

Improving care of the dying: What do the experts say?

This article reviews nine key points that experts at an NIH conference said characterize the challenges associated with improving end-of-life care.

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*But I have promises to keep,
And miles to go before I sleep
– Robert Frost, “Stopping by Woods on a Snowy Evening”*

A desperate 30-year-old man with end-stage cancer decides to pursue aggressive treatment even against expert medical advice. As a result, his last days become a succession of dashed hopes, angry frustration, and increasing suffering. A 78-year-old woman with Alzheimer’s disease lies in a contracted bundle, unaware of place and time. Her disease has absolved her of making end-of-life decisions, and her care now depends on the judgment of others. Both cases reflect the need to move beyond mere awareness of the need for improved care at the end of life to active implementation.

In 2004, the National Institutes of Health (NIH) sponsored a State-of-the-Science Conference on Improving End-of-Life Care.¹ The purpose of these conferences is to identify areas that need more research, and past state-of-the-science conferences have generated discussion and served as catalysts for change. The panel of experts who examined end-of-life care at the 2004 conference concluded, not surprisingly, that improvements were needed. Their final statement focused on nine key points.²

CURRENT PROBLEMS, RECOMMENDED CHANGES

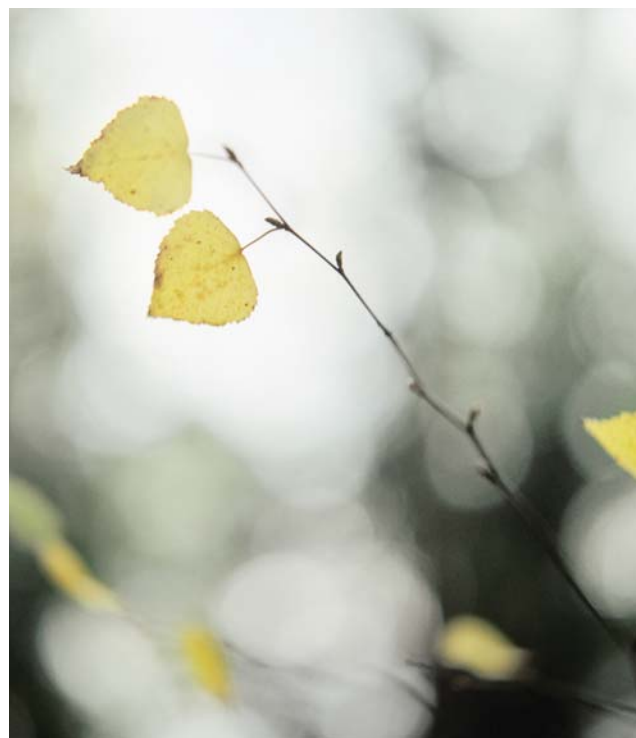
1. Circumstances surrounding the end of life are poorly understood, leaving many Americans to struggle through this life event.

Most Americans are familiar with high-profile legal cases involving end-of-life issues. But many are still unprepared for making similar decisions regarding the end of their own lives, and, for a large number, events during this time do not go as expected or desired. A study cited at the conference showed that “most patients [with cancer] were willing to accept intensive chemotherapy for a very small chance of benefit ... [and] much more likely to opt for radical treatment with minimal benefit than people who do not have cancer, including medical and nursing professionals.”³ A Gallup poll done for the Partnership for Caring showed that contrary to their wishes to die at home, most people die in hospitals.⁴

When faced with end-of-life decisions, even clinicians find benefit versus burden a difficult concept to judge. The many terms for *palliative care*—including *comfort care*, *supportive care*, and *hospice care*—are used interchangeably, further confusing the issue for patients and erecting barriers to care.

Though more research is needed, one speaker at the conference, Dr. David Casarett, said ethical considerations of the terminally ill patient’s vulnerability and difficulties in obtaining consent have in the past limited research in this area.² But Casarett, of the Center for Health Equity Research and Promotion at the Philadelphia Veterans Affairs Medical Center, has said such research would help define patient perception of risk versus benefit and capacity for decision-making.²

The NIH panel regards the work of educating practitioners and the public regarding end-of-life care as still unfinished. Medical professionals and the public alike can benefit



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from increased awareness of various issues. Research with this population is necessary to demonstrate and quantify that education goals are being practically applied and met.

2. 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.

By the year 2020, 35% of Americans will be older than 50 years.⁵ A major problem for many older terminally ill patients is that established dementia complicates end-of-life decision-making. One NIH panelist spoke of research involved with such patients.

Dr. Gregory Sachs, Chief of Geriatrics at the University of Chicago, praised the Palliative Excellence in Alzheimer Care Efforts, or PEACE, Program.⁶ Sponsored by the Robert Wood Johnson Foundation, the program enrolled 150 patients with various dementias and their caregivers in an attempt to integrate palliative care and multidisciplinary geriatrics care. The study outlined the stress placed on caregivers; those feeling strain at enrollment remained stressed despite referral to educational and support groups. The study also showed that 97% of patients and 93% of caregivers in the PEACE project rated the program care as the best possible. Further study is needed to determine which caregivers are at greatest risk for distress and what interventions may be appropriate.

