

Introduction: Papers from the National Institutes of Health State-of-the-Science Conference on Improving End-of-Life Care

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ABSTRACT

A 1997 Institute of Medicine report cited growing public concern about the quality of care in the U.S. health care system for persons at the end of life. The National Institute of Nursing Research (NINR), the lead Institute at the National Institutes of Health for end-of-life research, has conducted a number of public forums to gather information and to assist in identifying research priorities. The complexity of biomedical research requires new methods of discovery, and scientists must use a broad approach and explore new models of team science. In December 2004, NINR and the NIH Office of Medical Applications of Research, along with many co-sponsors, held an interdisciplinary State-of-the-Science Conference on Improving End-of-Life Care. The conference panel identified many gaps in our current state of knowledge and provided suggestions for future research directions. This supplement presents papers from a distinguished group of scientists with a wide range of backgrounds who participated in this state-of-the-science conference.

INTRODUCTION

THE 1997 REPORT FROM the Institute of Medicine (IOM), *Approaching Death: Improving Care at the End of Life*, found widespread dissatisfaction with end-of-life care and many gaps in our scientific knowledge.¹ Advances in medical treatment and care are helping people with multiple chronic and complex health conditions live longer. However, this extended life expectancy can have an impact on the quality of life. Management of chronic illnesses must address not only the treatment of symptoms such as pain, fatigue, and depression, but also respect patient and family decision making regarding treatment choices and use of alternative therapies. Ideally, health care planning that incorporates palliative and/or hospice care also acknowledges the end of life as an important phase of life.

After the release of the IOM report, the National Institute of Nursing Research (NINR), along with a number of other Institutes and the Office of Alternative Medicine (now the National Center for Complementary and Alternative Medicine, or NCCAM) at the National Institutes of Health (NIH), sponsored a workshop on the symptoms of terminal illness. Later that year, NINR was designated as the lead Institute within NIH for end-of-life research. This NINR science portfolio, which includes studies with elderly persons, chronically and critically ill persons, management of pain and other symptoms, family decision making, caregiving, and advance planning, provides an important base of knowledge on which to build. More recently, NINR brought together several groups of researchers and clinicians to explore new directions for end-of-life research. Topics have included

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end-of-life issues in AIDS, genetic diseases, and children with cancer, working with elderly populations, dealing with uncertainty, ethical challenges in palliative care research, and enhancing our capacity for end-of-life and palliative care research. In addition, NINR has sponsored several research initiatives and requests for research related to care at the end of life: the clinical management of pain and related symptoms at the end of life; patterns of communication among patients, families, and health care providers; support for both formal and informal caregivers; the context of care delivery; complementary and alternative medicine at the end of life; dying children and their families; and ethics and health care decision-making. Research initiatives by the Robert Wood Johnson and Soros Foundations have also supported advances in this field.

Many Americans continue to express concern with the way the health care system provides care for the dying, and NINR is spearheading the challenge to support research on end-of-life and palliative care across the spectrum of ages, health conditions, care settings, cultures, and socioeconomic groups. Our ongoing research emphasis on the management of chronic diseases and health conditions has evolved to include biobehavioral strategies in the study of the management of symptoms, long-term responses to chronic conditions, and changing life roles. Research on end-of-life care has focused on the areas of functional decline, decision making, and communication between patients and family caregivers. Combining these approaches provides evidence that the principles of symptom management research also apply to improving end-of-life care.

Locally, NINR helped establish the End of Life Special Interest Group (EOL SIG) on the NIH campus. The purpose of the EOL SIG is to provide a means for all agencies of the Department of Health and Human Services (DHHS) interested in end-of-life research to coordinate planning activities and to provide a means for communicating these DHHS activities to the broader community of those interested in end-of-life research.²

**NIH STATE OF THE SCIENCE
CONFERENCE: *IMPROVING
END-OF-LIFE CARE***

As an outgrowth of this work, NINR, along with the Office of Medical Applications of Research

(OMAR), sponsored the NIH State of the Science conference, *Improving End-of-Life Care*, in December 2004. Co-sponsors included the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the National Cancer Institute, NCCAM, the National Institute of Mental Health, and the National Institute on Aging. This conference brought together almost 1000 health care practitioners from around the world, including nurses, physicians, social workers, and others who work with dying persons, to evaluate the current state of the science in end-of-life care and to determine future directions for research initiatives.

The conference panel was charged with addressing several key questions:

- What defines the transition to end of life?
- What outcome variables are important indicators of the quality of the end-of-life experience for the dying person and for the surviving loved ones?
- What patient, family, and health care system factors are associated with improved or worsened outcomes?
- What processes and interventions are associated with improved or worsened outcomes?
- What are the future research directions for improving end-of-life care?³

Discussions at the conference extended beyond specific diseases, treatment options or populations, and identified important gaps in our understanding of the end of life. Some recommendations that arose from the conference include the need to develop the research infrastructure for end-of-life care; to enhance communication among patients, families, and health care providers; to include under-represented populations in research; and to create research networks that support coordinated, multi-site studies.

The conference also served to bring out many current challenges to research on the end of life, with the conference panel concluding that:

- Circumstances surrounding end of life are poorly understood, leaving many Americans to struggle through this life event.
- The dramatic increase in the number of older adults facing the need for end-of-life care warrants development of a research infrastructure and resources to enhance that care for patients and their families.

- Ambiguity surrounding the definition of end-of-life hinders the development of science, delivery of care, and communications between patients and providers.
- Current end-of-life care includes some untested interventions that need to be validated.
- Subgroups of race, ethnicity, culture, gender, age, and disease states experience end-of-life care differently, and these differences remain poorly understood.
- Valid measures exist for some aspects of end of life; however, measures have not been used consistently or validated in diverse settings or with diverse groups.
- End-of-life care is often fragmented among providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high-quality interdisciplinary care.
- Enhanced communication among patients, families, and providers is crucial to high-quality end-of-life care.
- The design of the current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life.³

CONCLUSION

“Enhancing the end-of-life experience for patients and their families” remains one of NINR’s primary Research Themes for the Future. Our future directions for end-of-life research will address the concerns and challenges identified in this conference by emphasizing interdisciplinary research partnerships, the development of biomarkers and other objective measures of impending death, the inclusion of end-of-life research in existing clinical trial networks, the recruitment of minority populations into research, and the improved use of technology to

provide care. Through these efforts, we hope to generate new research findings on the management of pain and other symptoms, planning and decision-making in care and treatment, and the involvement of family and friends in care. To improve the end-of-life experience within our health care system, we must apply “the best evidence that science can offer . . . to guarantee the quality of care” provided to dying individuals and their families.³

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