NINR20TH ANNIVERSARY

NINR FOCUS: END-OF-LIFE ISSUES

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

As medical advances extend life expectancy, care at the end of life has become a national concern. People are living longer with chronic, complex, and multiple conditions that affect quality of life. Issues of end-of-life care include respect for the dignity of dying patients; treatment of symptoms like pain, fatigue, and depression; patient and family decision-making; advance directives; alternative therapies; and hospice and palliative care. New end-of-life research is needed to help people of all ages and all ethnic and cultural backgrounds to live out their lives with the highest quality of care.

ABOUT THE NINR

Established in 1986 as the National Center for Nursing Research and redesignated as an Institute in 1993, 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 addressing problems encountered by families and caregivers. NINR also emphasizes the special needs of at-risk and underserved populations.

The strength of NINR throughout its history has been the talented and dedicated nurse researchers who have helped develop nursing science. Nurse researchers are the scientific vanguard of the largest profession in the health-care delivery system. NINR interacts with virtually all components of the National Institutes of Health (NIH), contributing both the scientific expertise of nurse researchers and the insights of a clinical profession to the NIH community.

As the 21st century progresses, our nation's population will continue to grow, age, and become more diverse, increasing the challenges facing our health care system. Diseases that were once acute and life-threatening, such as heart disease, diabetes, and HIV, are now long-term chronic conditions, and new global health threats continue to emerge. At NINR, we are working to make sure that nursing science stands ready to address these challenges and improve the health and well-being of all Americans.

A BRIEF HISTORY OF NINR'S END-OF-LIFE RESEARCH ACTIVITIES

The 1997 report from the Institute of Medicine, Approaching Death: Improving Care at the End of Life, found widespread dissatisfaction with end-of-life care and many gaps in our scientific knowledge of this phase of life. In response, NINR sponsored a workshop on the symptoms of terminal illness, and NINR was later designated the lead Institute within NIH for end-of-life research. NINR studies on the management of pain and other symptoms, family decision-making, caregiving, advance planning, and the care of the elderly and the critically ill provided an important base of knowledge on which to build.

NINR has sponsored several community events to get input on concerns related to end-of-life issues. We developed an educational video series for nurses on end-of-life experiences. In addition, several working groups of researchers and clinicians, brought together by NINR, have explored new directions for end-of-life research in a variety of populations, and helped to develop capacity for end-of-life care research.

In December 2004, NINR co-sponsored the National Institutes of Health State of the Science conference, *Improving End-of-Life Care*, bringing together almost 1,000 health care practitioners from around the world. This conference served to evaluate the current state of the science in end-of-life care and to determine future directions for research. The consensus statement from this conference is available at: http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm

RECENT NINR FINDINGS ON END-OF-LIFE CARE

• **Helping the caregivers of terminal patients.** Nurses visited family caregivers of patients with terminal cancer to teach them the COPE program, involving Creativity, Optimism, Planning, and Expert information. The caregivers reported the program helped decrease their burden of managing symptoms and performing caregiving tasks. It also helped improve their quality of life during the difficult and sensitive time of providing care for a dying loved one. *McMillan, University of South Florida, 2005.*

• **Inconsistent communication in discussing end-of-life issues.** Many family members of recently deceased terminal patients felt that doctors avoided discussions of prognosis with them until death was imminent, sometimes forcing them to make a quick decision related to life support measures. Nurses were seen as more available and more willing to share information. Most family members indicated they wanted doctors and nurses to offer hope, but also to be truthful and help them prepare for the worst. *Kaufman, University of California, San Francisco, 2005.*

• **The desire of terminal patients to hasten death.** In an initial survey, patients with late-stage cancer had a low desire to hasten death. Most were able to continue normal activities despite their symptoms, although one-quarter had signs of depression. Spouse caregivers spent around 40 hours a week providing care. When surveyed a second time, those patients who increased their desire for death had higher depression scores and required more caregiving time. They also had higher marital satisfaction, indicating they may wish to avoid becoming a burden to the spouse. *Weitzner, H. Lee Moffitt Cancer Center, 2006.*

• **Withdrawing life support.** Most family caregivers involved in a recent decision to withdraw or withhold life support from an elderly relative reported strain in the process that led to uncertainty, guilt, regret, and anger. However, some caregivers accepted their role and believed they were doing the right thing. Afterward, these caregivers were more at ease with their decision and felt that they had learned from the process and grown closer to other family members. *Hansen, Oregon Health and Science University, 2004.*

• **Documenting end-of-life wishes.** Among a group of patients with terminal cancer, less than half had an advance directive, although Whites were more likely to have one than Blacks. Between patients and their caregivers there was almost a 50% disagreement on the desire for life-sustaining measures in patients without advance directives. A later study found that Blacks were more likely than Whites to prefer hospitalization and life-sustaining measures when in a near-death condition; Blacks were also more likely than Whites to use spirituality to cope with their illness. *Phipps, Albert Einstein Healthcare Network, 2003, 2005.*

• **Missed opportunities in end-of-life meetings.** When a patient is dying in an intensive care unit (ICU), clinicians may meet with the family to explore the decision to withhold or withdraw life-sustaining treatment. However, an analysis of communication during these meetings found that clinicians often "missed opportunities" to address the concerns of family members, including: (1) failure to listen, (2) failure to acknowledge emotions, and (3) failure to explain ethical considerations or palliative care. *Curtis, University of Washington, 2004.*

RESEARCH THEME FOR THE FUTURE IN END-OF-LIFE CARE

NINR has identified *Enhancing the end-of-life experience for patients and their families* as a Research Theme for the Future. Many Americans are dissatisfied with the way the healthcare system provides care for the dying, and NINR has an obligation to support research on end-of-life and palliative care across the spectrum of care settings, ages, cultures, and socioeconomic groups. The full NINR Research Themes for the Future document is available at: http://ninr.nih.gov/ninr/research/themes.doc.

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Revised 5/2006