

Summary of the Capitol Hill Breakfast Briefing on

End-of-Life Care

March 16, 1998

The FRIENDS of the NINR held the first in a series of three breakfast briefings this year on March 16, 1998. The topic was End-of-Life Care. FRIENDS, an independent, non-profit membership organization, supports the NINR by promoting public awareness of the role of nursing research in advancing health care practice in the United States. Those attending the briefing included Congressional staff, nurse researchers and administrators, and members of public and private organizations having a special interest in the topic.

Colleen Conway-Welch, PhD, RN, FAAN, President of FRIENDS and Dean of Vanderbilt University School of Nursing, provided welcoming remarks and thanked the Congressional sponsors, Senator Ron Wyden (D-OR) and Representative Elizabeth Furse (D-OR). She also recognized Dick Thompson, Vice President of Government Affairs of Bristol-Myers Squibb, which hosted the breakfast.

Patricia A. Grady, PhD, RN, FAAN, Director of the National Institute of Nursing Research (NINR), opened the scientific discussion by providing background information about NINR's involvement in end-of-life issues. NINR's research portfolio over the past 10 years has included issues related to end-of-life, such as decisionmaking and managing symptoms, including pain. The Institute is therefore well grounded to go forward with these lines of scientific inquiry and has been designated by the NIH as the lead Institute in the area of palliative care research.

In the Fall of 1997, NINR convened a multidisciplinary workshop on end-of-life issues that identified four major areas in need of research: pain, dyspnea (difficulty breathing), cognitive disturbances, and cachexia (weight loss and wasting). A program announcement was issued in December to stimulate research in these areas. Other NIH Institutes joining NINR in issuing the program announcement were the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, the National Institute of Mental Health and the Office of Alternative Medicine.

THE RESEARCH

End of Life Care at Home: The Living Room as the Intensive Care Unit. Marcia Grant, RN, DNSc, FAAN, Director and Research Scientist, Department of Nursing, Research and Education, City of Hope National Medical Center, Duarte, California

Dr. Grant stated that as a result of improved health care, the nation's people are living longer lives but are also dying more slowly. More than 2 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. There has been a shift from patient care in the hospital to family care in the home, which presents a special challenge for health care professionals as they adjust their focus on providing support for these caregivers.

A 1997 Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, stated that people fear they will be technologically overtreated, leading to a protracted death. They also fear abandonment and untreated physical distress. There are gaps in knowledge as to how to best treat patients at the end of life and how to meet caregiver needs.

Recent surveys indicate family caregiver time spent in hands-on care can range from none to 15 hours a day. The average is 4 * hours. More than 20% of patients need 10 hours of care a day. To illustrate her point that caregiving is "not just chicken soup and fluffing pillows it's heavy duty," Dr. Grant provided an example of an end-stage patient with stomach cancer living at home. She had earlier experienced surgery, radiation and chemotherapy. Her family caregivers were her husband and her daughter, who had recently given birth. The home became an intensive care unit (ICU), with family members managing pumps, feeding her by a tube that sometimes leaked, and dispensing medications. They had to deal with wound care, incontinence, drug dementia, and her pain, which was particularly difficult. There were psychological problems for both the patient and the caregivers.

Clearly more resources need to be devoted to assisting family caregivers. Dr. Grant indicated that key areas for research include:

- Better pain management
- Strategies for families that care for relatives in a home setting
- Better transition from health care setting to home setting
- Effective ways to educate the public and the medical community about end-of-life issues.

Patient and Family Perspectives on End-of-Life Care. Virginia Tilden, RN, DNSc, FAAN, Professor and Associate Dean, School of Nursing; Associate Director, Center for Ethics in Health Care, Oregon Health Sciences University, Portland

In providing background on the issues of end-of-life care, Dr. Tilden stated that technology can extend life far beyond the quality of life point. The majority of patients end up in the intensive care unit, often in pain, unable to communicate with loved ones. Most people do not want treatment if it is futile, but this can be difficult to judge. Many patients receive aggressive care at the end of their lives for several reasons—uncertainty about the prospects of death and when it might occur (no one wants to make a mistake), and a built-in unwillingness to give up on the part of the medical staff.

Internists are treatment-oriented, not comfort-oriented. This can be expensive and denies the principle that patients are qualified to decide about their care. Aggressive medical treatments at the end of life are estimated to be many thousands of dollars more per patient than the costs of palliative care. For example, the cost of two days of hospital ICU care is roughly equivalent to that of 30 days of hospice care. A 1994 study of dying in the ICU found that 5% of patients that died used 22% of the ICU resources. When staff knew the patient's wishes about treatment, however, an average of \$14,000 was saved per patient.

Dr. Tilden described her joint (nursing/medicine) research project that began in 1990 and explores what patients and families want and expect in end-of-life care. Some of her findings are as follows:

- Families whose loved ones are dying in hospitals are willing to stop aggressive treatments if they understand the condition is terminal and they are convinced their loved one will receive high quality comfort-care.
- Families report that dying loved ones 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, bright pink 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 loved ones died in a hospital, certain physician and nurse behaviors—such as viewing death as a medical failure—greatly increases the family's grief and distress.

Dr. Tilden concluded her remarks by stating that affordable, high quality, low-tech home care, with the guidance of a nurse practitioner to effectively manage the symptoms of dying, such as pain, is the best alternative to a pain filled, lengthy and expensive dying process or to assisted suicide.

CHALLENGES

Supportive care and symptom management during the final weeks and months of a patient's life have received little attention, but it is becoming increasingly clear that distressing symptoms considered inevitable at the end of life can be eased and that a patient's quality of life, sense of control, and dignity can be maintained. Various issues remain to be resolved through multidisciplinary research:

The increased aging of the population necessitates a strong focus on how the health care system manages end-of-life care. More needs to be known about the proper course of treatment during the dying phase.

Despite the availability of painkillers, such as opioids, for terminally ill patients, reports indicate that pain is still inadequately treated. For example, a recent Institute of Medicine study found that 40 to 80% of patients with cancer, AIDS, and other diseases report inadequately treated pain. Concern about patient addiction to drugs has been largely unfounded.

There is a need for improved assessment tools to help health care professionals properly evaluate symptoms at the end of life so that proper treatment may be prescribed. While pain is a major symptom, other symptoms include breathing difficulties, cognitive disturbances, wasting and weakness, nausea, fatigue and depression. These symptoms often occur in combination and compound the suffering of dying patients and their caregivers.

Patients' comfort needs and their wishes for end of life care must be respected. Research has found discrepancies between patient desires and the treatment they receive at the end of life. A recent NIH investigation, "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments" (SUPPORT), found that:

Forty percent of the patients were treated aggressively in ICUs

Pain was commonly experienced by these patients

Almost half of the physicians did not know that their patients preferred not to be resuscitated

Family caregivers' needs must be addressed. They must become skilled in dispensing opiates, determining the changing food preferences of a dying person, and responding to changes in functioning and types of care required. They must also be helped to cope with stress and maintain their own health.