



Policy brief: The Institute of Medicine report *Dying in America: Improving quality and honoring individual preferences near the end of life*

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ABSTRACT

The Institute of Medicine's 2014 report *Dying in America: Improving quality and honoring individual preferences near the end of life* provides recommendations for creating transformational change in the models of end-of-life care delivery, clinician–patient communication, and advance care planning; improving professional education, reforming policies, and payment systems; and engaging and educating the public toward high-quality, coordinated, and comprehensive care that is person centered and family oriented. This article provides a policy brief of this recently released report. The role of nursing in advancing these recommendations is discussed.

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Background

Death in America has increasingly become a medical event attributed to the evolution and availability of complex technologies, social perceptions of death and dying, the lack of successful models of advance care planning and clinician–patient communication, and the organization of health system and reimbursement structures that favor a more medicalized death. The last few months of an individual's life is characterized by frequent hospital admissions, intensive care stays, and burdensome transitions across care settings. A

large proportion of deaths continue to occur in hospitals with implications for quality of care at the end-of-life and unsustainable cost to the health care system.

These issues have been previously examined by the Institute of Medicine (IOM) in two reports related to palliative and end-of-life care in America; the first was issued in 1997 (*Approaching death: Improving care at the end of life*; IOM, 1997) and focused on the dying and deaths of adults in America, and the second was released in 2003 (*When children die: Improving palliative and end-of-life care for children and their families*; IOM, 2003) and focused on children dying in America. The

Dr. Meghani and Dr. Hinds served on the Institute of Medicine Committee report *Dying in America: Improving quality and honoring individual preferences near the end of life*.

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reports examined the policies, funding, clinical care, legal guidance, and empirically based findings related to life-limiting illness and dying, and both produced recommendations for improving care.

Although these earlier reports made important and broad recommendations, progress in implementing the recommendations has remained slow. A number of recent changes in the health care environment including the passage of the Affordable Care Act in 2010 and national imperatives of simultaneously improving the quality of health care while controlling costs provided an opportune time for the re-examination of how values and preferences of individuals nearing death can be honored while quality of care and cost containment can be assured.

Given the significance and magnitude of individualizing care for dying persons in America that is high quality and of reasonable cost, the IOM conducted a study *Dying in America: Improving quality and honoring individual preferences near the end of life* (IOM, 2014a), examining the current state of evidence on end-of-life care with respect to delivery of medical care and social support services; patient-family-provider communication of values and preferences; advance care planning; health care cost, financing, and reimbursement; and education and engagement of health professionals and public. The IOM study committee examined the issues from a variety of perspectives including clinical care and delivery; resources and workforce; economics; spirituality; public engagement; and special challenges for subgroups such as children, racial, and ethnic minorities, those with limited health literacy, and individuals with disabilities.

A committee of 21 members was appointed by the IOM in 2012 to review available evidence and craft recommendations for further improvements in care. The committee represented diverse disciplines including nursing, medicine, law, bioethics, social sciences, epidemiology, economics, geriatrics, and pediatrics. Unlike previous reports that tackled the end-of-life issues of children and adults separately, this report integrates and examines end-of-life care and policy issues across the life span. The work of this committee was sponsored by an anonymous donor, and the oversight for the committee work was with the IOM and supported by the IOM's well-established rigorous processes to create highly credible reports that have the potential to positively affect the health of a nation.

The committee was tasked to conduct a consensus study to produce a comprehensive report on the current state of health care for persons of all ages with a serious illness or medical condition who are likely approaching death. The specific charge focused on (a) reviewing progress since the two aforementioned IOM reports, *Approaching death: Improving care at the end of life* (IOM, 1997) and *When children die: Improving palliative and end-of-life care for children and their families* (IOM, 2003); (b) evaluating strategies to integrate the care of those who are likely approaching death into a person-

and family-centered, team-based framework in the context of demographic shifts, cultural changes, and fiscal realities; (c) developing recommendations for changes in policy, financing mechanisms and payment practices, workforce development, research and measurement, and clinical and supportive care; and (d) developing a dissemination and communication strategy to promote public engagement.

What Is in the Report?

The report (IOM, 2014a) contains five recommendations and corresponding chapters. A brief background on each recommendation follows.

Recommendation 1: Delivery of Care

Government health insurers and care delivery programs as well as private health insurers should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.

KEY FINDINGS: DELIVERY OF PERSON-CENTERED, FAMILY-ORIENTED CARE (IOM, 2014B)

- People nearing the end of life often experience multiple transitions between health care settings, including high rates of apparently preventable hospitalizations, which can fragment the delivery of care and create burdens for patients and families.
- Demand for family caregiving is increasing, and the types of tasks performed by family caregivers are expanding from personal care and household tasks to include medical and nursing tasks, such as medication management.
- Palliative care is associated with a higher quality of life, including better understanding and communication, access to home care, emotional and spiritual support, well-being and dignity, care at time of death, and lighter symptom burden. Some evidence suggests that, on average, palliative care and hospice patients may live longer than similarly ill patients who do not receive such care.
- Although professional guidelines and expert advice increasingly encourage oncologists, cardiologists, and other disease-oriented specialists to counsel patients about palliative care, the widespread adoption of timely referral to palliative care appears slow.

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