
Fact Sheet

End-of-Life

Thirty Years Ago

- In the past, death typically occurred over a short period of time from illness or injury.
- Often times, death occurred at home, and family members served as caregivers.
- Issues surrounding end-of-life experiences were poorly understood and little studied.
- Improvements in medical technology were beginning to prolong life in many life-threatening situations, raising issues of end-of-life care.

Today

- A 1997 report from the Institute of Medicine found widespread dissatisfaction with end-of-life care.
- NIH studies on management of pain and other symptoms, family decision-making, caregiving, advance planning, and the care of the elderly and the critically ill provided a foundation for current research in end-of-life care.
- End-of-life care is a major part of the national nursing research agenda, with new discoveries in improving the end-of-life experience and enhancing the evidence base for care.
- For example, a recent survey found most family caregivers involved in a recent decision to withdraw or withhold life support from a relative reported feeling uncertainty, guilt, regret, and anger. However, those caregivers who accepted their role and believed they were doing the right thing were more at ease with their decision, felt that they had learned from the process and grown closer to other family members.

- Among 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 desired treatment interventions.
- When a patient is dying in an intensive care unit, clinicians may meet with the family to explore the decision to withhold or withdraw life-sustaining treatment. 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 treatment for patient pain or discomfort.
- Many family members of recently deceased terminal patients felt that doctors avoided discussions of prognosis with them until death was imminent. Nurses were seen as more available and willing to share information. Most family members indicated they wanted clinicians to offer hope, but also to be truthful and help them prepare for the worst.

Tomorrow

The NIH is poised to improve the *prediction* of end-of-life care trajectories, to *personalize* individual treatments, and to use this information to *preempt* discomfort in the patient and stress in the family at this sensitive time.

- *Predicting end-of-life care needs.* Studies are looking into the different trajectories that people experience in their last years, months, and days of life. This will help clinicians predict patient needs, design appropriate care, and prepare loved ones for this delicate transition. It will also inform policy-makers as they decide how to fund and support end-of-life care services.

- *Personalized treatments.* The end-of-life experience is different for each individual and for each family. Personalized care that incorporates cultural beliefs and practices will alleviate pain while maintaining awareness, address other discomforting symptoms, and help patients prepare advance directives.
- *Preemptive approaches.* Studies are underway to find ways to improve communication between patients, families, and clinicians in end-of-life situations. Improved communication will improve the process of decision-making, help address patient concerns, and decrease stress on family caregivers.