A recent study by Aminoff and Adunsky confirms the conference panel's suggestion that research involving patients with dementia at the end of life is valuable.⁷ This study points out the paucity of clinical evidence regarding suffering in dementia patients, who cannot communicate their needs, understand treatment options, or express suffering. This may account for inappropriate evaluation or lack of palliative treatment.

Aminoff was also an author in a study presenting a tool for assessing suffering in dementia patients, the Mini Suffering-State Exam (MSSE).⁸ This test evaluates 10 items relative to a patient's condition as observed by caregiver staff or family, including pain, decubitus ulcers, agitation, and malnutrition.⁸ The MSSE score is then supplemented by clinical data such as laboratory test results, presence of a feeding tube, fever, or the use of antibiotics.⁸

The NIH panel concluded that financial cost and burden to the patient, family, and health care system should be assessed and provisions made, as the cost-effectiveness of interventions will be an important factor in determining whether they can be implemented now or in the future.² This information will be critical as America's aging population reaches the end of life.

3. Ambiguity surrounding the definition of the end of life hinders the development of science, the delivery of care, and communications between patients and providers.

Currently, no operational definition exists for the end of life. Usually a period of transition rather than an acute event, it includes physical, emotional, spiritual, and financial elements. Experts admit it is a complex, multidimensional experience, encompassing a poor prognosis, increased chances of dying, and decisions to forego curative treatment.

One of the conference speakers, Dr. Thomas Finucane of Johns Hopkins University School of Medicine, cited a study that showed the extreme denial of many patients who "never experience a time during which they are clearly dying of their disease."⁹ Prognosis as a temporally specific estimate of life plays an important role in whether patients seek hospice and palliative care. Studies show that health care providers may give overly optimistic prognoses because of concern over their own accuracy as well as worries about the reaction of the patient to a terminal prognosis.¹⁰

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment showed that patients who were mistakenly hopeful regarding their diagnoses often requested treatment most physicians would consider futile.¹¹ An accurate prognosis is the key to helping the patient prepare for the course the disease will take. In a survey done by the American Society of Clinical Oncology, US-based members were asked how they communicated with patients when death was expected.¹² Of the 559 oncologists who responded, only 5% said they "always" give patients estimates of the time they have left to live.¹² But 75% of the same doctors said they would want an estimate of time if facing death themselves.¹²

The NIH panel noted the need for consensus about common definitions and constructs as they relate to end-of-life and palliative care.²

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KEY POINTS

- A National Institutes of Health conference on Improving End-of-Life Care concluded, not surprisingly, that improvements in end-of-life care were needed.
- The NIH final statement focused on nine key points, several of which are listed in the next bullet point.
- Circumstances surrounding the end of life are poorly understood; ambiguity surrounding the definition of the end of life hinders the development of science, the delivery of care, and communications between patients and providers; current end-of-life care includes some untested interventions that need to be validated; dying patients experience end-of-life care differently depending on their race, ethnicity, culture, gender, age, and disease; end-of-life care is often fragmented among providers and settings; and enhanced communication among patients, families, and providers is crucial.

COMPETENCIES

- Medical knowledge
- Interpersonal & communication skills
- Patient care
- Professionalism
- Practice-based learning and improvement
- Systems-based practice

4. Current end-of-life care includes some untested interventions that require validation.

Although palliative care and hospice interventions have increased in recent years, assisting more patients, the field could benefit from more supporting research. More randomized studies with control groups are necessary to validate the positive benefits of end-of-life interventions. The conference statement suggests creating a network of end-of-life investigators, all using equivalent and valid measuring tools.² It also proposes that more research be done with a sensitive population, terminal patients, while maintaining the highest ethical standards.²

Panelist Betty Ferrell, PhD, RN, spoke of the value of the National Consensus Project (NCP) for Quality Palliative Care as a resource in this area. NCP, a coalition of three hospice and palliative care organizations, released its guidelines in 2004.¹³ The guidelines outline eight domains of end-of-life care: structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care.¹³ Besides Clinical Practice Guidelines, NCP focuses on developing and structuring new palliative care services.

The NIH panel advises that studies involving end-of-life care must include a diverse group of patients and care settings in order to generalize the results to the entire population.² Earlier studies were limited in size and in selection of patients and care settings, making results less generalizable to all dying patients and therefore less useful.

“Better communication among patients, families, and providers is crucial to being able to deliver high-quality end-of-life care.”

5. Dying patients experience end-of-life care differently depending on their race, ethnicity, culture, gender, age, and disease, and these differences remain poorly understood.

Not all dying patients are the same. Race, culture, and ethnicity affect access to health care, quality of health care delivery, and health care outcomes.² Hospice is more likely to be available in wealthy communities, which represents an obstacle to care for poorer patients.¹⁴ There are a few exceptions, one being The Balm of Gilead, a Robert Wood Johnson Foundation-funded comprehensive program for end-of-life care for medically underserved people, primarily low-income, uninsured African-Americans, in Birmingham, Alabama. In addition, providers may be biased against the patient, stereotyping by ethnic group. Lack of adequate translation and interpreting services can also contribute to the problem. Patients themselves have diverse values, attitudes, preferences,

and beliefs regarding the end of life. Some minority groups have shown a preference for intense therapy instead of hospice at end of life. Minorities are also underrepresented in research.

