terminate life-sustaining kidney dialysis treatment and to examine the quality of death that ensues.

In a smaller pilot study, Dr. Cohen found that patients and their families usually made the decision to stop treatment because of progressive deterioration, often sought spiritual counseling in making the decision, did not view the decision as being a suicidal act, and did not appear to be unduly influenced by psychiatric disorders such as depression. Seven of 11 patients were judged to have had a "good" death, dying shortly after stopping dialysis without evident physical or psychological suffering.

Center for Ethics in Health Care

Oregon Health Sciences University
Portland, OR
Susan Tolle, M.D., and Virginia Tilden, R.N., D.N.Sc.

$8,000

Planning Meeting for Research on End-of-Life Care in Oregon

$150,000

Research on End-of-Life Care in Oregon

In November 1994 and again in November 1997, voters in Oregon approved the legalization of physician-assisted suicide. The new law has changed the health care environment in the state. Five months after the 1994 vote, hospice directors reported a 20 percent increase in referrals and hospitals had started expanding comfort care resources. Oregon, with its progressive living-will legislation, its highest-in-the-country rate of DNR documentation in nursing homes, and its physician-assisted suicide measure, is an ideal setting for this study of end-of-life care in acute care hospitals, nursing homes, and homes/hospices.

The investigators will interview the service providers and families of persons recently deceased to collect data about, among other things, the prevalence of advance directives, the extent to which deaths followed such advance planning, access to hospice, preference for location of death vs. actual location of death, degree of suffering and effectiveness of comfort care, family satisfaction with care and barriers to compassionate care.

Dartmouth-Hitchcock Medical Center

Dartmouth College
Norris Cotton Cancer Center
Hanover, NH
Marguerite M. Stevens, Ph.D.

$100,000

Multimethod Research to Understand the Experience of Dying in Seriously Ill Adults

Multimethod, cross-disciplinary analyses will be developed to understand the dying experiences of seriously ill adults through analyzing patient and family reports of severe pain and developing descriptive models of "good" and "bad" dying from the viewpoints of the patient and family. Some of the innovative methods used in this study of 132 cases will be from an already successfully developed pain intervention database titled, "The Study to Understand Prognoses and Outcomes and Risks of Treatments" (SUPPORT), which integrates and summarizes findings via the use of interview, narrative, and quantitative data.

With new understanding, the project hopes to influence changes in the quality of dying and the existing culture of the dying experience through public and professional education. The completed analyses will contribute to books that the Center to Improve Care of the Dying is committed to writing for the public.

Indiana University

Regenstrief Institute
Department of Medicine,
Regenstrief Health Center
Indianapolis, IN
Gregory P. Gramelspacher, M.D.

$146,185

Dying Poor: End-of-Life Care in a Public Hospital System

Through interviews with community focus groups, dying patients, their families, and health care providers, the researchers will add to the knowledge of the complex terminal care issues faced by the dying poor and their families. The study will describe the particulars of death; availability and use of support services; physical, psychological, and spiritual experiences; and unmet needs. It will examine the intersection of death with poverty, race, culture, spirituality, and health care.

Poynter Center for the Study of Ethics and American Institutions

Indiana University
Bloomington, IN
David H. Smith, Ph.D.

$35,000

The Social Face of Death

Attempts to improve the lot of dying Americans have focused on institutional issues, including hospital protocols and doctor training, and legal and ethical issues surrounding physician-assisted suicide. These issues, while important, may have distracted us from social, personal, and religious issues of greater significance to the dying: the difficulties of communication within the family; the prolongation of the dying process; the financial burden. The Poynter Center will conduct an ethnographic study of the residents of four diverse Indiana communities to better understand the meaning that ordinary people attach to death.

Stanford University
Center for Biomedical Ethics
Palo Alto, CA
Barbara A. Koenig, Ph.D.

$154,116

Dying in an African American Community

The bioethical practices governing end-of-life care which have evolved over the past 20 years are not meeting the needs and desires of African Americans, who often voice preferences about terminal care which differ from whites. This ethnographic study of death across the life cycle in an African American community in California will attempt to learn why African Americans tend not to use services such as hospice and home care, and why many African Americans shun bioethical practices such as advance directives.

The study will document the experience and process of dying in four age groups for both preventable and inevitable deaths. Insights from the study will prove helpful in educating health care professionals, improving clinical care, and developing end-of-life policies sensitive to cultural differences.

Staten Island University Hospital
Geriatric Fellowship Program
Gerontology Department
Staten Island, NY
Barbara Malach, M.D.

$25,000

End-of-Life Issues Among the Elderly Russian Immigrant Population

Elderly Russian immigrants face not only the difficulties of residing in a new environment but also the issues of aging in a strange land. Approximately 2,000 Russian patients over the age of 65 visit this not-for-profit, 633-bed, multisite health-care delivery system per month. The project will assess the Russian immigrant population's attitudes, beliefs, and knowledge regarding dying and bereavement and develop a culturally sensitive, educational program regarding these issues for patients and health care professionals.

Strong Museum
Rochester, NY
G. Rollie Adams

$90,000

Memory and Mourning: American Expressions of Grief

This unique exhibition combines historical artifacts and documents, images, and interactive stations to examine the cultural history of grief and its expression in America since the middle of the nineteenth century. *Memory and Mourning* will travel to approximately ten museums over a three-year period with support for public conferences, school lessons, and other educational programs at each of the host museums.

After the bombing, an Oklahoma City teacher told of a children's game in which several children dressed up as rescue workers and pretended to go into a bomb site. When they returned with a living victim, the other children cheered. When they recovered dead bodies, the children grieved and held a funeral—after which they simply sat, not knowing what to do next.

University of California-San Diego
Department of Family and Preventive Medicine
La Jolla, CA
Lawrence J. Schneiderman, M.D.

$149,437

A Comparison of Treatments Provided to Terminally Ill Patients in Managed Care and Fee-for-Service Settings

Advocates of managed care claim that health plans will lead to improvements in care and reductions in cost by encouraging physicians to do more to educate terminally ill patients and their families about the likely course of the illness and the poor quality of life that may result from attempts to prolong life; and by emphasizing home care and hospice options in helping the terminally ill prepare for death.

Critics contend that, in their zeal to reduce costs, managed care organizations will withhold a wide variety of hospital services and other interventions, including measures that would ease the suffering of terminally ill patients and their families. This research project seeks to determine whether the treatments provided to Medicare beneficiaries during their last year of life are different in managed care and fee-for-service settings.

University of Oklahoma Health Sciences Center
Department of Psychiatry and Behavioral Sciences
Oklahoma City, OK
Betty Pfefferbaum, M.D., J.D.

$120,000

Traumatic Bereavement in Children Who Lost Family in the Oklahoma City Bombing

The 1995 Oklahoma City bombing killed 168 people, including 19 children. The tragedy offered the opportunity to examine the effects of trauma and the influence of external forces such as extensive media coverage and a protracted legal case on the bereavement process. The Health Sciences Center conducted a survey on the effects of loss on schoolchildren and an intensive biopsychosocial assessment of children and their parents who lost family members. Preliminary results support concern about the emotional importance of exposure to trauma and the media, and about the use of coping strategies on the development of posttraumatic symptoms.

Wellesley College
Department of Psychology
Wellesley, MA
Paul Wink, Ph.D.

$150,000

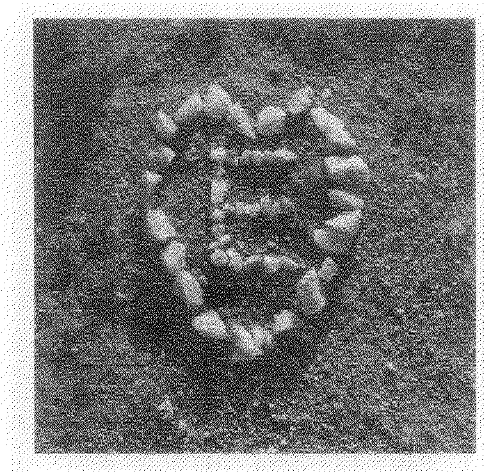
Integrating Life and Death: Coming to Terms with Old Age and Mortality

Although increasing numbers of Americans are living well into their 80's, relatively little is known about the psychological processes that help bring about a healthy adaptation to old age and mortality. This project draws upon existing archival data from two longitudinal studies of men and women (The Oakland Growth and Berkeley Guidance Studies), which include a rich array of personality, cognitive, and health data gathered in childhood, adolescence, and at three points in adulthood. The study will investigate, among other influences, past and present religious beliefs and spirituality, long-term, interpersonal relationships, and gender differences in attitudes toward health, old age, death, and bereavement. Participants in the study are currently, on the average, between 68 and 76 years of age.

Memorial
Oklahoma City Bombing

Physical, Emotional, Spiritual, and Existential Components of Dying and Bereavement

The objective in this funding category was to improve the prospects for better outcomes: "gentle closure," reconciliation, physical comfort, and a coming to terms with the life that was led. The Project on Death in America supported both traditional and nontraditional approaches, from within and outside the medical model, that help sustain the emotional and spiritual needs of dying persons and their families; that identify and respond to the unique needs of specific communities, such as those experiencing high rates of mortality from disease or violence; and that develop and implement strategies for incorporating spiritual and humanistic values into the dying and grieving process.



Foundation for Interfaith Research and Ministry
Houston, TX
Ronald H. Sunderland, Ed.D.

$126,826

Grief Care Teams

The Grief Care Team project was created to develop coordinated community-based programs in grief education and support to bereaved individuals and families. Participating local congregations are given options to develop grief/dying/death education modules for all ages; grief support groups; in-depth, continuing care of bereaved members; and support of caregivers caring for terminally ill loved ones. Particular attention is directed to assisting community groups, as well as dying individuals and their caregivers, in identifying and resolving end-of-life concerns and decisions.

The Care Team model, which assigns volunteers in teams in contrast to the more traditional one-to-one types of support, was designed to provide effective and compassionate in-home support to people facing terminal illness as a result of chronic health conditions that burden family caregivers.

The HealthCare Chaplaincy
New York, NY
Rev. Walter J. Smith, S.J., Ph.D.

$150,000

Training for Clergy and Laypeople about Death and Bereavement

As more and more people, by choice and circumstance, stay home to die, families are discovering that they are ill-equipped to handle the many realities of dying. Unfortunately, the clergy and lay volunteers to whom they turn for support and guidance often lack the training to help the dying find value in their remaining days and to help their loved ones deal with loss and grief. The HealthCare Chaplaincy will develop and offer community education programs on death, dying, and bereavement to clergy, laypeople, volunteers, and the bereaved. The project will also promote the necessity of pastoral care education for clergy and laypeople on issues of death, dying, and bereavement through a national forum.

In Loving Memory
Reston, VA
Linda Nielsen

$8,800

Conference for Parents with No Surviving Children

This volunteer organization hosts conferences for bereaved parents who have lost their only children and are just beginning their journey of grief and recovery. The conferences provide a safe environment for parents (and professionals) to network and attend workshops on many subjects that will help them find a positive resolution to their grief. The conference in August 1995 was held, in part, in response to the Oklahoma City bombing.

Interfaith Neighbors
New York, NY
Eileen Lyons, C.S.W.

$150,000

Children's Bereavement Project

The Children's Bereavement Project (CBP) organizes school-based bereavement groups for junior high school students in the East Harlem and Yorkville areas of New York City. These 12-week mutual aid groups are designed to create a safe place where young people, all bonded through loss, can begin to heal together and to explore the effects of the loss on their lives. CBP is conducting a two-year empirical study to research and evaluate the effectiveness and impact of the group intervention on the grieving and coping mechanisms of adolescents. The results of this research, in addition to informing CBP's bereavement group curriculum, will be published to facilitate the development of a nationwide model for providing bereavement services to young people.

Park Ridge Center
Chicago, IL
Laurence J. O'Connell, Ph.D.

$110,000

Retrieving Spiritual Traditions in End-of-Life Care

Recognizing that current approaches to end-of-life care often overlook the religious values of the elderly living in long-term care facilities, researchers at the Park Ridge Center are designing two educational programs: 1) a congregation-based lay ministry program to provide spiritual support to enable institutionalized elderly to die in ways informed by their religious values; 2) a program to educate health care professionals about the importance of religious beliefs in the care of older people approaching the end of life, and about ways to make the daily procedures of nursing homes sensitive to the religious and spiritual values of their residents. Through these programs, people will be better able to reinvigorate their personal spiritual resources and those of their religious and cultural traditions to overcome some of the serious barriers to dying well.

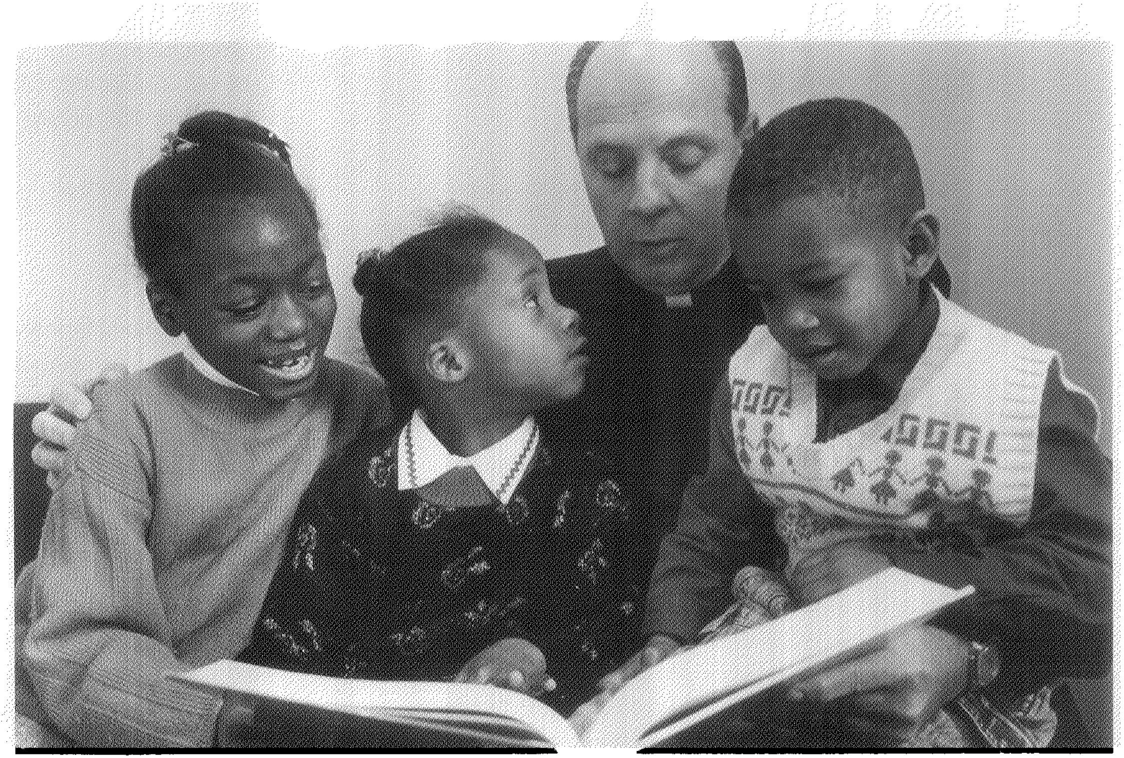
St. Francis Center
Georgetown University School of Medicine
Department of Psychiatry
Washington, DC
Janice L. Krupnick, Ph.D.

