



Yesterday

- In the past, death occurred at home after a short illness with help provided to the dying person through the care of family members. Treatments often focused on making the individual as comfortable as possible.
- Issues surrounding end-of-life experiences, pain, symptom management, and advance care planning were poorly understood and little studied.
- At the time, advancements in medical health technologies were beginning to prolong life in many life-threatening situations, raising new challenges surrounding decision-making for end-of-life care.

Today

- In 1997, a report from the Institute of Medicine found widespread dissatisfaction with end-of-life care. While most individuals with serious, advanced illnesses preferred to die at home and receive a more conservative pattern of end-of-life care; the majority died in hospitals and received more aggressive care than was desired. Many dying persons feared abandonment and untreated physical distress.
- Today, death is often more complicated. Many people suffer from progressive or chronic, critical illnesses that eventually reach a point when curative approaches are no longer possible. When advanced illnesses become terminal, new treatments, medications, and technologies are now available to provide greater comfort, assist in symptom and pain management, and ease the burden of an illness. Patients now can choose or change the focus of their care from treatment to comfort and elect to receive palliative or hospice services in a growing number of health care settings.
- Research has now increased our understanding and awareness of advanced illnesses and the need to provide holistic care for those at the end of life. NIH studies on the management of pain and other symptoms, communication and medical decision-making, caregiving, and safe transitions between care

settings for those with serious, advanced illnesses provide a foundation for current research in end-of-life care.

- End-of-life care is a major part of the national nursing research agenda. Today, new discoveries are improving the end-of-life experience. New strategies and interventions are building the biological and behavioral evidence-base that will increase health-related quality of life and enhance excellence in the care of those with advanced illnesses.
- Today, hospital palliative care consultation teams are associated with significant hospital cost savings and have been shown to improve physical and psychological symptom management, caregiver well-being, and family satisfaction.
- Today, hospice care affirms a patient's and family's full participation in end-of-life care and serves a growing number of patients with neurologic, cardiac, or nonspecific terminal diagnoses. Various studies on the cost-effectiveness of hospice are providing evidence that hospice is a less costly approach to care for those at the end-of-life.
- Today, most pain can be controlled during end-of-life care, but quality management of non-pain symptoms is also needed. In one study of older nursing home hospice/palliative care patients, common non-pain symptoms (such as constipation, nausea/vomiting, fever, and diarrhea) were often undertreated in more than half of the patients.
- Approximately 25% of all U.S. deaths occur in the long-term care setting, and this figure is projected to rise to 40% by the year 2040. Care coordination as patients transition from one form of care to another during a progressive, advanced illness can improve care and cut costs. A study showed that when elderly heart-failure patients received specialized nursing care throughout their hospital stay and at home following hospital discharge, the patients had a better quality of life and fewer hospital readmissions. Instead of costing more money for this specialized care, the study showed that

the care resulted in a nearly 38% savings in Medicare costs (<http://www.transitionalcare.info/>).

- Advance planning can help make sure that patients get the care they wish when they want it. But, many individuals and their families still struggle with a lack of continuity of care and poor communication with health care practitioners about their treatment wishes, especially at the end of life. A new study has shown that residents with POLST (Physician Orders for Life-Sustaining Treatments) forms are less likely to receive unwanted life sustaining treatments when compared to patients with traditional Do-Not-Resuscitate orders (<http://www.ohsu.edu/polst/>). Using the POLST did not impact the degree of comfort care received for symptom management and helped individuals make more informed choices about the type and level of end-of-life care they wish to receive.
- Communication between patients, families and providers is important across the span of end-of-life care. Up to 20 percent of all deaths in the United States occur in or shortly after an ICU stay. Many of these patients are surrounded by family members who experience stress, fear, anxiety and depression. The desire for information and emotional support is a common theme among all ICU families. In a recent study, family members reported a high degree of satisfaction when opportunities were presented for inclusion in decision-making. Families benefited from providers that gave emotional support, respect and compassion; demonstrated a willingness to answer family questions; and considered family needs. In fact, clinician-family communication was possibly the most important factor driving family satisfaction in the ICU (<http://depts.washington.edu/eolcare/currentprojects/index.html>).
- New health technologies and IT tools are helping to address important concerns about planning for end-of-life care. By creating outlined plans that translate individual values and goals into meaningful directives that explicitly reflect preferred healthcare wishes, new computer tools are educating users about advance care planning. These tools help to identify, clarify, and prioritize factors that influence decision-making about future medical conditions. They can help users articulate a coherent set of wishes readily interpretable by physicians, and help individuals both choose a spokesperson and prepare to engage family,

friends, and health care providers in discussions about advance care planning.

Tomorrow

The NIH is poised to continue to support research that will identify new strategies to improve end-of-life care, create new interventions for pain and symptom management, identify effective, accessible treatments, and develop new health technologies to provide quality, end-of-life care to patients and families.

- Studies are exploring the different trajectories that people experience in their last years, months, and days of life. This research will help clinicians predict patient needs and design appropriate care, and will prepare loved ones for this delicate period of transition.
- New research is defining the unique end-of-life experiences and health care needs of each individual and family. Personalized care that incorporates cultural- ethical beliefs and practices, sensitivity to vulnerable populations and age groups, and integration of services across the course of an advanced illness will alleviate pain while maintaining awareness, address other discomforting symptoms, and help patients prepare advance directives to guide preferred plans of care.
- Studies are underway to find ways to improve communication between patients, families, and clinicians in end-of-life situations to improve the process of decision-making, help address patient concerns, and decrease stress on family caregivers.

Contact: NINR Office of Science Policy and Public Liaison,
info@ninr.nih.gov, 301-496-0207

National Institute of Nursing Research (NINR):
<http://www.ninr.nih.gov/>