The NIH panel recommends the development and use of research tools that are sensitive to racial, ethnic, age, and cultural differences.²

6. Valid measures exist for some aspects of the end-of-life experience; however, measures have not been used consistently or validated in diverse settings or with diverse groups.

Despite best efforts to support all patients near death, research to validate interventions has mainly focused on cancer patients. The conference statement recommends increased funding for end-of-life research.² The research should include diverse populations, such as children; people with end-stage heart, lung, and kidney disease; and those with psychiatric disabilities and addictions.

Several recent studies have focused on dying children. A study by Kreicbergs and colleagues in the *Journal of Clinical Oncology* concluded that physical pain and the moment of death were the two most important issues for parents of children with cancer.¹⁵ Another study by Solomon and colleagues in *Pediatrics* stated the “need for more hospital-based ethics education and more interdisciplinary ... discussion of inherently complex and stressful pediatric end-of-life cases.”¹⁶ Areas at issue included appropriate goals of care, medically supplied nutrition and hydration, appropriate use of paralytic agents, and regard for the dead donor rule.¹⁶ A study employing parts of the adult Needs at the End of Life Screening Tool (NEST) used screening questions to determine the needs of children at the end of life.¹⁷ Using the NEST data, Donnelly and colleagues proposed a model that included the following cluster of needs: pain, decision-making, medical system access and quality, dignity and respect, family-oriented care, spirituality, and psychosocial issues.¹⁸ The same study called for development of a clinical measure to evaluate pediatric needs at the end of life.¹⁸

The NIH experts concluded that more studies like these need to be done with the other special populations and that varied settings such as the home, hospice, and long-term and acute care institutions should be investigated.² Finally, the panel recommended the creation of a network of end-of-life investigators and well-defined cohorts to facilitate interdisciplinary, multisite studies.²

7. 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.

Continuity of care, so crucial for this population, is often missing. Numerous specialists cobble together treatment approaches. Not all services are available under one roof or from a single provider. Patients often feel left out of discussions and decision-making. Current financial incentives foster lower quality of care and lack of continuity. Differing skill levels of providers and lack of information exchange further erode outcome.²

8. Enhanced communication among patients, families, and providers is crucial to high-quality end-of-life care.

Good communication is critical for effective interventions in symptom management, the spiritual aspects of dying, decision-making regarding life-sustaining treatment, family caregiving, and bereavement. Communication among providers, patients, and families can improve the quality of care and generate gratitude as well as useful criticism. The NIH panel suggests using demonstrations in clinical settings to evaluate models of care delivery and to overcome barriers to effective care. The panel encourages inter-institute coordination and increased funding to enhance provider knowledge related to end-of-life care.² A study published by Casarett and colleagues demonstrates that a simple, low-cost communication intervention “can improve the quality of end-of-life care and decrease resource utilization.”¹⁹

9. The current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life.

“The NIH panel recommends developing, testing, and evaluating new models of end-of-life care for Medicare beneficiaries.”

In order to qualify for hospice under the Medicare Benefits Act, four criteria must be met: 1) the patient must be eligible for Medicare Part A; 2) a doctor and the hospice medical director must certify that the patient has a terminal illness with 6 months or less to live; 3) the patient must sign a statement choosing hospice care instead of other Medicare-covered benefits; and 4) care must be provided by a Medicare-approved hospice program.²⁰

The Centers for Medicare and Medicaid Services decided that the 1997 Balanced Budget Act’s Medicare provisions regarding coverage of services by PAs did not apply to hospice. Medicare beneficiaries currently cannot receive hospice care from PAs, and the current Medicare Hospice Benefit does not allow PAs to write orders for hospice referral. The AAPA continues to encourage members of Congress to support the Physician Assistants Continuity of Care Act, which, if passed, would allow PAs to order home health, hospice, and skilled nursing facility care as delegated by their supervising physicians and to provide hospice care directly to patients.²¹

The NIH panel recommends developing, testing, and evaluating new models of end-of-life care for Medicare beneficiaries. As the largest payer for hospice care in the United States, Medicare has considerable influence on the use of hospice and the finances connected to it.²² New measures are needed to overcome limitation and barriers to the current Medicare hospice benefit.

SUMMARY

The NIH State-of-the-Science Conference showed that much work still needs to be done to address the needs of patients at end of life. Whether young or old, such patients need and deserve the highest possible quality of life as they are dying. More randomized controlled studies need to be done, and appropriate new legislation needs to be passed. PAs can download the NIH State-of-the-Science Conference Statement at <http://consensus.nih.gov/PREVIOUSSTATEMENTS.htm#EndOfLifeCare> or obtain a written copy from the Office of Medical Applications of Research, National Institutes of Health, 6100 Executive Blvd, Rm 2B03, MSC 7523, Rockville, MD 20892; (800) 644-2667. **JAAPA**

Joan Malespina lives in South Orange, New Jersey. She has indicated no relationships to disclose relating to the content of this article.

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