$125,000

The School-based Mourning Group Project: A New Approach to Assisting Bereaved Inner City Youth

Many inner city children lose parents at an early age to violence, substance abuse, and, increasingly, HIV infection and AIDS. Their devastating parental loss, combined with the multiple environmental disruptions and deprivations that characterize life in low-income, urban America, can have troubling social and psychological consequences, including depression, suicide, school failure, teenage pregnancy, substance abuse, and violence.

The project, working with public schoolchildren who have experienced the death of a parent or parent surrogate, is developing and testing a treatment model that, among other techniques, uses play therapy, including role playing and drawing, to help children get in touch with hidden feelings of pain and loss.



Facing the Death of a Parent
St. Vincent's Services
Brooklyn, NY

> **"Recollections of the dying are etched in one's memory like on stone. As health professionals, we are in a particularly unique position to shape the legacy left for those who have cared for the dying."**
>
> **Gerri Frager, PDIA Faculty Scholar**

St. Jude Children's Research Hospital
Memphis, TN
Pamela S. Hinds, Ph.D., R.N., C.S.

$125,000

Deciding to End Curative or Life-Sustaining Efforts for Children or Adolescents with Cancer

Many health care professionals desire to include the adolescent patient in end-of-life decision making, yet they are reluctant to do so because of a fear that the child may lack sufficient understanding of his or her situation to participate competently. No research-based guidelines exist to help the physician resolve this dilemma. This study will define the factors that pediatric oncology patients, their parents, and health care providers consider when deciding to end curative or life-sustaining care. It will also identify the actions of health care providers that contribute to the ability of parents to cope with the death of their child. Guidelines will be developed from the research findings.

St. Vincent's Services
Positive Caring Services
Brooklyn, NY
Sister Elizabeth Mullane

$50,000

Spiritual and Emotional Journey of Parents Dying of AIDS

This special program for parents in advanced stages of HIV infection uses a variety of interventions to assist them in celebrating life and greeting death. Interventions include group "wellness" sessions, individual counseling, pastoral and spiritual services, and support for parents as they discuss their impending death with their children. Retreats and outings help rejuvenate the spirit and provide children with a way of seeing their parents in a new light, away from daily routines. Rituals of cleansing, forgiveness, healing, and remembrance give expression to inner feelings the parents might not be able to put into words.

The Universalist Meeting House of Provincetown
Provincetown, MA
Rev. Jennifer Justice

$25,000

Spiritual Support Programs for the Dying

Provincetown, with the second highest AIDS population per capita in the country, is living with multiple layers of grief. The Universalist Meeting House provides community programs to ease the suffering: a support group for HIV-positive people and for partners and friends who are grieving the loss of loved ones; an eight-week course on "Living and Dying;" a volunteer team that offers additional spiritual support to people who are dying.

"Imagine a gentle revolution with death. Imagine communities and families compassionately supporting the dying with contemplative care. Imagine dying without fear."

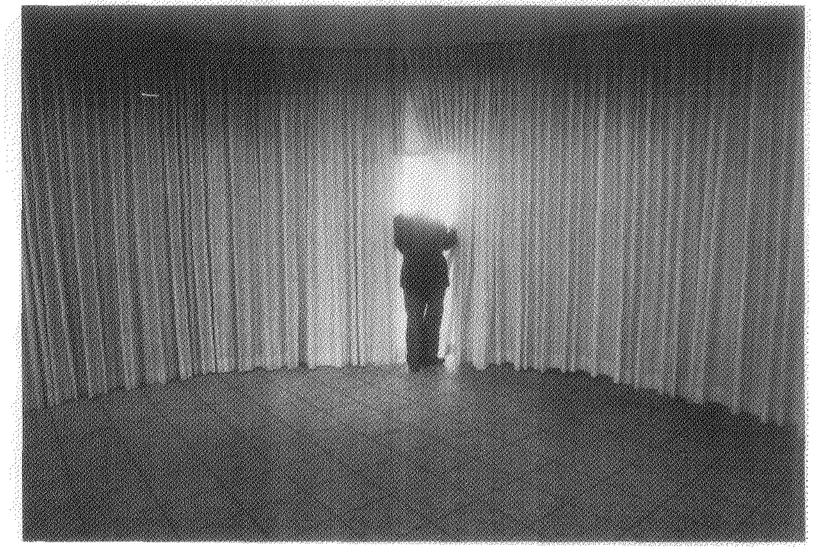
Joan Halifax, Institute for Contemplative Work with Dying People

Upaya
Santa Fe, NM
Joan Halifax, Ph.D.

$50,000

Institute for Contemplative Work with Dying People

Through work with the dying and their caregivers, Joan Halifax's Project on Being with Dying has developed an approach to death that is kind, open, and dignified. Her program, based on Eastern and Western psychology, philosophy, and contemplative practices, emphasizes mindfulness and the awareness of death as a way to experience living and dying. The new institute will expand upon this work by creating a center for spiritual inspiration, education, and continuing support for dying people, their families, and caregivers as well as health care professionals, educators, and administrators.



Contribution of the Arts and Humanities

The Project on Death in America encouraged persons from the literary, visual, and performing arts to use their skills and insights to identify, create, and convey meaning in facing disability and death; and to evoke and deepen our understanding of the diverse myths and metaphors that shape the experience of suffering, dying, and bereavement.

Horse: "I remember what it felt like when my mom got very sick. I was really scared. How was I going to get along without her? Who was going to take care of me? I couldn't understand how she could leave me. But before she died, she told me, 'I'll still be there for you, to watch over you and be with you.' "

Wolf: "When you're dead, you're dead. Everyone forgets you."

Bastienne Schmidt and Philippe Cheng

Staten Island, NY

$60,000

On Death and Dying in America: A Photographic Exploration

The project will explore and document through photography and video our evolving culture of death in America; how we emotionally, spiritually, and practically experience mourning, grief, and loss; and how our social and cultural environments impact and shape these responses. The photographers will record not only the traditional rituals surrounding the process of dying, death, and mourning, but also the emerging cultural and social rituals that are in response to more recent trends in dying—for example, how diverse segments of our population deal with premature deaths due to AIDS and violence.

Continuing Support Services, Inc.

Medford, NJ

Antoinette Griffith, M.S.A., M.S.W., C.S.W.

$25,000

When Puppets Grieve

Two traveling musical puppet shows for children address the grief associated with the loss of a loved one and issues surrounding HIV/AIDS. The shows are called "Good Grief, It's Sky Blue Pink" and "Birds of a Feather... Learn about HIV/AIDS Together." A workshop in conjunction with the puppet shows gives children the opportunity to discuss disease, death, and grief with their teachers, counselors, and fellow students.

Tony Howarth

Hastings-on-Hudson, NY

$10,000

Sundown

The ability of art to identify, create, and convey meaning in facing disability and death cannot be underestimated. Playwright Tony Howarth will explore the dying process with a play about the experience of an elderly man whose living is complicated by the chaos of dementia.

Horse and Chicken: "I'll never forget my mom." "I'll never forget my egg."

Wolf: "I once had a friend. She died. And I didn't want her to. She liked yellow roses. Now when I see them, I'll think of her and her blue eyes and her smile. The roses will help me remember her."

(excerpt from the puppet show "Good Grief, It's Sky Blue Pink," Continuing Support Services, Inc., of Medford, NJ.)

National Hospice Foundation
Arlington, VA
John J. Mahoney

$100,000

Hospice: A Photographic Inquiry

The exhibition *Hospice: A Photographic Inquiry* opened at the Corcoran Gallery of Art in Washington, DC, in early 1996 to favorable reviews and large audiences. It will tour to over 17 museums and galleries in the United States through the year 2000. Organized by the Corcoran and the National Hospice Foundation, the exhibition contains the work of five internationally recognized photographers, Jim Goldberg, Nan Goldin, Sally Mann, Jack Radcliffe, and Kathy Vargas, who created evocative images and essays about the emotional and collaborative experiences of living and working in hospices. Accompanying the exhibition is *Letting Go: A Hospice Journey,* a documentary produced and directed for HBO by Susan Froemke, Deborah Dickson, and Albert Maysles. The exhibition is generating widespread interest and awareness about hospice care.

New York University
Tisch School of the Arts
New York, NY
Peggy Phelan, Ph.D.

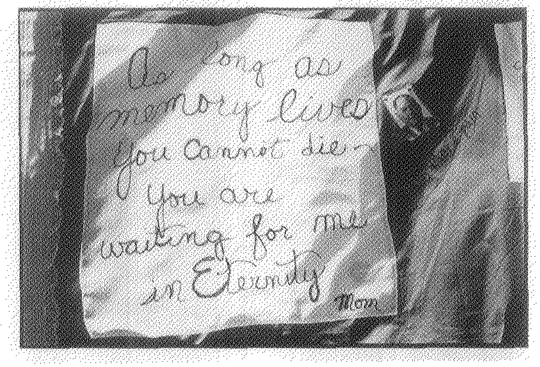
$60,000

Theater as a Rehearsal for Death

This book will examine the ways in which significant North American artists respond to the trauma of contemporary death in America and create extraordinary art about the relationship between death and theater. A central theme to the book will be Antonin Artaud's conception of theater as a way to prepare for the dual responsibilities of death: learning to watch one another's deaths with love and trust so that we might learn to die with love and trust; and reexamining the ethical challenges posed by witnessing one another's deaths.

New Service Delivery Models for the Dying and Their Families and Friends

The Project on Death in America sought to promote measures to assess existing systems of care for the dying and to develop appropriate new systems of care that improve the care of dying persons and support their families and friends. PDIA provided funding for programs that examine various settings for death, including the home; identify barriers to needed services; and design strategies to overcome them. PDIA also supported the evaluation of special programs in palliative and hospice care as well as efforts to integrate their principles and practices into the delivery of services to all dying persons. Improving continuity of care and stimulating ongoing quality improvement were also concerns as was the dissemination and replication of promising modes of delivery.



Bailey-Boushay House

Seattle, WA

Wayne C. McCormick, M.D.

$22,000

Cost of Care in AIDS Hospices

Many AIDS patients prefer to live their final days in non-hospital settings such as hospices or their homes. Bailey-Boushay's study of persons residing at its hospice will focus on the management of pain and the costs of care. The study will provide other physicians with information about therapeutic options in managing AIDS patients near the end of life. If care in special non-hospital AIDS facilities proves cost-effective or cost-neutral, then payers may be more willing to cover the cost of such care.

City of Hope National Medical Center

Duarte, CA

Betty R. Ferrell, Ph.D., FAAN

$76,650

HOPE: Home care Outreach for Palliative care Education

In recent years, home care has been the fastest growing segment of the health care industry and an increasingly large part of chronic and terminal illness care. The trend is fueled by the rising costs of institutional care, the increasing desire of terminally ill patients to remain at home, and the transfer to the home of health services previously found only in hospitals. Many nurses entering home care positions, however, have little knowledge of palliative care. City of Hope's model education program seeks to improve the quality of care for patients and families in non-hospice home care agencies. The program's curriculum, based on a survey of 134 home care agencies, includes five modules: Overview of End of Life Care, Pain Management, Symptom Management, Communicating with Dying Patients and Families, and the Death Event.

The Compassionate Friends

Oak Brooks, IL

Karl M. Snepp, Jr.

$100,000

Leadership Training Program

The Compassionate Friends is a mutual assistance, self-help organization aiding parents and siblings to reach positive resolution of their grief following the death of a child. The Compassionate Friends will develop and implement a training program for its chapter leaders, all of whom are volunteers and bereaved parents, in the skills and knowledge essential to leading an effective chapter and facilitating a supportive and healing environment for newly bereaved parents and siblings.

Edmonton General Hospital

Palliative Care Program
Grey Nuns Community Health Centre
Edmonton, Alberta, Canada
Eduardo Bruera, M.D.

$94,765

Assessment of Cancer Patients and Their Families

The project will develop a simple multidimensional kit for the daily or weekly evaluation and follow-up of terminally ill cancer patients and their families. The key component of the kit is an assessment tool for patients to describe their physical and psychological symptoms, cognitive function, and spiritual needs and family support. The kit will enable the health care provider to be aware of these symptoms together with the patient's other vital signs. The design of the kit lends itself to use in the acute, long-term care, home health, or hospice setting.

Ellen Stephen Hospice

Pine Ridge, SD
Bruce A. Williams, R.N.

$150,000

Hospice Service Model on the Pine Ridge Reservation

The 23,000 Lakota Sioux living on the Pine Ridge Reservation in South Dakota have an infant mortality rate of 39 per 1,000 births and an average male life expectancy of 45 years. The nearest hospice is in Rapid City, a 200-mile round trip from the reservation. By the time a Native American goes to the hospital, he or she is in an advanced state of illness.

The Ellen Stephen Hospice is the first tribally sanctioned hospice to serve Native Americans. The hospice's first patient, Oliver Old Horses, died on November 14, 1994. The service enabled him to die at home in peace and dignity surrounded by family and friends. Hospice care and management is provided by an interdisciplinary professional and volunteer team according to national hospice quality standards and within the Native American belief system. The hospice will serve as a model for other Native American communities.

George Whitmore Foundation

New York, NY
Judith Lauterstein, Ph.D., and Suzan Anson, Ph.D.

$75,000

Hospice for the Deaf

When hospitalized, the deaf frequently sustain long periods of social isolation. They cannot communicate with doctors and other hospital staff unless a qualified interpreter is present. Currently, there are no hospice programs actively serving the deaf. The George Whitmore Foundation, in collaboration with the Jacob Perlow Hospice, has created a program of hospice care for the deaf at the end-stage of life. In order to understand the special needs of the deaf, this pilot program will gather data from the deaf community about their experiences with end-stage illness.

The Hastings Center
Briarcliff Manor, NY
Daniel Callahan, Ph.D.

$75,000

Death and the Research Imperative

A fundamental tension exists within medicine between helping people die peacefully and combating all known causes of death. The center will attempt to better understand the research imperative to overcome death and seek a reconciliation between efforts to cure lethal diseases and to provide care for dying people.

The Hospice Foundation
Torrance, CA
Claire Tehan, M.A.

$10,000

Hospice Education and Outreach to Japanese Americans

One of the greatest challenges in hospice work is recognizing and supporting patient and family beliefs and practices around death and dying. In an effort to meet this challenge in Los Angeles and Orange Counties, the Hospice Foundation will create distinct hospice services for Japanese nationals and Japanese Americans as well as an education program for hospice staff and health care professionals. Both initiatives will enable health care professionals to overcome the language and cultural barriers that too often stand between the patient and quality end-of-life care.

Institute for Healthcare Improvement
Boston, MA
Donald Berwick, M.D.

