



# NINR FOCUS: END OF LIFE ISSUES

one in a series of focus papers on research directions and non-funded research advances

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*Care at the end of life has become a national concern. Medical advances have not only extended life expectancy, but they have allowed people of all ages to live longer with chronic, often severely painful and disabling conditions. A corresponding assurance of quality of life, however, is not guaranteed. The health care system must respond to the needs of incurably ill patients with adequate relief from suffering, and to their families with assistance in managing their burden of care and possible financial hardships.*

*The end of life is an important phase of life. People have the right to expect the highest quality of care possible and have their wishes about care respected. They also deserve the opportunity to address key personal issues and have their symptoms well controlled to permit the highest quality of life possible until life's end.*

## End of Life Research Activities

- In 1997, responding to societal concerns, NINR identified end of life care as an area of major program emphasis. NINR's extensive portfolio in the management of pain and other symptoms, family decision-making for patients who are incapacitated, end of life caregiving practices, and the environment of critically ill patients provides an important base of knowledge for this research. In recognition of this, NINR has been designated as the lead institute within NIH for palliative care research.
- In September 1997, NINR played a leadership role in a trans-NIH state of the science conference on "Symptoms in Terminal Illness." The conference

addressed end of life issues in four areas—pain, shortness of breath, cognitive disturbances, and general wasting—and identified opportunities for further research across disciplines and institutes.

- In December 1997, together with the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Mental Health, and the Office of Alternative Medicine, NINR issued a Program Announcement to stimulate research in the areas highlighted by the conference to address the constellation of symptoms at the end of life across disease conditions. The announcement includes research to address ethical issues and family decision-making.

## Factors that Impact End of Life Care

The aging and growth of the population portend an increase in the prevalence of chronic illnesses. More than two million Americans will die in 1998, most from chronic illness that they have endured for a long period of time. More than 70% of deaths occur in those over 65 years of age. Furthermore, a shift is taking place from patient care in the hospital to family care in the home, which presents a special responsibility for family caregivers. More than 20% of patients need ten hours of care a day.

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## Conclusions of Two National Reports on End of Life Issues in America

- The **Institute of Medicine (IOM)**, in its report **“Approaching Death – Improving Care at the End of Life,”** defined a good death as “one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.” The IOM also determined that people fear they will be technologically over-treated, leading to prolonged dying. They fear abandonment and untreated physical distress. The IOM identified deficiencies within the health care system in helping patients achieve a good death and called for more research in palliative care.
- There appears to be a widespread dissatisfaction in the United States with care at the end of life. A recent investigation supported by the **Robert Wood Johnson Foundation** revealed many problems with palliative care. They found that 40% of dying patients were treated aggressively in intensive care units. Pain was common to half of hospitalized patients during their last few days. There were discrepancies between patient desires and actual treatment. And almost half of physicians in the study did not know that their patients’ preference was not to be resuscitated.

## An Example of an NINR-Supported Study’s Findings on End of Life

### Understanding what patients and families want and expect in end of life care:

- Families whose relatives are dying in hospitals are willing to stop aggressive treatments if they understand the condition is terminal and they are convinced their relatives will receive high-quality comfort care.
- Families report that dying relatives in the last week of life have much more pain and other physical distress, e.g., nausea, shortness of breath, than physicians and nurses think they have.
- In the present health care environment in which patients are discharged quickly from one setting to another, discontinuity and lapses in health services are very distressing to patients and families.
- Americans with inadequate health insurance lack access to good palliative care during dying. They are
- much more likely to arrive at emergency rooms in acute distress and require expensive hospitalization for symptoms that could have been managed by hospice or home-health nurses
- A simple, noticeable form in the front of nursing home residents’ medical records can prevent unwanted transfer to the hospital when a resident is dying and prefers to stay in the nursing home.
- For families whose relatives died in a hospital, certain physician and nurse behaviors – such as viewing death as a medical failure – greatly increase the family’s grief and distress.

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The National Institute of Nursing Research (NINR) supports clinical and basic research to establish a scientific basis for the care of individuals across the life span. NINR-supported research seeks to improve the management of patients during illness and recovery, reduce the risks for disease and disability, promote healthy lifestyles, and improve the clinical settings in which care is provided, including problems encountered by families and caregivers. To accomplish its mission, NINR provides grants to universities and other research organizations and conducts intramural research and research training on the campus of the National Institutes of Health. These efforts foster multidisciplinary collaborations to ensure a comprehensive approach to research on illness and disabling conditions. NINR emphasizes the special needs of at-risk and underserved populations, and with the ongoing goal of implementing knowledge to reduce health disparities.

Rev. 07/2002



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