$50,000

Breakthrough Series Collaborative on Improving Care at the End of Life

In the past, the Breakthrough Series has been successful in improving the care of patients by targeting specific interventions, implementing changes quickly, measuring the effects, and institutionalizing desirable changes. The series will now turn its attention to end-of-life care. The experiences of the institutions participating in the effort will be documented and widely disseminated. In addition, measurement tools, quality improvement techniques, benchmarks, and expert referral will be made available to sites not participating in the series.

Johns Hopkins University
Baltimore, MD
Matthew Loscalzo, M.S.W.

$125,000

A Problem-solving Approach to Helping Families Care for the Dying Person with Cancer

People who die of cancer and other chronic diseases receive most of their care, during the period just prior to death, from family members who are unprepared and unskilled in dealing with the complex and demanding tasks they face. This project will teach family members the problem-solving skills needed to manage care at home during the terminal period, and provide the support of health professionals and peers for their problem-solving efforts.

Joseph's House
Washington, DC
David Hilfiker, M.D.

$50,000

A Home for Homeless Men with AIDS

Joseph's House invites homeless men with AIDS who are losing their independence to join their community of caring people. Most of the men are African American and nearly 90 percent have histories of drug and alcohol addiction. The men enter Joseph's House when they are still well enough to participate in the life of the community. Most stay until they die. In providing housing, food, medical and nursing services, addictions counseling, spiritual support, and ultimately hospice care, Joseph's House struggles with the experience of living and dying in the contexts of a minority population, poverty, addiction, and the shredded "safety net" of needed support systems.

Community of Caring People
Joseph's House
Washington, DC

Malachi House

Cleveland, OH

Daniel B. Cotter

$25,000

Caring for the Indigent Dying

Malachi House is a pioneer in serving the indigent dying who are without appropriate caregiving support and who cannot afford or are ineligible for nursing home care. Care is provided 24 hours a day without cost or regard to gender, race, religion or national origin. Since opening in September of 1988, the home has served over 450 residents with the help of over 165 active volunteers who assist a staff of 16.

Marquette University

Milwaukee, WI

Sarah A. Wilson, Ph.D., R.N.

$60,000

Fostering Humane Care of Dying Persons in Nursing Homes

Little is known about how long-term care facilities (LTCFs) deal with issues of death and dying. A series of focus groups with staff and administrators will address the unique needs of LTCFs in providing care to terminally ill residents. Family members will also be interviewed to obtain their perspectives. Analysis of data from these focus groups and interviews will provide material for a guidebook containing teaching modules on terminal care and educational programs for staff and administrators in long-term care.

Mayo Clinic

Rochester, MN

Mary E. Bretscher, M.D.

$6,989

Quality of Life of Hospice Patients and their Caregivers

Previous studies have shown that health care personnel are inadequate judges of the quality of life of their patients. Patients with advanced cancer, for example, tend to rate their quality of life better or higher than observers do. The Mayo Clinic will assess the quality of life of hospice patients with the goal of establishing objective criteria for the guidance of hospice teams. The clinic will also assess the quality of life of primary caregivers.

Miriam's House

Washington, DC

Carol Marsh

$5,000

Miriam's House, A Project of Joseph's House

Joseph's House for homeless men living with AIDS extended its mission by creating a new project, Miriam's House, which provides a permanent home and support for homeless women living with AIDS, some of whom have children. Miriam's House brings compassionate attention to the physical, emotional, social, and spiritual needs of each resident within the context of a loving and respectful community.

Missoula Demonstration Project

Missoula, MT

Ira R. Byock, M.D., and Barbara Spring, Ph.D.

$150,000

Quality of Life's End

Most people anticipate that dying will be a time of suffering to be avoided or suppressed. They see dying as a medical phenomenon, rarely as a major spiritual, psychological, social, and integrating life experience. The available support systems focus on sustaining life, rather than relieving suffering and nurturing an important life process.

The Missoula Demonstration Project, a community-wide organization of health care agencies, city government, aging services, the University of Montana, faith communities, and local senior consumer groups, seeks to change people's perceptions about death and dying. The project will begin by researching cultural attitudes toward dying—values, expectations, experiences—of people in Missoula County. These studies will provide direction for future interventions and research focused on bringing quality to the end of life.

National Prison Hospice Association

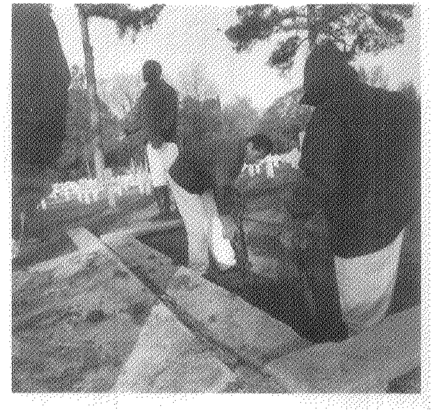
Boulder, CO

Elizabeth Craig

$85,000

Development of Hospice Care in Correctional Facilities

The effort to promote hospice care in prisons includes the development of inmate-staffed hospice volunteer programs; development of national prison hospice guidelines; and the creation of a national network for the exchange of information between hospices and prisons.



National Prison Hospice Association

Boulder, CO

Florence S. Wald, M.N., M.S., FAAN

$18,000

Hospice Care for State Correctional Facilities: A Feasibility Study in Connecticut

The aim of this study is to assess the need for adapting hospice care services for terminally ill patients in the Connecticut State Department of Correction. Six prison infirmaries serving the state's 23 correctional facilities will undergo an evaluation of the health management practices, support services, and ancillary programs that provide terminal care for dying inmates and the potential of existing services in the community to contribute to the end-of-life care. This project is cofunded by OSI's Center on Crime, Communities & Culture.

The Neurological Institute

Columbia-Presbyterian Medical Center

New York, NY

Lewis P. Rowland, M.D.

$125,000

Palliative Care Decision-Making and Outcomes in Amyotrophic Lateral Sclerosis (ALS)

ALS, also known as Lou Gehrig's disease, is an inexorably progressive and ultimately fatal disease. Respiratory failure is probably the most common cause of death. Some patients choose to have a tracheostomy and may live for a decade or more unable to move anything other than their eyes. The investigation will uncover the relationship between physicians' preferences and attitudes toward life-sustaining treatment; how patients make their choices among the several options offered; the disease's impact on quality of life; spirituality and adaptation to the progession of illness; and the medical outcome.

Pennsylvania State University College of Medicine

Hershey, PA

David Barnard, Ph.D.

$134,303

Case Narratives in Palliative Care

The case narratives will describe the experiences of dying patients, their families, and health care providers as they interact over the course of the patient's illness and treatment. Each narrative will tell the story of the patient's experience of illness and care—with particular emphasis on the patient's "inner life" or subjective experience—and the caregivers' experiences of giving care. The program intends to go beyond conventional case reports in medicine, which concentrate on symptoms and treatment, to depict how patients, families, and providers find personal meaning in illness, and how personal meanings influence the experience and outcome of care. The final product will be a casebook aimed at heightening health professionals' and society's awareness of the needs of the dying and the role of palliative care in the health care system. Codirecting the project with Dr. Barnard is Anna Towers, M.D., of the Palliative Care Service at the Royal Victoria Hospital in Montreal, Canada.

Providence Health System

Portland, OR

Alicia Super, R.N., B.S.N., O.C.N.

$50,000

Supportive Care of the Dying: A Coalition for Compassionate Care

This collaborative effort of six health care systems has developed an innovative response to dying that honors individual values, diverse cultural attitudes and norms, the integrity of the human spirit, a demand for autonomy, the sacredness of life's final phase, and the reality of shrinking resources. The project will determine the needs of people affected by life-threatening illnesses, rather than relying on care providers' assumptions of those needs; develop an educational model of comprehensive supportive care that will meet those needs; and create a mentorship program for health care providers that encourages compassionate care for the dying.

United Hospital Fund

New York, NY

David A. Gould, Ph.D.

$300,000

Palliative Care Initiative in New York City Hospitals

The Fund will organize a consortium of 12 New York City hospitals to design, implement, and evaluate a palliative care initiative for assessing and changing the way hospitals provide care to persons at the end of life. The project will assess obstacles to appropriate care for patients dying in hospitals, including inadequate clinical preparation of health care professionals; their poor communication with one another as well as with patients and their families; disincentives presented by the regulatory and financing system, and by medical education; and the legal context of end-of-life care decision making in hospitals. Grants to five hospitals will support the development of major palliative care programs.

$15,000

Paying for Care: How Reimbursement Policies and Insurance Coverage Affect End-of-Life Care in New York State

A series of in-depth interviews will be conducted with care providers, consumer and advocacy organizations, insurers and others to explore the current landscape in New York concerning payment for care at the end of life, and a report describing current payment practices and defining key coverage gaps and associated service problems will be developed and distributed widely.

University of New Mexico Health Science Center

Albuquerque, NM

Walter Forman, M.D., F.A.C.P.

$201,321

Palliative Care in Multicultural Settings

In collaboration with hospices in Taos, Santa Fe, Gallup, and Alamogordo, the project will develop a regional educational, training, consulting, and research service in palliative care. A priority will be to investigate issues relevant to various cultures using hospice services.

University of South Florida College of Medicine

Tampa, FL

Ronald S. Schonwetter, M.D.

$169,947

Decision to Enter Hospice in the 1990s

The past decades have seen the relocation of death from the home to the hospital with its sterile environment and complex medical treatments. Hospice care offers an alternative. This study of a group of cancer patients with limited life expectancy will try to identify the factors that go into deciding whether to choose hospice care or to continue with a traditional curative approach. Interviews with patients, caregivers, and physicians should result in ways to overcome barriers to receiving hospice care and increase access for terminally ill patients in need of such care.

Visiting Nurse Association of Los Angeles

Los Angeles, CA

June Simmons

$146,594

End-Stage Dementia Hospice Program

Alzheimer's disease (AD), the most common dementing illness among older Americans, is a degenerative neurological disorder which inevitably leads to death. The prevalence of Alzheimer's disease in individuals over 85 is 47.2 percent. From onset of symptoms until death, Alzheimer's victims live an average of eight years. Since there are no widely accepted methods of predicting survival time, only 1 percent of demented elderly patients enter Medicare hospice programs, which require a survival prediction of six months or less. End-stage patients, who are often agitated, incontinent, and unable to speak, eat, or drink, cannot be cared for at home without assistance.

The purpose of this program is to develop a nationally replicable model for the provision of comprehensive end-stage care to patients dying from Alzheimer's or other fatal dementing diseases and for supportive services to their families. The program also seeks to improve access to end-stage care and to increase public awareness of care options for this population of patients. One of the unique features of the care model is the attempt to offer spiritual solace through prayer, scripture readings, and religious music and ritual, which may elicit emotional reactions from patients who can no longer participate in life review and other techniques for meaning.

Wishard Health Services

Indianapolis, IN

James Y. Greene, Ph.D.

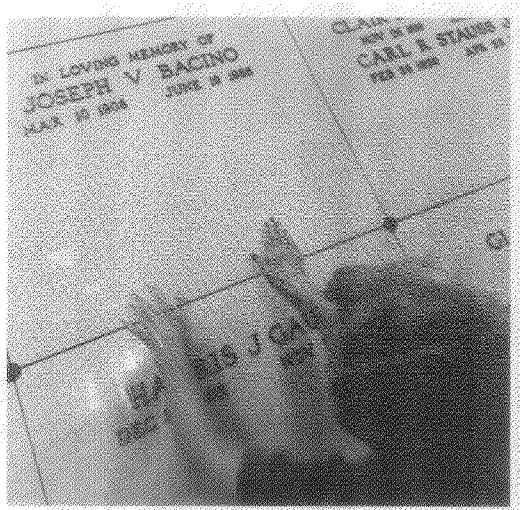
$82,437

End-of-Life Care Interventions in a Public Hospital System

This follow-up to an earlier PDIA-funded study, "Dying Poor: End-of-Life Care in a Public Hospital System" (see Indiana University, page 13), will apply the insight gained through the initial study to improve end-of-life care for patients, their loved ones, and health care providers. The steps to be taken include the development of culturally sensitive materials and programs for educating health care providers in end-of-life care; collaboration with existing patient education groups to better prepare dying patients and their families for the challenges they will face; and the creation of a comprehensive, integrated program that will serve as a model in coordinated end-of-life care for other public hospitals across the country.

Educational Programs for the Public about Death and Dying

PDIA promoted the effective use of education and the media to increase discussion of dying, death, and bereavement. It supported strategies for informing the public about available programs for providing support during the dying and grieving process. It supported teaching approaches that build upon the regular and unexpected experiences of students with dying. It advanced strategies for addressing the needs of special populations.



American Medical Association

Chicago, IL
Mark Wolfe

$80,000

Media Symposium on End-of-Life Care

On April 17, 1997, the American Medical Association and the Coalition for Quality End-of-Life Care organized a program entitled "Exploring the Issues: A Symposium for the Media on End-of-Life Care." The overall goal of this national symposium was to present a balanced, open forum to educate the media regarding the myriad challenges faced by caregivers in meeting the needs of dying patients and their families. The American Medical Association, the American Nurses Association, the American Academy of Neurology, the American Geriatrics Society, and the National Hospice Organization are among the 52 members of the coalition.

American Society on Aging

San Francisco, CA
Gloria Cavanaugh

$6,000

Special "In Focus" Section of Aging Today Devoted to Death and Dying

The pull-out section in the January/February 1996 issue contained articles on prevailing myths and fears of death; the role of medical care and hospice; the economics of death; key public policy issues; spiritual concerns; and the legal and ethical issues in end-of-life decisions.

Americans for Better Care of the Dying

Washington, DC
Joanne Lynn, M.D., M.A.

$400,000

Americans for the Better Care of the Dying (ABCD) is a non-profit charity dedicated to social, professional, and policy reform, and to education aimed at improving services for patients with serious illness and their families. The award is to fund the continuing programs of ABCD.

> **"I think the toughest part will be to get people to let down their defenses and talk about death. It's a subject people like to keep hidden in the closet."**
>
> **Michael Murphy, Hospice of Midcoast Maine**

Harlem Interfaith Counseling Service

New York, NY

Doris W. Dennard, A.C.S.W., D.C.S.W.

$5,000

Planning for a Community-based Bereavement Support Center

The center will serve Central Harlem, where family members—frequently grandparents and children—too frequently mourn the loss of loved ones due to the higher than average rates of death from AIDS and violence. As the lead agency, the Harlem Interfaith Counseling Service, a family mental health clinic, will provide consultation to a consortium of service groups developing the center.

Health Force: Women and Men Against AIDS

Bronx, NY

Chris Norwood

$100,000

Dear Death Project: Helping Communities Cope with Massive Death

The project is designed to confront the meaning and consequences of the massive death rates in poor neighborhoods across the United States. Individuals participating in the project write letters to death as a way of coming to terms with their loss and grief. An exhibit of the "Dear Death" letters will travel to other communities coping with the impact of mounting deaths from AIDS, violence, drugs, and other causes. In addition, the exhibit will be shown at the United Nations. An accompanying survey showed that, on average, the letter writers had lost six people close to them in the past 10 years and 19 percent had experienced 10 deaths.

Hospice Foundation of America

Washington, DC

Jack D. Gordon

$125,000

Video Teleconference Series

The video teleconference series on grief is a resource for both the public, health care professionals, and social workers. The teleconference in April 1997, "Living with Grief: When Illness Is Prolonged," dealt with the grief felt by both the dying and their caregivers when faced with a terminal, progressive illness such as cancer or AIDS. "Living with Grief: After Sudden Loss," the 1996 video teleconference, focused on the grief faced by survivors after losing a loved one, colleague, or community member to sudden and traumatic death. A resource book has been developed in conjunction with each teleconference and videos of both are also available.

> **"Palliative care is not widely available in this country. It would be available tomorrow, if we just changed our attitudes and behavior toward care of the dying."**
>
> **Kathleen Foley, Director, PDIA**

Hospice of Midcoast Maine

Brunswick, ME

John A. Norton and Michael J. Murphy

$115,000

Coalition for Dialogue on Death and Dying

The coalition of community organizations will work to improve the culture of dying; deliver services more effectively to dying persons and their families during the period of illness and bereavement; and serve as a catalyst for systemic change by bringing together hospitals and other providers of medical care, insurance companies, major employers, and citizens in Midcoast Maine.

KPFA Radio/Pacifica Foundation

Berkeley, CA

Susan G. Stone

$40,000

Multicultural Radio Series on Death and Bereavement

Public broadcasting entity KPFA/Pacifica Radio will produce, market, and distribute a five-part series exploring diverse ethnic and cultural traditions in the United States for experiencing, mourning, and commemorating death.

Medicare Rights Center

New York, NY

Diane Archer

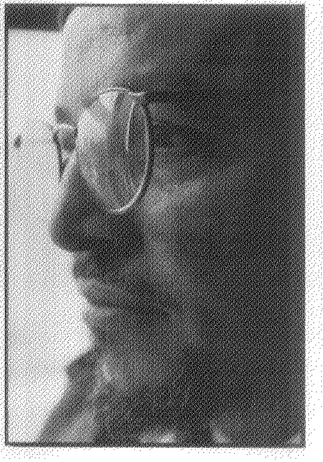
$150,000

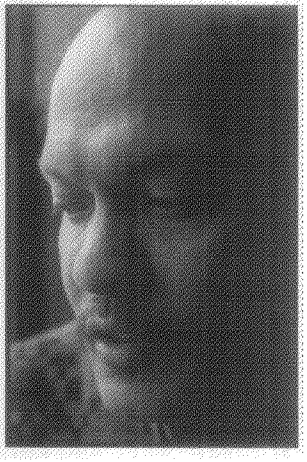
Initiative for the Terminally Ill on Medicare

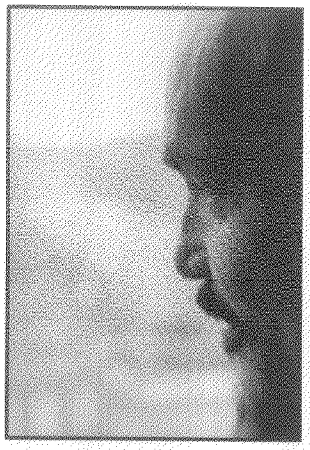
Lack of information about financing options for end-of-life care is a substantial barrier to obtaining quality end-stage care. This initiative will educate consumers, their families, caregivers, professional counselors, and clinicians about Medicare hospice and home health benefits for the terminally ill in both the fee-for-service and HMO settings.

Wall Memorial for Her Cousin
Coney Island, New York City

"Dear Death, I am writing to you to let you know what I would like you to do for me. The first thing I would like is that you give me a chance to let my loved ones know everything is okay. Second thing is that death for me would not be painful only cause my life has been painful for me. So in death I would like it without pain. The third thing is that my remains look as good as I looked in life. It's important that my remains look good cause it is my friends and loved ones who will be looking at my last performance in this world. And my enemies will be looking for ways to talk about me and I would like to disappoint them. So I will not give you a hard time when you come for me. But be sweet and gentle for I deserve a kind death."

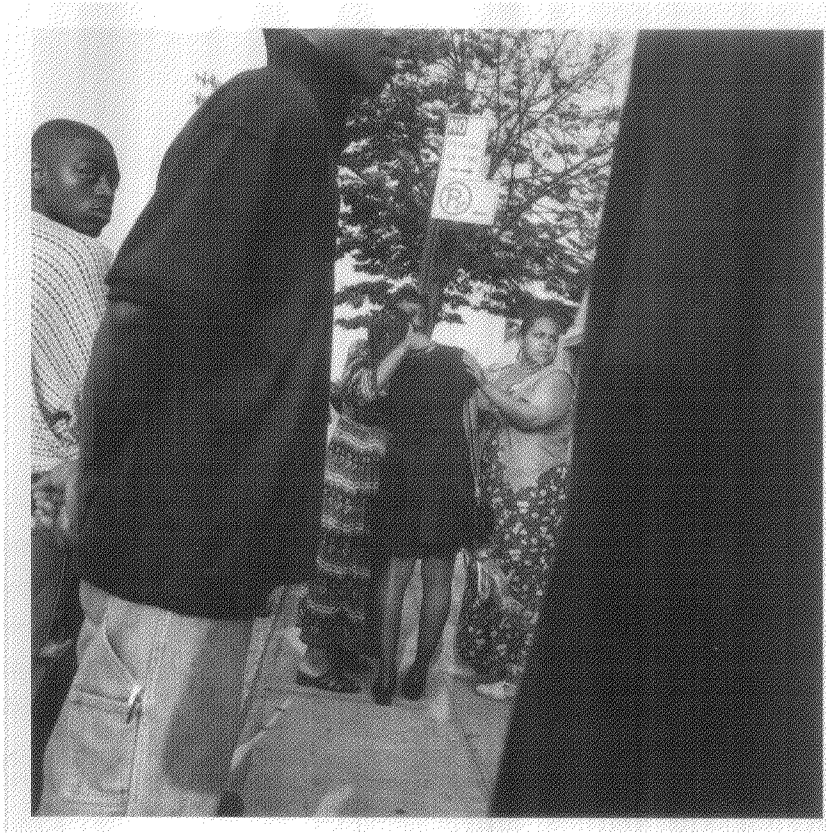






"Dear Death, How are you doing? This is Sylvia. So many times we have met and you didn't stay. I just want you to know that I am still here and just to let you know that I am not afraid of you. Thank you for sharing. And until you return to come for me I am going to live life to the fullest."

Letters written by participants in the Dear Death Project,
Health Force: Women and Men Against AIDS, Bronx, New York



Tears for Alex Who Was Shot
Coney Island, New York City

Educational Programs for the Health Care Professions

PDIA supported the development of innovative curricular materials, educational methods, patient-centered clinical teaching, and system-level quality improvement activities at all levels of health care professional education. The project focused on programs that enhance the interpersonal skills needed for working with dying persons and their families and friends.

Cancer Care
New York, NY
Diane Blum, A.C.S.W.

$71,675

Education on End-of-Life Care for Cancer Patients

To improve end-of-life care for terminally ill cancer patients, Cancer Care sought to enhance the practical, spiritual, and communication knowledge and skills of their health care professionals through a national, multidisciplinary, four-part teleconference series and a two-part case management discussion group. The series targeted social workers, nurses, physicians, community workers, psychologists, pharmacists, and chaplains working in health care. Four hundred professionals from 38 states participated in each teleconference, and 30 professionals in each case-management group. All participants received patient education fact sheets, newly developed by Cancer Care, that provided information and resources to patients about end-of-life care.

Center to Improve Care of the Dying
George Washington University
Washington, DC
Joan M. Teno, M.D.

$119,944

Advance Care Planning for Improving End-of-Life Care in Managed Care Settings

The evidence to date suggests that advance directives (ADs) do not affect medical care or result in a good death. In an earlier study, Dr. Teno found that ADs did not produce an increase in the writing of DNR (do not resuscitate) orders even when the patient desired to forgo CPR. Physicians rarely counseled patients about ADs while only 41 percent of patients discussed their ADs with a physician. Only a third of physicians were aware of a patient's AD by the second week of hospitalization.

All of these findings indicate a need for improved communication, not just increased use of advance directives. ADs should be part of a broader activity called advance care planning, which ensures that clinical care will be shaped by patient preferences when the patient is unable to participate in decision making. An expert panel will research the preferences of patients and health care professionals on the subject of care near the end of life and recommend practical and ethically justified guidelines for advance care planning in managed care.

College of Physicians & Surgeons of Columbia University
Departments of Neurology and Psychiatry
New York, NY
Nancy S. Wexler, Ph.D.

$100,000

Death Now, Dying Later: Predictive Testing for Huntington's Disease and Other Late Onset Disorders

Huntington's disease was one of the first disorders for which predictive testing was possible. Since then genes for CF, breast and colon cancer, AD, ALS, and others have been discovered. The capacity to tell individuals—when they are healthy—that they are destined to die in a particular way raises important issues for the development of a testing protocol and curriculum. Some of the questions the project will address are: How do you help people choose whether or not to be tested? What components should the testing process include? How do you help people live with the knowledge of how they will die?

> **"If we make it to 90, then we are all dying no matter how healthy we are."**
> Joanne Lynn, Center to Improve Care of the Dying

Death with Dignity Education Center

San Mateo, CA

Charlotte P. Ross

$25,000

Consensus Development Conference on Physician-Assisted Dying

The organization, which believes in the right of patients to physician aid-in-dying, held a consensus development conference in 1996 that brought together critics and proponents of physician-assisted death in an attempt to reach a consensus beneficial to terminally ill patients. The conference was one in a series exploring all aspects of care for the dying with the aim of providing guidance to physicians, nurses, and health care institutions.

Education Development Center

Newton, MA

Mildred Z. Solomon, Ed.D.

$189,951

Ethics, Law, and Pain Management: Improving Terminal Care for Cancer Patients

Over the past 20 years, innovative treatments and some impressive successes have led to conflicts in the goals and values of cancer medicine, between aggressive attempts to cure versus attempts to relieve suffering and provide for a dignified, peaceful death. This multidisciplinary, institution-based leadership initiative challenges health care institutions to improve the quality of care provided to dying cancer patients and their families by undertaking a program which educates staff in ethics, law, and pain management, fosters better decision making about treatments, and stimulates action planning to improve palliative care. Launched at a leadership retreat in January 1997, the program is now in use in 19 cancer care institutions.

Institute for the Study of Health and Illness

Bolinas, CA

Rachel Naomi Remen, M.D.

$80,000

Curriculum on Detoxifying Death for Physicians

"Detoxifying Death" is a multimodal, continuing medical education curriculum that integrates cognitive, behavioral, psychological, and valuational approaches. The goal is to provide the physicians of terminally ill patients with a different approach to caring for their patients as well as strategies for themselves for preventing burnout and maintaining personal growth.

McGill University

Montreal, Quebec, Canada

Balfour Mount, M.D.

$12,000

Seminar on "Searching for the 'Soul' of Euthanasia"

The seminar, held on September 11, 1996, in conjunction with the 11th International Congress on Care of the Terminally Ill, discussed the issue of euthanasia and the implications of the current debate for the future.

New York Citizens' Committee on Health Care Decisions

New York, NY

Beatrice Greenbaum

$100,000

Senior Partners in Health

The New York Citizens' Committee will develop a model train-the-trainer program for health care educators so that they can empower senior adults to advocate on their own behalf in the physician-patient relationship. American Health Decisions, the Older Women's League, and the Elderhostel Network are among the national organizations that have expressed an interest in assisting with this project.

Rush University

Chicago, IL

Erich E. Brueschke, M.D.

$5,000

Conference on End-of-Life Issues

This interdisciplinary conference in May 1996 sought to contribute to the understanding of dying and serve as a catalyst for a national dialogue to improve the experiences of the dying. Representatives from the legal and health care professions, religious and civic leaders, and professional ethicists participated in the two-day conference.

Tibet House New York

New York, NY

Beata Tikos

$5,000

The Art of Dying II

The primary aim of these conferences is to "humanize" the dying process by promoting innovative approaches to death and dying that professionals can integrate into their work. At the second conference, organized by Tibet House and the New York Open Center in March 1997, a diverse group of speakers, health professionals, educators, and administrators examined perspectives on death and dying and shared methods of care provision and preparation for death.

United States Cancer Pain Relief Committee

New York, NY

Russell K. Portenoy, M.D.

$50,000

First International Meeting on Research in Palliative Care: Methodologies and Outcomes

Cosponsored by the National Institutes on Health and the United States Cancer Pain Relief Committee, this conference, to be held May 7-9, 1998, will provide an open forum for an exchange of new research findings and methods of investigation relevant to palliative care. A monograph on palliative care research will be published in the *Journal of Pain and Symptom Management*.

University of Pittsburgh Medical Center

Pittsburgh, PA

Gary Fischer, M.D.

$29,785

Evaluating Health Providers' Communication with the Terminally Ill

Over the last ten years, medical educators have identified deficiencies in the care of the terminally ill and developed interventions to correct the problems, yet it is difficult to know if these interventions are improving physicians' interactions with dying patients. The research team will develop techniques for evaluating the abilities of doctors and medical students to perform two critical tasks in the care of the dying—giving bad news and eliciting patient preferences.

A Healing Touch
Zen Hospice Project

Vermont Ethics Network

Montpelier, VT
Arnold Golodetz, M.D.

$64,970

Journey's End Project: Vermont Voices on Death and Dying

Using a grassroots approach, the Vermont Ethics Network held a series of 35 community forums to discuss what Vermonters think about care of the dying, based upon their personal experiences, and what recommendations they have for improving care of the dying in this state. Information from the forums will be collected in a report and shared with health care providers and others in order to develop practical guidelines for achieving the public's goals. The goals and guidelines will then be presented to policy makers for further discussion and eventual implementation.

Zen Hospice Project

San Francisco, CA
Frank Ostaseski

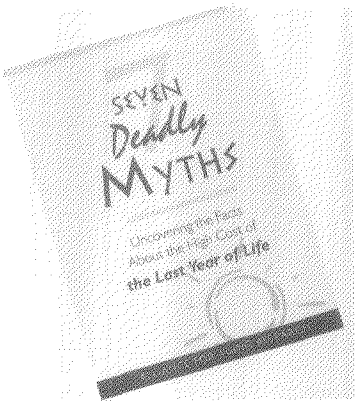
$90,000

Cultivating Compassion: Education Program for Caregivers

Inspired by a 2,500-year-old Buddhist tradition of contemplating sickness, old age, and death as a means of being fully alive, Zen Hospice Project provides a spectrum of collaborative volunteer programs, residential care, and training which aim at cultivating wisdom and compassion through service. "Conscious caregiving" allows for an openness to death as a vehicle for transformation while attempting to meet resistance, anger or denial with equanimity and kindness. This community, professional, and client education program will encourage a more mindful and compassionate approach to care of the dying.

The Shaping of Governmental and Institutional Policy

PDIA's interests in this category included evaluating and changing federal, state, and local government policies around dying and bereavement; the role of large health care delivery systems; government reimbursement issues; the development and maintenance of an appropriate work force through, among other practices, the establishment of accreditation and certification standards; the role of professional clinical practice guidelines; and the implications of health care reform for the care of the dying and bereaved.



Alliance for Aging Research
Washington, DC
Daniel Perry

$74,509

A Study of the Health, Financial, and Psychoscocial Burdens Faced by Older Women at the End of Life

$93,959

Health Care Costs of the Elderly, Terminally Ill

Extensive research reveals that physician and hospital costs for people in their 80s and 90s are lower than for younger groups. Yet the myth of the elderly, terminally ill patient consuming large amounts of resources shortly before he or she dies still pervades our national consciousness. The Alliance seeks to shatter such myths with its study of current literature and scientific data, *Seven Deadly Myths: Uncovering the Facts about the High Cost of the Last Year of Life*.

Association of Academic Health Centers
Washington, DC
R. Knight Steel, M.D.

$35,000

Education of Physicians About Dying

It is now well documented that persons deemed to be dying, either because of extreme old age or disease, may be viewed negatively by the medical profession or, worse, somehow judged to be unworthy of concentrated medical effort. In part, this mind-set is fostered by an educational process which has focused attention on "aggressive" intervention and the usual three-step sequence of diagnosis, treatment, and cure. This is true notwithstanding the changing nature of disease from acute to chronic and the aging of the population.

In order to address these shortcomings, the project attempted to influence care by directing its attention to the education of physicians, specifically the requirements for training as detailed by the Residency Review Committees and the contents of examinations administered by the specialty boards. Both clearly have a profound effect on the curriculum in the postgraduate years and on what is "really important to know" by physicians in training.

Canadian Palliative Care Association
Ottawa, Ontario, Canada
Linda Lysne

$25,000

Canadian Palliative Care Initiative

Only 5 percent of Canadians have access to comprehensive palliative care services. Many recent palliative care discussions have taken place within the context of debates regarding the rights of terminally ill patients to euthanasia/physician-assisted suicide. A growing literature strongly suggests that these requests often emanate from patients with poorly controlled symptoms accompanying end-stage disease. The Canadian Palliative Care Association will serve as a catalyst for advancing and integrating palliative care throughout Canada and will consist of a faculty scholars program, studentships, and a grants program. Inspired by the work of the Project on Death in America, the initiative was launched by the three Canadian PDIA Faculty Scholars Harvey Chochinov, Gerri Frager, and David Kuhl.

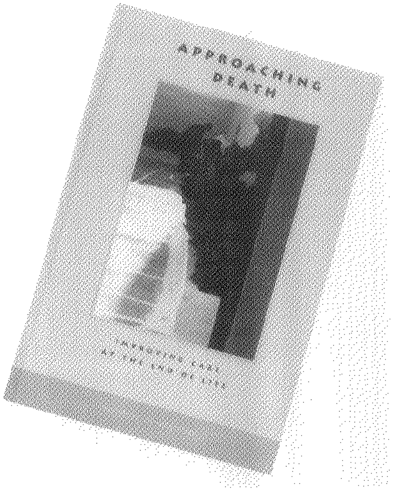
Choice In Dying

New York, NY
Karen Orloff Kaplan, M.P.H., Sc.D.

$35,000

Promotion of Advance Directives

Choice in Dying is a national, not-for-profit organization dedicated to serving the needs of the dying. The organization's activities focus on public and professional education and counseling for the preparation and use of advance directives—the general term for a living will and a medical power of attorney.



Institute of Medicine

National Academy of Sciences
Washington, DC
Marilyn J. Field, Ph.D.

$200,000

Approaching Death: Improving Care at the End of Life

In *Approaching Death*, a book-length report published in September 1997, the Institute of Medicine examined the state of knowledge about clinical, behavioral, legal, economic, and other important aspects of care for patients with life-threatening medical problems; evaluated methods for measuring outcomes and assessing quality of care; identified factors that impede or promote high quality care for patients approaching death; and recommended steps that policy makers, practitioners, and others could take to improve care.

Mount Sinai Medical Center

Geriatrics and Adult Development
New York, NY
Christine K. Cassel, M.D.

$75,000

National Committee on Financing Care at the End of Life

The committee seeks to create a Disease Related Group (DRG) for payment for terminal care services delivered to hospitalized patients. This new code will legitimize the practice of palliative medicine by hospital professionals on behalf of their dying patients since a reimbursed activity is much more likely to be viewed as an appropriate function for doctors and hospitals. The program will also train hospital coding administrators and other health care providers on the implementation of the code and develop a brochure on the different issues, questions, and needs of individual audiences.

State of New York
Office of the Attorney General

Albany, NY

Lucia M. Valente

$50,000

Commission on Quality Care at the End of Life

This commission, created by New York State Attorney General Dennis Vacco, will conduct a comprehensive examination and review of current state laws and regulations concerning quality care at the end of life. Among the topics to be explored are existing regulations that improperly limit adequate medication levels; methods of identifying patient depression and fear that often accompany pain; enhanced medical training standards for pain management; and the still-emerging role of for-profit insurers and HMOs in determining patient care levels and needs.

University of Washington

Seattle, WA

Paul G. Ramsey, M.D.

$150,000

Assessing Physician Performance in End-of-life Care

Despite increasing interest in improving end-of-life care, no one has developed a systematic method to assess a physician's performance in directing care and resources to dying patients. The University of Washington's evaluation system will use professional associate ratings from peer physicians and nurses, as well as ratings from patients and their primary surrogates (family or close friends), to assess the physician's skills at the end of life.

University of Wisconsin Medical School

Pain Research Group/WHO Collaborating Center

Madison, WI

David E. Joranson, M.S.S.W.

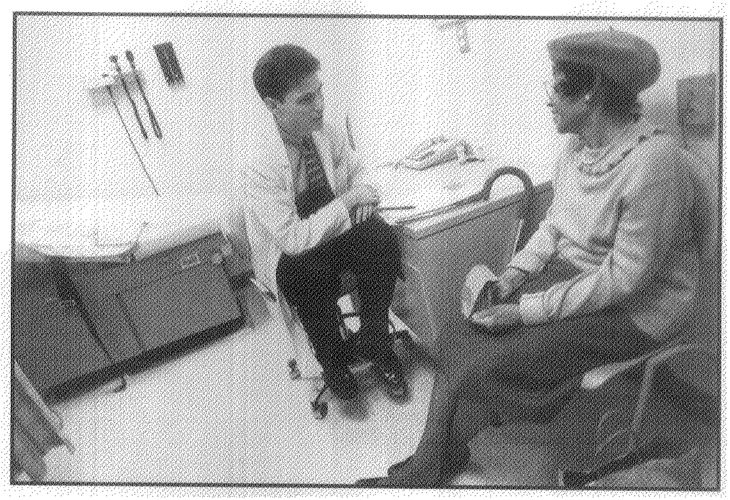
$150,000

Resource Program to Address Barriers to Availability of Opioids for Pain Relief

There are significant barriers to the availability of opioid analgesics, such as morphine, for medical use, although opioids can relieve most, if not all, pain associated with cancer and AIDS. These barriers include inadequate knowledge of pain physiology, pain management, and pharmacology; exaggerated fear of addiction; legal and regulatory restrictions; uneven health care coverage; lack of funding for health care services; high costs of some opioid medications; lack of opioid policy-related studies; and lack of opioid policy initiatives.

A resource program will be developed to improve the capability of the Pain and Policy Studies Group to promote policies for the increased availability of opioid analgesics and to help develop a cancer pain and palliative care initiative for Central and Eastern Europe. The Comprehensive Cancer Center will produce and disseminate a resource guide and create a World Wide Web site. The program is cofunded with The Lindesmith Center.

FACULTY SCHOLARS PROGRAM



R. Sean Morrison, M.D., with patient

IN just three years time, the Faculty Scholars Program has catalyzed interest and activity in improving care for the dying and their families in academic health centers. From its inception in July 1994 through December 1997, the program funded 32 Project on Death in America Soros Faculty Scholars and six Open Society Institute Soros Faculty Scholars, representing 27 of 125 U.S. medical schools and 3 of 16 Canadian medical schools. The program has committed $7 million for awards and administration. The awards of up to $70,000 a year provide scholars with two to three years of support for 60 percent of their time on activities to improve professional practices and education related to end-of-life and bereavement issues. As a result of the program, faculty with an interest in end-of-life care are receiving recognition and support for their efforts to improve care of the dying.

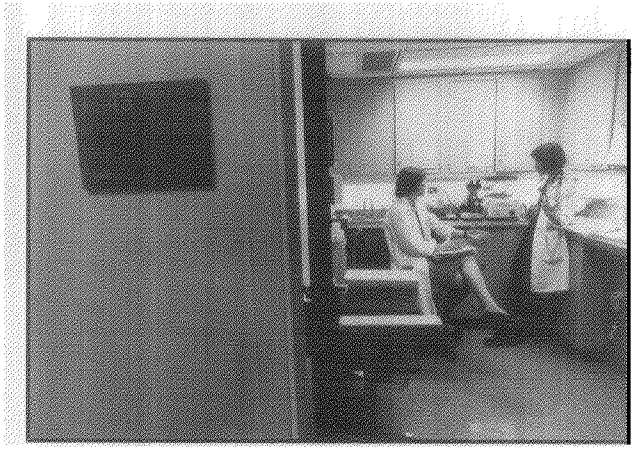
During the three years, the faculty scholars worked on creating new models of care for the dying and bereaved, new knowledge about the experiences and needs of the dying and their families, and new educational offerings for health professionals in this area. The broad range of activities included three projects on psychiatric aspects of end-of-life care; a project on prognostication and hospice referral; an examination of end-of-life care among chronically ill children and their families; the development of five new service-delivery systems for the dying and their families; a project on emotional and spiritual suffering among the dying; six programs related to physician education about end-of-life issues; three quality-improvement projects related to end-of-life care; an examination of end-of-life care practices in managed care; a study of the cost effectiveness and efficacy of end-of-life care; and a project on quality of end-of-life care measurement.

Of the 38 faculty scholars, 24 are men and 14 are women. The scholars include three nurses, a physician-sociologist, and a psychologist. The Faculty Scholars Program is increasing its efforts to recruit minorities as well as faculty in nursing, social work, law, pastoral care, and the medical social sciences.

The Faculty Scholars Program organized five retreats, including two that emphasized the scholars' own work, one on "Teaching Communication Skills for End-of-Life Care," and another on "Changing the Terrain of End-of-Life Care." These retreats and other meetings have helped bring the scholars together as a community with common intellectual interests, patient-care dilemmas, and a commitment to education. Since there is still relatively little interest in the field of end-of-life care among medical school faculty, the community offers members an opportunity for collective problem-solving, consultation, and peer review. Scholars are collaborating on projects such as the development of a process for evaluating communication skills related to end-of-life care and the creation of an end-of-life curriculum for primary care residents.

The program has enhanced the visibility of the faculty scholars and provided them with the recognition and support to become more effective leaders and mentors within their fields. Institutional publications profiled many of the scholars; in addition, several received broad local and national publicity for their end-of-life care activities. The scholars attest to the critical importance of their awards in moving them into more central and valued positions within their institutions and confirming that work with the dying is legitimate, important, and an opportunity for professional growth and recognition.

Susan Block, M.D.
Director, Faculty Scholars Program

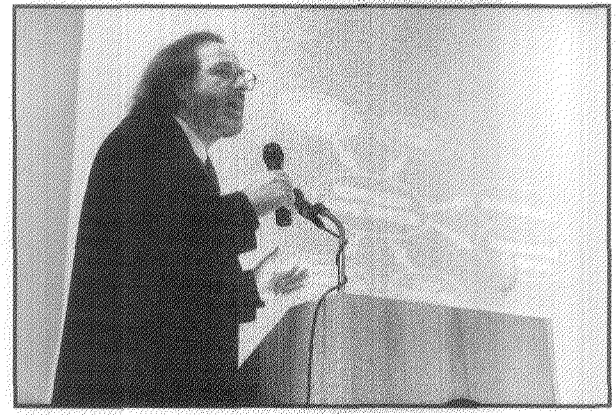


Jane Morris, R.N., and Diane E. Meier, M.D.

Mission

The Faculty Scholars Program of the Project on Death in America supports outstanding clinicians, educators, and researchers in disseminating existing models of good care, developing new models for improving the care of the dying, and creating new approaches to the education of health professionals. One of the goals of the scholars program is to promote the visibility and prestige of clinicians committed to this area of medicine and to enhance their effectiveness as academic leaders, role models, and mentors for future generations of health professionals.

1995-1996
Faculty Scholars



William Breitbart, M.D.

J. Andrew Billings, M.D.
Harvard Medical School
Cambridge, MA

Palliative Care Service at Massachusetts General Hospital

In the United States, modern principles of palliative medicine have not been adopted in the hospitals where the majority of Americans still die and where so many physicians learn to practice. In the prevailing medical culture, death is often viewed by physicians as a personal and professional failure, rather than a fact of life to which we can attend skillfully and compassionately. The project will bring hospice-like care into the general hospital, support ambulatory services for dying persons, and promote excellent terminal care in the home, nursing home, and other institutional settings.

William Breitbart, M.D.
Memorial Sloan-Kettering Cancer Center
New York, NY

Training and Education in the Psychiatric Dimensions of Palliative Care

Major psychiatric disorders such as depression, suicidal tendencies, anxiety, and delirium complicate the course of illness in over 50 percent of individuals dying with advanced cancer or AIDS. Yet the vast majority of these psychiatric complications go unrecognized and untreated. This deficiency in the care of the dying has enormous consequences, influencing how death is viewed by family members for generations to come and by society at large. Dying is seen as a horrific experience, and so avoidance, denial, and escape become the major forms of relating to death in our culture. This project will address the problem of inadequate psychiatric care of dying patients through a program of education and training activities undertaken in collaboration with colleagues at Memorial Sloan-Kettering and other institutions in North America.

Nicholas Christakis, M.D., Ph.D., M.P.H.

University of Chicago Medical Center
Chicago, IL

Physicians' Prognoses about Death and Their Relation to Patient Referral to Hospice

In 1993, 246,000 patients received hospice services from approximately 2,000 hospice care providers. To reap maximum benefit from hospice care, the decision to refer a patient must be properly timed so that the services provided are neither unnecessarily short nor long. This study expands our understanding of how physicians make prognoses about death and how such predictions influence decisions to refer patients for hospice care. Physicians show substantial optimistic bias in their survival predictions and may thus be needlessly delaying hospice referral.

Stuart Farber, M.D.

Multi-Care Health System
Tacoma Family Medicine
Tacoma, WA

Curriculum on Dying for a Family Medicine Residency Network

This innovative curriculum on the care of the dying will teach residents and faculty of the Family Practice Residency Network of the University of Washington School of Medicine the attitudes, knowledge, values, and skills to assist patients in achieving as "good" a death as possible. The residency network consists of 15 programs in Washington, Alaska, Montana, and Idaho, training over 225 residents each year.

Gerri Frager, R.N., M.D.

Dalhousie University
Isaak Walton Killam-Grace Health Centre
for Children, Women & Families
Halifax, Nova Scotia, Canada

Pediatric Supportive Care Program for Children with a Life-threatening Disease

In many childhood diseases, such as AIDS and some cancers, there is often a blurring of the boundary between cure and palliation. Aggressive treatment directed against the disease is often continued while the child is in a prolonged terminal phase. The majority of parents and physicians find it difficult to make the transition to palliative care when dealing with a child. The project will develop an education program and provide information and support to health care professionals and families of children with a life-threatening disease.

> **"Part of the philosophy of hospice is that it neither hastens nor postpones death. It just recognizes that dying is part of life."**
>
> Nicholas Christakis

Carlos F. Gomez, M.D.
University of Virginia School of Medicine
Charlottesville, VA

Narrative Database in a Palliative Care Program

The University of Virginia serves a predominantly rural, indigent population that has developed unique ways of describing pain, suffering, death, and their desires and needs with respect to end-of-life care. Analyzing the narratives of patients and their grieving families will increase knowledge of the needs of terminally ill patients in the region and help in developing a model program in palliative care.

Sarah J. Goodlin, M.D.
White River Junction VA Medical Center
and Dartmouth Medical School
White River Junction, VT

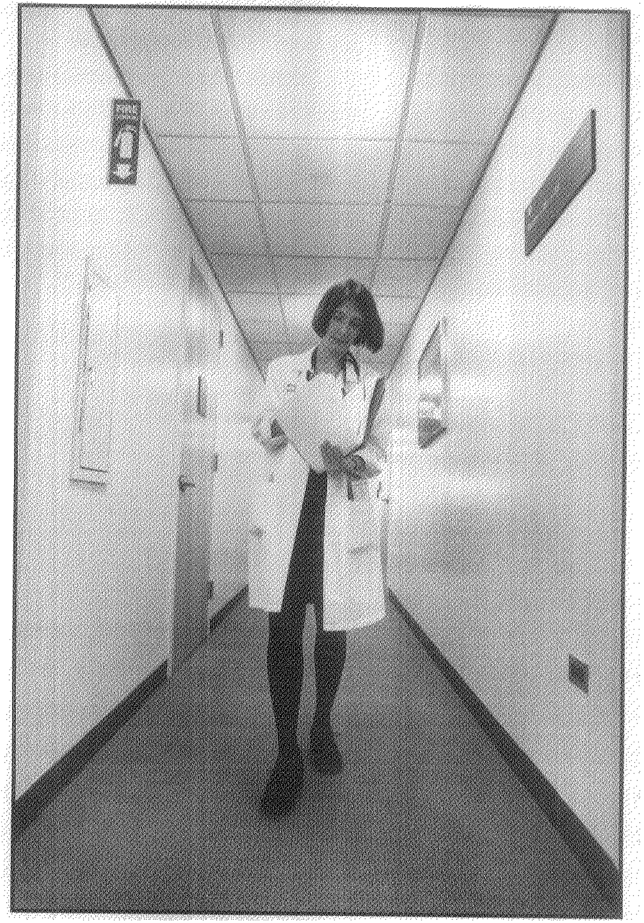
Care of Dying Patients in the Connecticut River Valley

Quality in palliative care is dependent not only on knowledge but on establishing effective systems and coordinating an interdisciplinary team of providers, including physicians, nurses, social workers, spiritual counselors, and hospice volunteers. The project will create a care "pathway" of hospitals, clinics, hospices, and nursing homes for delivering palliative care in the region.

Diane E. Meier, M.D., Ph.D
Judith C. Ahronheim, M.D.
Jane Morris, R.N.
R. Sean Morrison, M.D.
Mount Sinai School of Medicine
New York, NY

Palliative Medicine in the Acute Care Hospital: A Model for Education, Professional Development, and Clinical Care

As recently as 1989, a study found that only 18 percent of 111 responding hospitals required a separate course on death and dying. The vast majority of doctors in training have no exposure to hospice care. The project will develop a corps of physicians trained in palliative care to serve as teachers and mentors to students, residents, and other physicians, and to provide palliative care consultation to patients in hospital and home care settings.



Diane E. Meier, M.D.

Steven H. Miles, M.D.
University of Minnesota,
Center for Biomedical Ethics
Minneapolis, MN

Curriculum on End-of-life Care in a Managed Care Program

Managed health care systems are the fastest growing part of the health care system, and will likely be the dominant delivery system in the United States in 10 to 15 years. Managed care covers approximately 80 percent of the market in the Minneapolis–St. Paul metropolitan area. The project will assess end-of-life care in managed care systems and then, using its findings, develop a curriculum for teaching appropriate end-of-life care.

Thomas J. Smith, M.D.
Virginia Commonwealth University
Massey Cancer Center
Richmond, VA

Efficacy and Cost Effectiveness of End-of-life Care

Cancer is costly, and will become more costly. The aging population, shrinking resources, new technologies, and the switch to managed care will make attempts to control cost inevitable. Dr. Smith's project is evaluating the efficacy and cost effectiveness of end-of-life care options, including hospice. Before the decision to switch to hospice, patients use many more health care dollars during the active phase of their treatment. The group that switches to hospice is the group that may need the resources least: white, upper middle class, well educated. Dr. Smith's team has set up a hospice and palliative care unit for the medically underserved to assess their needs and costs of care.

James A. Tulsky, M.D.
Duke University Medical Center
Durham, NC

Model for Improving Physician Communication with Dying Patients

The dying patient confronts a complex series of challenges: severe pain and suffering, decisions about the use of life-sustaining treatments, emotionally disturbing changes in body image and function, and spiritual questions that may result in a disrupted sense of personal integrity. Physicians often speak to these patients solely in the "medical voice," concentrating on biomedical issues, without acknowledging the patient's personal concerns. The goal of this intervention is to develop a model for teaching medical students and house staff how to communicate better with the dying patient. To provide proper care, doctors must learn to listen, understand, and respond with honesty and sensitivity.

Charles F. von Gunten, M.D., Ph.D.
Northwestern University Medical School
Chicago, IL

Visiting Palliative Care Education Program for Health Care Professionals

Most health care professionals have received inadequate education about end-of-life care. Using the clinical setting of the Palliative Care Service of Northwestern University Medical School, the program will provide practical training in the care of the dying for professionals who have completed their formal training and begun their careers.

> **"If I am known as a doctor who specializes in the care of the dying, then maybe a frightened, overwhelmed intern will know to call me for help rather than walk away because he mistakenly thinks there is 'nothing more that can be done.' There is a joy in helping other physicians, whether they be medical students, residents, fellows, or physicians in practice, to learn to care for patients with advanced, incurable illness in the context of palliative care. The new skills they learn enable them to make patients and families 'heal' in ways they hadn't thought possible, and to feel a new sense of competence as physicians."**
>
> Charles F. von Gunten

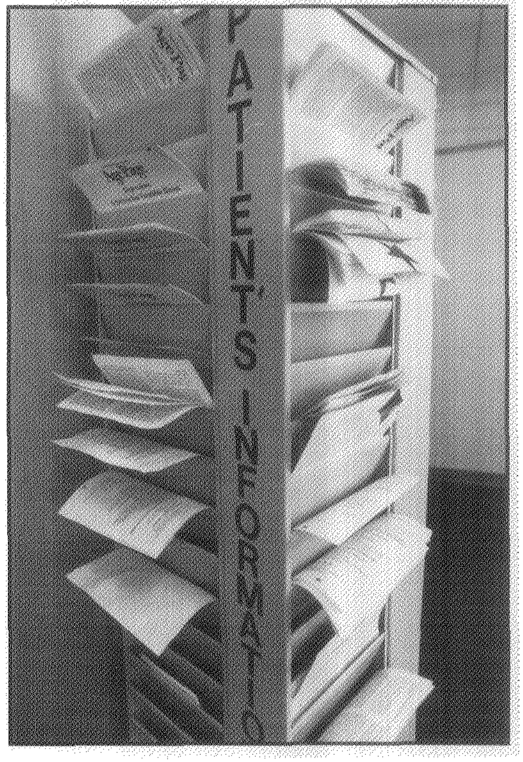
1996-97

Faculty Scholars

David E. Weissman, M.D.
Medical College of Wisconsin
Milwaukee, WI

Death Education Curriculum in Primary Care Residency Programs

Graduate physician education in the area of end-of-life care has received very little attention in the United States. As key providers of end-of-life care, primary care physicians are in a tremendous position to influence the type and manner of such care for patients and families. To meet the need for education in end-of-life care, Dr. Weissman's project is designing a comprehensive death education curriculum for primary care residency programs. Residency programs in family medicine and general internal medicine at the Medical College of Wisconsin are currently participating in the project. The goal is to develop a self-sustaining education and evaluation program using the unique resources of each individual program.



Harvey Max Chochinov, M.D., F.R.C.P.C.
University of Manitoba
Winnipeg, Manitoba, Canada

Psychiatric Dimensions of Palliative Medicine

Some of the factors leading to a patient's desire for death may be remediable not only by improved pain management but by the treatment of psychological distress. Dr. Chochinov's project will explore the role of screening instruments in identifying clinical depression in dying patients, the extent to which psychological variables are associated with physical sources of symptom distress, and the inherent transience of many terminally ill patients' expressed desire to die.

Timothy J. Keay, M.D., M.A.-Th.
University of Maryland School of Medicine
Baltimore, MD

End-of-Life Medical Care in Nursing Homes

Over one-fifth of Americans die in nursing homes, yet little has been done to systematically improve the quality of their end-of-life care. The primary goal of Dr. Keay's project is to develop a model curriculum for educating nursing home physicians and providing such education in selected nursing homes in the Baltimore area. It is expected that the educational intervention will measurably improve the quality of end-of-life care for nursing home residents.

David R. Kuhl, M.D.
University of British Columbia
St. Paul's Hospital
Vancouver, British Columbia, Canada

Spiritual and Psychological Issues at the End of Life

Much of what physicians know about dying is based on observation of the patient. Very little medical literature exists that describes the experience from the perspective of the one who is dying. Only in hearing the stories of the dying will our understanding and knowledge of this stage of life be enhanced. Dr. Kuhl will study the psychological and spiritual components of pain and suffering as experienced by persons with terminal illness. This information will be used to develop an educational module for family physicians and a training program for palliative care teams so that they are better prepared to provide emotional, psychological, and spiritual support.

Marcia Levetown, M.D.
University of Texas Medical Branch at Galveston
Galveston, TX

Cross-disciplinary Model for Teaching Palliative Care

Most graduating medical students have no compunction about asking patients about sexual activities or drug use, yet medical practitioners remain reluctant to raise the subject of dying or to talk about treatment options prior to death. Dr. Levetown's project will assess physician and nurse attitudes toward death, then develop and implement a cross-disciplinary model for teaching palliative care. The survey will cover health care professionals caring for terminally ill pediatric as well as geriatric patients. The lack of acceptance of childhood death has led to a dearth of pediatric palliative care programs, often leaving families with no options but continued "curative" management.

Michael Lipson, Ph.D.
Columbia College of Physicians and Surgeons
Harlem Hospital
New York, NY

Attentional Dynamics Training: Personal Death Awareness for Health Professionals

Physicians who cannot answer the pager or nurses who cannot enter the room of a dying patient—and many less blatant manifestations of avoidance—show how much remains to be done in terms of health professionals' own reconciliation to death. Dying cannot be viewed by physicians and nurses in the same way as conditions resulting in physical recovery. The project aims at the development of a training program for health professionals that recognizes the unique quality of dying. In Attentional Dynamics Training, participants learn the fundamental skills of attending the dying, recognize and ameliorate their own problematic relationship to issues of death and loss, and apply what they have learned in communicating with terminally ill patients.

Susan J. McGarrity, M.D.
Pennsylvania State University Hospital
Milton S. Hershey Medical Center
Hershey, PA

The Role of the Academic Institution in Palliative Care

As we approach the new millennium, more Americans will survive into advanced age, and the number suffering from chronic diseases such as cancer and AIDS will continue to rise. In Central Pennsylvania, approximately 15,000 patients will be newly diagnosed with cancer each year. All of these patients will need appropriate pain and symptom management at the end of life.

The goal of Dr. McGarrity's program is to improve the quality of life for terminal patients and their families by optimizing pain and symptom management, providing psychological, social, and spiritual support services, and offering grief counseling and bereavement support follow-up. The program will help define the role of the academic institution in palliative care by conducting education and research and establishing a network of palliative care services.

Walter M. Robinson, M.D., M.P.H.
Harvard Medical School
Children's Hospital
Boston, MA

Terminal Care for Children Dying of Noncancer-related Causes

The clinical and ethical basis of compassionate terminal care developed out of the experiences of patients and clinicians with cancer. In the cancer model, the high morbidity of the anti-neoplastic agents used in chemotherapy meant that the decision to halt therapy and redirect the goal of care led to increased comfort for the patient. As a result, the designation of terminal care as "comfort care only" is commonplace, and it has been suggested that the continued provision of therapeutic care to the terminally ill indicates an unhealthy ambivalence on the part of the caregivers.

Dr. Robinson's recent clinical study of children and adults dying of another terminal illness, cystic fibrosis, demonstrated that no clear demarcation between therapeutic and palliative care could be established. Therapeutic and palliative goals were pursued simultaneously even in the last 24 hours of life. In this new study, Dr. Robinson will continue to examine the medical and ethical aspects of end-of-life care for children dying of noncancer-related illness and develop a specialized team of physicians, nurses, and other caregivers to meet their particular needs.

John Lee Shuster, Jr., M.D.
University of Alabama at Birmingham
UAB Hospice
Birmingham, AL

Curriculum for Neuropsychiatric Complications of Terminal Illness

Neuropsychiatric conditions, especially anxiety, confusion (delirium), and depression are common complications of terminal illness. In terminal cancer, the prevalence of depressive disorders has been reported to be as high as 77 percent, the prevalence of delirium as high as 85 percent. Effective, reliable, readily available treatments exist for all these conditions, but they are underutilized because the nonpsychiatric physicians who care for the dying lack the training to recognize and treat the disorders. Dr. Shuster will develop clinical and educational programs focusing on psychiatric issues in terminal care.

Daniel P. Sulmasy, O.F.M., M.D., Ph.D.
Center for Clinical Bioethics
Georgetown University Medical Center
Washington, DC

Quality Time: Measuring and Improving the Quality of Care Rendered to Inpatients at the End of Life

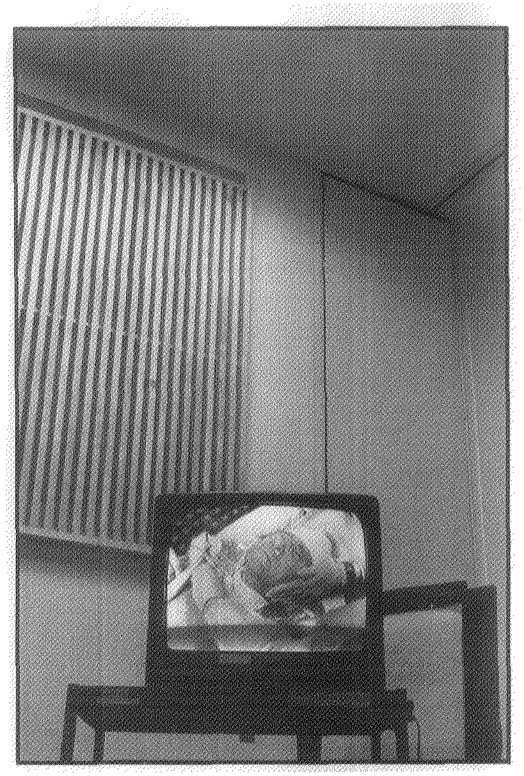
Hospital staff often interpret a Do Not Resuscitate (DNR) order to mean that their services are no longer needed. Placing limits on technologically sophisticated care may, in fact, signal a need to spend more time at the bedside, providing such comfort measures as simple human contact and empathy. Dr. Sulmasy's project will assess the differences in the quality of care between patients with and without DNR orders and study the impact of an educational initiative for improving patient care and family satisfaction.

Sharon M. Weinstein, M.D.
University of Texas
M.D. Anderson Cancer Center
Houston, TX

Palliative Intervention in Tertiary Cancer Care

Health care providers are not educated in ways to integrate primary and palliative goals of treatment. Profound confusion in American culture about the use of opioid drugs as analgesics and poor assessment of pain and other symptoms add to the problem. In order to improve the care of the dying, Dr. Weinstein will study medical decision making at the transition points from curative to palliative care for cancer patients, and from the tertiary center to hospice care. Improvement in the quality of end-of-life care by integrating palliative care interventions into cancer treatment will be attempted through the development and implementation of standardized clinical care plans.

1997-98 Faculty Scholars



Janet L. Abrahm, M.D., F.A.C.P.
University of Pennsylvania
Philadelphia, PA

Disease Management Program for the Care of the Dying

To provide quality care at an affordable price, the University of Pennsylvania Health System has chosen disease management, an integrated, system-wide, information-driven approach to patient care. Disease management strategies, which are commonly used for asthma, cancer, diabetes, and cardiovascular diseases, can also be applied to many categories of dying. Those dying from cancer or AIDS, for example, share many of the same distressing symptoms and may develop similar complications. And those dying from heart or lung failure may experience the anorexia, dyspnea or delirium that afflict those with cancer or AIDS.

Dr. Abrahm will develop a disease management program for the care of the dying within the university's health system that will identify "critical junctions" in the dying process to assure quality of care and effective use of resources. The project will help health care personnel attend to the medical, psychosocial, and spiritual needs of the dying and the bereaved whether in a hospital, nursing home, or their own homes.

Robert Mark Arnold, M.D.
University of Pittsburgh
Montefiore University Hospital
Pittsburgh, PA

Teaching Physician Change-Agents to Communicate with Terminally Ill Patients About Psychosocial and Ethical Aspects of Care

A major barrier to competent palliative care is the inability of many physicians to communicate well with dying patients. Physicians find it difficult to inquire directly about the emotional status of a dying patient. When patients express negative emotions, doctors often distance themselves with false reassurance or selective attention. This behavior precludes doctor and patient from working together to develop strategies for facing death and finding meaning from loss and suffering.

Dr. Arnold and his colleagues will teach oncologists, geriatricians, and doctors caring for HIV-positive patients how to communicate more effectively about the ethical, psychosocial, and existential issues surrounding terminal care. These physician change-agents, in turn, will train other health care providers at their respective institutions in an effort to improve the care of dying patients in Western Pennsylvania.

J. Randall Curtis, M.D., M.P.H.
University of Washington
Seattle, WA

Quality of Communication About End-of-Life Care

This study is based on the hypothesis that effective patient-doctor communication about end-of-life medical care can improve the quality of the dying experience for persons with AIDS and minimize unnecessary intensive medical care. The main goals of the study are to develop a method to measure the quality of the dying experience among persons with AIDS, assess the relationship between quality of patient-doctor communication about end-of-life care and the quality of the dying experience, and train physicians in health services research concerning the quality of end-of-life care.

Joseph J. Fins, M.D.
New York Hospital-Cornell Medical Center
New York, NY

Reconstructing the Care of the Dying through the Integration of Clinical Ethics and Palliative Care

In the acute care setting, clinical ethicists have focused on crisis management and uncommon ethical dilemmas while, in hospices, practitioners of palliative care have concentrated on the more common needs of the dying patient and his or her family. Recognizing that the care of the dying can be improved through integrating clinical ethics and palliative care, Dr. Fins will establish a model educational program that links the two disciplines in a hospice-like Alternative Care Unit currently under development. The centerpiece of the program will be a joint fellowship in clinical ethics and palliative care, producing professionals whose integrated knowledge of both fields will help transform institutional attitudes and behavior.

Laura C. Hanson, M.D., M.P.H.
Martha Henderson, M.S.N., D.Min.
University of North Carolina at Chapel Hill
Chapel Hill, NC

Improving Nursing Home Care for the Dying

As hospital stays shorten and nursing homes develop more sophisticated health services, the number of deaths in nursing homes is increasing. One in two individuals who reach the age of 65 can expect to spend time in a nursing home, and about one in four older adults will die in a nursing home bed. Death is therefore a familiar experience for residents and those who care for them, yet little attention is given to the needs of the dying in nursing homes.

In two skilled nursing facilities serving 180 residents, with a staff of 10 physicians and 168 nurses and nursing aides, Laura Hanson and Martha Henderson will determine the unique social characteristics and health care needs of dying residents and develop a nursing home resident-centered model of terminal care to meet these needs.

> **"Ms. J. was an alert, though acutely ill, 86-year-old woman with deforming arthritis. She confided in me, her young registered nurse, 'My body is worn out. I am tired. I am ready to die.' Later that day, when Ms. J. arrested, I had to call a code. As the intern and I crunched her frail chest and tried to bring back life, I told him her wishes. He listened, and we stopped, but it felt too late. This incident, 28 years ago, affected me greatly. I know there had to be a better way for people to die."**
>
> Martha Henderson

Nancy Hutton, M.D.
Johns Hopkins Children's Center
Pediatric HIV/AIDS Program
Baltimore, MD

Completing the Circle: End-of-Life Care for Children with AIDS

The model for home hospice care for the dying child—which assumes a bereaved but otherwise healthy family with personal and financial resources—barely exists for many children with AIDS. The child's mother, inflicted with the same disease, may also be dying, precluding her ability to provide care for her dying child. She may feel guilty about giving her child HIV in the first place; she may be isolated from family and friends; she may be an active substance abuser. The purpose of Dr. Hutton's project is to design, implement, and evaluate a comprehensive model program of care at the end of life for children with HIV/AIDS at Johns Hopkins. This program includes comprehensive medical and social services for the children and their families.

Betsy MacGregor, M.D.
Beth Israel Medical Center
New York, NY

Project on Dying and the Inner Life

The inner life, which might be defined as the psychological-spiritual dimension of human experience and awareness, can play a significant role in preparing for the end of life. This project will investigate the inner life experiences of people with terminal illnesses, their family caregivers, and health care professionals. Through the use of relaxation and self-reflection techniques, together with in-depth interviews and research, the project will evaluate the potential in attending to the inner life as a resource for those involved with dying.

Marianne LaPorte Matzo, Ph.D., R.N., C.S.
New Hampshire Community Technical College
Manchester, NH

Care for the Dying Patient: An Educational Program for the Associate Degree Nursing Student

In New Hampshire, 75 percent of the nursing candidates are from associate degree programs and are primarily employed in acute and long-term care settings. For the majority of people who are dying, it will be these nurses who will help manage their pain and symptoms as well as support them through this process. Yet there are no curriculum materials regarding care of the dying patient written specifically for the Associate Degree in Nursing student. Dr. Matzo will develop an educational program for associate degree nursing students to improve the quality of care to dying adult patients and their families.

> **"When others feel there is nothing else to do, I feel my work has started anew with a fresh vision of 'healing'—relief from pain, loneliness, and fear."**
>
> **Nancy Hutton**

Peter A. Selwyn, M.D., M.P.H.
Yale University School of Medicine
New Haven, CT

Care of Patients with Late-Stage AIDS in a Skilled Nursing Facility

A recent development in the continuum of HIV care services has been the emergence of the need for long-term institutional care, especially skilled nursing care, for late-stage patients. This need will only grow over time due to managed care pressures and improvements in HIV therapy which can prolong life but often at a level of severe debility, requiring more intensive medical and nursing care as patients approach death. At Leeway, a 30-bed skilled nursing facility for people with AIDS, Dr. Selwyn is creating a model center for care, teaching, and research involving late-stage patients. The center aims to improve clinical outcomes for patients and their families and provide care providers with a greater understanding of the unique end-of-life issues faced by this population.

Wayne A. Ury, M.D.
St. Vincent's Hospital & Medical Center
of New York
New York, NY

A Palliative Medicine Curriculum for an Internal Medicine Residency Program

The patient population of St. Vincent's, an 800-bed acute care facility, consists of a large number of persons with AIDS (21 percent) and various types of cancer (8 percent). The internal medicine residency program places great emphasis on primary care medicine and humane patient care, yet palliative care is not included in the residency curriculum. A review of the literature indicates that there are very few palliative care curricula for medical residents. The goal of this institution-specific palliative care curriculum is to improve the care of the dying, change the attitudes and practices of doctors, and transform the hospital milieu with regard to care of the dying.

Neil S. Wenger, M.D., M.P.H.
University of California at Los Angeles
Los Angeles, CA

Measuring and Improving the Quality of Care for Seriously Ill Inpatients toward the End of Life

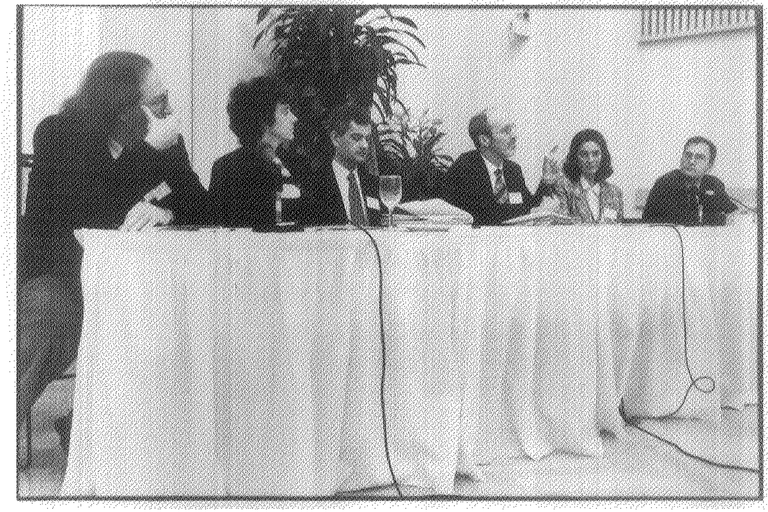
The low quality of death in American hospitals and rapid changes in medical economics to reduce expensive care demand the development of objective performance measures for the quality of care at the end of life. This project will develop criteria to assess the quality of care delivered to seriously ill and dying patients, and use these new indicators to evaluate an intervention designed to improve care through more effective physician communication, decision making, and documentation.

PDIA Faculty Scholars

Standing (left to right): Peter Selwyn, Laura Hanson, Randall Curtis, Charles von Gunten, Walter Robinson, Susan Block (Faculty Scholars Program director), John Shuster, Judith Ahronheim, Stuart Farber, Jane Morris, Neil Wenger, Sean Morrison, James Tulsky, Joseph Fins, Marianne Laporte Matzo, Robert Arnold, Nicholas Christakis, William Breitbart, Daniel Sulmasy, David Kuhl, Andrew Billings.

Kneeling (left to right): Wayne Ury, Susan McGarrity, David Weissman, Nancy Hutton, Martha Henderson, Joanne Lynn (PDIA Advsory Board), Harvey Chochinov, Janet Abrahm, Thomas Smith, Steven Miles.

Sitting (left to right): Kathleen Foley (PDIA director), Diane Meier, Marcia Levetown, Michael Lipson, Gerri Frager, Betsy MacGregor, Sharon Weinstein, Sarah Goodlin, Robert Burt (PDIA Advisory Board), Timothy Keay.



Physician-Assisted Suicide and America's Culture of Death
Conference speakers: William Breitbart, M.D., Susan W. Tolle, M.D., John J. Collins, FRACP, Timothy E. Quill, M.D., Judith C. Ahronheim, M.D., and Carl H. Coleman, J.D.

FOUNDATION NETWORKS

Grantmakers Concerned with Care at the End of Life

PDIA continued to develop and expand networks for increased public engagement in end-of-life issues by participating in the creation of Grantmakers Concerned with Care at the End of Life. A steering committee of PDIA, the Commonwealth Fund, the Nathan Cummings Foundation, the Robert Wood Johnson Foundation, and the Rockefeller Family Office, formed after an initial meeting of interested funders in November 1995, defined the new group's mission, activities, and organizational structure and announced its establishment in the fall of 1996.

The purpose of Grantmakers Concerned is to educate other foundations about what they can do to aid the research and development of new systems of care, help shape governmental and institutional policy, and provide broad public and professional education programs that focus on improved care for the dying, their families, and their caregivers. Grantmakers Concerned also aims to provide a forum for the rational debate of all end-of-life issues and to increase inter-foundation communications about projects funded and knowledge acquired. To accomplish its mission, the new funders group plans to organize conferences for foundations on the various issues of concern and disseminate information through a newsletter and over the Internet. Its first conference, organized by PDIA in November 1996, focused on Physician-Assisted Suicide and America's Culture of Death. The Robert Wood Johnson Foundation prepared the group's second conference in June 1997 on Paying for Care at the End of Life.

Inner Life Meeting

In another effort to inform people about issues in dying, PDIA, the Nathan Cummings Foundation, and the Fetzer Institute organized a meeting on dying and the inner life at Fetzer's retreat center in Kalamazoo, Michigan. The meeting of some 30 physicians, medical educators, clergy, social workers, hospice workers, and foundation directors focused on inner life because of the belief that the emotional, psychological, and spiritual lives of the dying, their families and caregivers need to be understood and supported.

The participants explored both Western religious traditions and Eastern contemplative traditions as alternatives and companions to the current approach to death in America, where dying is handled primarily as a physiological medical event to be managed in a highly isolated, medicalized setting. Among the initiatives supported by participants were increased public discussions about death and dying; better training of medical and social service professionals about inner life issues; and further study of the factors that contribute to a "good death," including the beliefs and practices of various religious and cultural groups.

LAW AND POLICY

Supreme Court Amicus Brief on Physician-Assisted Suicide

In the 1996-97 session, the Supreme Court heard arguments on whether terminally ill patients had a constitutional right to physician-assisted suicide. Two federal appellate courts, in cases involving the states of New York and Washington, had ruled that such a right did exist for people who are terminally ill, mentally competent, and acting voluntarily. The case heightened debate over an issue that deeply divides the public and the medical profession.

In an amicus brief written by Advisory Board member Robert Burt of Yale Law School, PDIA argued against a definitive ruling on physician-assisted suicide at this time, because the states have not had a chance to explore different solutions to a complex societal problem or, if physician-assisted suicide becomes an option, to fashion effective safeguards against abuses. A dying person suffering from intense pain, for example, cannot voluntarily choose suicide unless available, effective pain treatment is offered. Likewise, a dying person suffering from clinical depression may not be mentally competent to request physician-assisted suicide. Establishing the right to treatment for these conditions is crucial to the care of the dying and may make the question of a constitutional right to physician-assisted suicide moot.

In June 1997, the Supreme Court agreed with PDIA, ruling against a constitutional right to physician-assisted suicide.

Task Force on Human Experimentation on Persons Near Death

Persons near death have long served as subjects in medical experimentation. Although much of this research has been of high quality and of benefit to its human subjects, the practice has also been marked by numerous instances in which very sick patients were exposed to grave experimental risks without their consent or any realistic chance of therapeutic benefit to them. The vulnerability of persons with incurable fatal illnesses, desperate for cure or comfort, led to federal regulations that protect the research subject by placing restrictions on participation. In recent years, however, the AIDS epidemic has produced a movement toward challenging protective protocols. People living with AIDS, weighing risks against potential benefits, have demanded the right to be part of scientific research programs.

PDIA established the Task Force on Human Experimentation on Persons Near Death to explore the ethics of experimentation at the end of life in the context of the two different models for treating research subjects. In making policy recommendations, the task force will attempt to find ways to strengthen regulatory protection of terminally ill subjects—limiting the power of surrogate decision makers, for example—while increasing opportunities for gravely ill subjects to obtain promising experimental drugs as participants in clinical trials or as volunteers outside the bounds of formal research. The task force, which includes a number of PDIA Advisory Board members and faculty scholars, is co-chaired by Sherry Brandt-Rauf, J.D., of the College of Physicians & Surgeons of Columbia University and Neil MacDonald, M.D., director of the Center for Bioethics at the Clinical Research Institute of Montreal.

MEDICAL EDUCATION AND PRACTICE

Conference on Medical Education for End-of-Life Care

PDIA's wide-ranging programs, as well as the work of other foundations and professional groups, present an opportunity for collaboration in setting values and priorities for medical education for care near the end of life. A consensus statement would be an important force in promoting improvements in medical education and care of the dying. A major challenge in such a collaboration is to recognize the differences in clinical settings for end-of-life care and make educational recommendations honoring these differences—from emergency medicine to pediatrics to the care of persons with AIDS.

PDIA Advisory Board member Susan Block, M.D., David Barnard, Ph.D., and Faculty Scholar J. Andrew Billings, M.D., organized a National Consensus Conference on Medical Education for Care Near the End of Life. The conference, held in early 1997, brought together a range of professional groups and individuals to share innovative educational methods, promote collaboration, and create a consensus statement on medical education for end-of-life care. The consensus statement and conference proceedings and papers will be published in book form. Individual papers for medical educators and practitioners in particular clinical specialties will be prepared and published in appropriate professional journals.

NIH Consensus Conference on End-of-Life Care

PDIA Director Kathleen Foley, M.D., and Advisory Board member Robert Butler, M.D., met with the directors of the various branches of the National Institutes of Health to promote the need for an NIH conference on the care of the dying. NIH consensus conferences bring together researchers, physicians, consumers, and others in an effort to reach general agreement on a given medical procedure or practice. One of the objectives of a conference on end-of-life care would be the creation of a diagnostic code for palliative care that would set standards for quality and permit insurance reimbursements.

A major focus of the conference would be on research questions, needs, and opportunities. What are the common physical and emotional symptoms suffered by those who are dying? What are the key research questions in symptom control? What are the key health care system issues relevant to the dying? Do current reimbursement policies in Medicare, Medicaid, and managed care promote or discourage optimal treatment of the dying?

A History of Death in America

As part of its mission to transform the culture of death, PDIA decided to undertake a multidisciplinary history of death in America in order to analyze the social, cultural, and intellectual forces that have shaped American attitudes toward death, dying, and bereavement. The PDIA Advisory Board felt that understanding the evolution of attitudes and practices over time was crucial to efforts to alter contemporary policy. A history of death in America would shed light on many issues. For example, how did death become a medical event controlled by doctors in a hospital, instead of a life passage at home central to family and community? Why did the country change from a death-accepting culture in the 19th century to today's death-denying culture?

Directed by PDIA Advisory Board members David Rothman, Ph.D., and Robert Butler, M.D., the history project draws upon the contributions of scholars in the fields of historical demography, epidemiology, social history, the history of medicine, legal history, economic history, and the arts. The resulting book will include essays on life expectancy and changing patterns of causes of death; the changing place of death in medical education and practice; the economics of death and dying, including the commercialization of death with the rise of the professional mortician and the cemetery business; popular cultural ideas about death, as revealed in art, music, film, television; remembering the dead, including memorial photography and the wake; and class and ethnic differences in the attitudes and rituals surrounding death.

Project to Improve How Textbooks for Medicine and Nursing Address Issues of Dying

At the turn of this century, medical textbooks described the course of a disease through to death. Today's medical textbooks have completely forgotten to develop—or even retain—this knowledge. Many devote dozens of pages to the pathophysiology of an inexorably progressive disease, addressing the pharmacology of the drugs to use or the fine points of its diagnosis or staging. However, nowhere does the text detail what happens to patients as the physiology fails, or what can be done to make the course of the disease more tolerable for the patient.

The textbook project, directed by PDIA Advisory Board members Joanne Lynn, M.D., M.A., and Robert Butler, M.D., will review current textbooks for shortcomings and promote improvements by meeting with textbook editors to offer study findings and their recommendations and assistance. Follow-up efforts will include a review of new textbooks to evaluate changes in education on end-of-life care. The before and after studies will be published and disseminated. The expectation is that the project will increase the volume and improve the quality of texts addressing dying as well as create a demand for more information about specific dying situations where little is available.

Susan Tolle, M.D., of the Center for Ethics in Health Care, speaking at the conference on physician-assisted suicide.

NEW PROGRAM PRIORITIES

THE end of 1997 marked the close of the Project on Death in America's first three-year funding period. The accomplishments of those three years are a credit to the hard work of PDIA's small, energetic staff and the highly integrative, participatory Advisory Board, whose members possess a range of expertise in the complex issues surrounding the care of the dying. In light of the progress in improving the care of the dying that this report of activities describes, the Open Society Institute committed $15 million to PDIA to continue its work for another three-year period. In this second phase, PDIA will focus its efforts on several major initiatives while maintaining a commitment to health care professional education and training. A summary of PDIA's new program priorities appears on the following pages.

Professional Education Initiatives

Faculty Scholars Program: For the next three years, PDIA will support up to eight faculty scholars a year for a period of two years each. By continuing the faculty scholars program, PDIA will increase the network of scholars and institutions committed to improving care of the dying through appropriate practices and effective teaching. This large network of scholars will transform the care of the dying into a recognized and defined specialty field.

Professional Initiatives in Nursing, Social Work, and Pastoral Care: Nursing, social-work, and pastoral-care professionals play a major role in the care of dying patients and their families. PDIA's strategy for supporting these professional groups involves focus groups of recognized leaders, discussions of each profession's unique needs, and individual "summit" meetings to develop priorities, strategies, and programs for implementation and to identify areas in need of funding. In this way, PDIA hopes to encourage the major professional organizations to adopt agendas for end-of-life care and to create their own innovative approaches to education, training, and research.

Educational Meetings and Conferences: In addition to organizing meetings of nurses, social workers, and pastoral care workers, PDIA will continue sponsoring other conferences to educate health care professionals and the public about the culture of death and the care of the dying. At this writing, the following conferences are scheduled or planned for 1998:

> A national conference on the Care of the Dying in Prisons and Jails. Cosponsored with OSI's Center on Crime, Communities & Culture.

> The First International Conference on Palliative Care Research, at the National Institutes of Health, May 7-9, 1998. Cosponsored with the NIH. The goal of the conference is to bring together PDIA's faculty scholars and grantees and international leaders in palliative care research to present current research activities and outline future research needs.

> A national conference presenting the projects and research of PDIA faculty scholars and grantees.

Humanities Initiatives

On January 30-31, 1998, PDIA hosted an exploratory meeting to generate ideas and possible projects to support and enhance the role of the humanities in transforming the culture of death and dying in America.

To participate in the discussions, PDIA invited distinguished scholars who had explored the subjects of death, dying, grief, and loss in literature, poetry, drama, history, cultural studies, film, video, and photography. The goal of this initiative is to develop an agenda for fundable projects that engage these disciplines and support scholarship and creativity toward cultural change. The humanities program will serve as a model for similar projects in the social sciences and medical humanities.

Public Policy Initiatives

Very few economists have devoted attention to the cost of dying in the United States so little or no data exists to guide the formulation of public policy on this critical issue. PDIA believes that there is an urgent need to research and address the economic questions in order to assure adequate reimbursement for end-of-life care. PDIA will convene a group of economists, health care policy experts, and PDIA faculty scholars and grantees to explore the major issues for economic reform of the current reimbursement systems for end-of-life care. The meeting will help to identify the requisite data and appropriate questions to inform the debate and develop innovative strategies to insure appropriate care for dying patients in hospitals and at home.

PDIA will also support a study of physician perceptions of the economic barriers to the provision of appropriate care for the dying. This initiative will serve to frame a public education agenda on financing end-of-life care for PDIA and other foundations. It is possible that some easily identifiable economic barriers can be eliminated without major legislative efforts. Such remedies might include providing payment for pain medications and developing a palliative care DRG code.

Legal Initiative

At a PDIA-sponsored meeting on January 16, 1998, litigators representing right to life, right to die, disability, and civil liberties groups explored the advantages and disadvantages of litigation to address state and federal legal barriers to adequate care at the end of life. According to Robert Burt of PDIA's Advisory Board, who wrote PDIA's amicus brief on the physician-assisted suicide cases, the Court's ruling provides the foundation for a constitutional claim to overturn such legal barriers. The meeting considered whether further litigation to develop this claim would be a promising course of action.

Community-based Initiative

PDIA's de Tocqueville Enterprise focuses attention on the development of community-based caretaking networks that encourage individual volunteers, as well as volunteer groups, to work on improving the care of the terminally ill in collaboration with professional caretaking organizations. Such grassroots efforts have a truly transformative potential for the American culture of dying. By sponsoring public discussions at the local level, PDIA will identify community needs as well as existing services and develop local structures for meeting those needs. These community-based networks will provide supportive care for a wide variety of people, including communities of immigrants, victims of violent crime, children orphaned by AIDS, and other vulnerable or marginalized populations.

Expansion of Grantmakers Concerned with Care at the End of Life

PDIA will continue to play a leading role in the growth of this coalition of funders working on improving end-of-life care. A program officer will organize GCCEL conferences and meetings to inform funders about the major political, social, economic, and medical issues in end-of-life care and encourage them to address these issues in their grantmaking.

COMMUNICATIONS

The Project on Death in America takes every opportunity to spread its message about the care of the dying to as large an audience as possible through media activities, publications, and a website.

MEDIA ACTIVITIES

In addition to its support for public and professional education efforts through the Grants Program, PDIA serves as a resource center for the media, providing reporters and editors with information and assistance, including access to the PDIA network of experts on the issues surrounding dying and grieving. PDIA's communications activities helped expand knowledge and coverage of dying issues beyond the debate over physician-assisted suicide.

Faculty scholars, grantees, and board members appeared in newspapers, magazines, and television news programs, including the *Boston Globe*, *Chicago Tribune*, *Chronicle of Philanthropy*, *Detroit News*, *Globe & Mail*, *Los Angeles Times*, *Milwaukee Sentinel*, *Newsday*, *New York Times*, *Philadelphia Inquirer*, *Portland Press Herald*, *St. Petersburg Times*, *Toronto Star*, *USA Today*, *Washington Post*, *New England Journal of Medicine*, *Time*, *U.S. News & World Report*, NPR's "All Things Considered," CNN's "The World Today" and "Your Health," "NewsHour with Jim Lehrer," "Nightline," and "60 Minutes." The *Philadelphia Inquirer's* five-part series "Final Choices: Seeking the Good Death" won a 1996 Pulitzer Prize for Explanatory Journalism.

PUBLICATIONS

PDIA provides its network of health care professionals, nonprofit organizations, and media with research reports, news summaries, and updates on PDIA's work through the publication of the *PDIA Reader* and the *PDIA newsletter* and the occasional dissemination of important new reports. The *PDIA Reader* is a bibliographic resource of articles on end-of-life issues, compiled by PDIA staff from professional publications and press clippings. *The Reader*, distributed by fax or mail, also appears on PDIA's website.

The *PDIA newsletter* reports on PDIA's activities, especially the programs of grantees that are changing America's culture of death and improving the care of the dying. The first issue of the newsletter was instrumental in sparking interest among funders in establishing Grantmakers Concerned with Care at the End of Life (see page 72). PDIA also helped create a publications series for the new organization with the preparation of reports on its conferences on physician-assisted suicide and the cost of end-of-life care.

WEBSITE

PDIA's website <http://www.soros.org/death.html> is a continually expanding collection of information on the Project on Death in America and a gateway to the most recent resources on death, dying, and bereavement. The site includes home pages for general information, programs, PDIA publications, physician-assisted suicide, and links. The PDIA Programs Home Page includes program guidelines and lists of grantees and faculty scholars, selections from PDIA-sponsored exhibits, and a calendar of related events. The PDIA Physician-Assisted Suicide Home Page presents a range of viewpoints on this controversial issue, including Supreme Court amicus briefs from, among others, PDIA, Compassion in Dying, Not Dead Yet, ACLU, and the National Hospice Organization. The PDIA Links Home Page connects to websites in the following areas: cancer, palliative care, chat groups, grief and bereavement, death and dying, elder care, health care, suicide and euthanasia, HIV/AIDS, the arts, publications and literature, and hospice.

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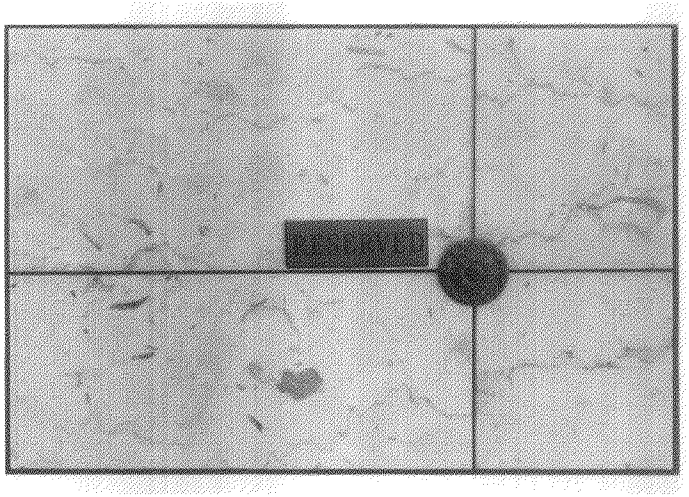

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“For most of human history, people died fast. Now suddenly, we have the opportunity to grow old, to have an illness for a long period of time, and to know what’s coming. We could make this an important phase of life.”

Joanne Lynn
PDIA Advisory Board

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