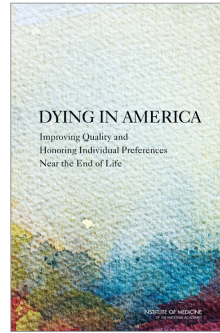


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Dying in America

Improving Quality and Honoring Individual Preferences Near the End of Life



For patients and their loved ones, no care decisions are more profound than those made near the end of life. For the millions of Americans who work in or with the health care sector—including clinicians, clergy, caregivers, and support staff—providing high-quality care for people who are nearing the end of life is a matter of professional commitment and responsibility. Health system managers, payers, and policy makers, likewise, have a responsibility to ensure that end-of-life care is compassionate, affordable, sustainable, and of the best quality possible.

A substantial body of evidence shows that broad improvements to end-of-life care are within reach. In *Dying in America*, a consensus report from the Institute of Medicine (IOM), a committee of experts finds that improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.

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The Pressing Need to Improve End-of-Life Care

A number of factors make the IOM study particularly timely, including the rapidly increasing number of older Americans with some combination of frailty, physical and cognitive disabilities, chronic illness, and functional limitations. The U.S. population also is quickly becoming more culturally diverse, heightening the need for responsive, patient-centered care.

In addition, the nation's health care system is increasingly burdened by factors that hamper delivery of high-quality care near the end of life, including

- barriers in access to care that disadvantage certain groups;
- a mismatch between the services patients and families need and the services they can obtain;

- inadequate numbers of palliative care specialists and too little palliative care knowledge among other clinicians who care for individuals with serious advanced illness; and
- a fragmented care delivery system, spurred by perverse financial incentives, that contributes to the lack of service coordination across programs and unsustainable growth in costs.

Opportunities for Improvement

Although the systems that support people at the end of life face increasing challenges and strain, there are new and encouraging opportunities for improvement. For example, there is growing knowledge within medical and social care communities about how to better engage patients and families in advance care planning and shared decision making, including seriously ill children and adolescents who may be able to participate in their own end-of-life care decisions. Other promising opportunities to improve care include utilization of new communications technologies, growing recognition and support for family caregivers, and the development of quality measures to increase accountability. Finally, according to the IOM committee, the greatest potential for positive change may lie in health care system reforms that affect the organization and financing of health services.

The committee makes recommendations in the areas of care delivery, clinician–patient communication and advance care planning, professional education and development, payment systems and policies, and public engagement and education.

Delivery of Person-Centered, Family-Oriented End-of-Life Care

Ideally, health care should harmonize with social, psychological, and spiritual support to achieve the highest possible quality of life for people of all ages

with serious illnesses or injuries. Toward this end, the IOM committee recommends that integrated, person-centered, family-oriented, and consistently accessible care near the end of life be provided by health care delivery organizations and covered by government and private health insurers.

The committee finds that a palliative approach typically affords patients and families the highest quality of life for the most time possible. For the purposes of the report, the committee defines palliative care as that which provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care may begin early in the course of treatment for a serious condition. Hospice is an important approach to addressing the palliative care needs of patients with limited life expectancy and their families. For people with a terminal illness or at high risk of dying in the near future, hospice is a comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions. It therefore has many features in common with palliative care.

Although palliative care is well established in most large hospitals and professional education programs, the committee identifies the need for greater understanding of the role of palliative care—by both the public and care professionals—as one of the greatest remaining challenges in the delivery of high-quality end-of-life care.

Clinician–Patient Communication and Advance Care Planning

Many people nearing the end of life may not be physically or mentally capable of making their own care decisions. In addition, family members and clinicians may not be able to accurately guess what a person’s care preferences may be. Therefore, advance care planning is critically important to ensure that patients’ goals and needs are met. Although advance directive documents can be useful, they should allow health care agents and care providers to make informed decisions

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in certain circumstances and should not take the place of open, continuous communication. According to the IOM committee, the advance care planning process can begin at any age or state of health and should center on frequent conversations with family members and care providers. Electronic storage of advance directives, statements of wishes, or other relevant materials holds promise for improving access to and effectiveness of these materials. Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning. Payers and health care delivery organizations should adopt these standards as a necessary component of high-quality care for individuals with advanced serious illness and their families and enable them to seek these services from their physicians and providers.

Professional Education and Development

The education of health professionals who provide care to patients at the end of life has substantially improved in recent decades. Hospice and palliative care is now an established medical specialty, and palliative care has a strong presence in clinical education, professional organizations, and research communities. However, the IOM committee finds that important deficiencies persist. First, recent knowledge gains have not necessarily translated to improved patient care. Second, the supply of palliative care and hospice specialists is small, meaning that many patients must rely

on other clinicians who provide care for individuals with serious advanced illness but who may lack training and experience necessary to meet their patients' palliative care needs. The committee recommends that educational institutions, professional societies, accrediting organizations, certifying bodies, health care delivery organizations, and medical centers take measures to both increase the number of palliative care specialists and expand the knowledge base for all clinicians.

Policies and Payment Systems to Support High-Quality End-of-Life Care

Sustainable improvements in the organization and financing of end-of-life care must take into account the need to stabilize health care costs over time. The IOM committee finds that reform is needed in how resources for care provided near the end of life are organized.

Current financial incentives encourage a reliance on acute care settings that often are costly and poorly suited to the needs, goals, and preferences of patients and their families. The committee recommends a major reorientation of payment systems to incentivize the integration of medical and social services, the coordination of care across multiple care settings, and the use of advance care planning and shared decision making to better align the services patients receive with their care goals and preferences. This reorientation will improve access to services that better respond to the needs of patients and their loved ones and may also help stabilize health care costs.



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Public Education and Engagement

The IOM committee identifies a need for public education and engagement about end-of-life care planning at several levels:

- the societal level, to build support for public and institutional policies that ensure high-quality, sustainable care;
- the community and family levels, to raise awareness and elevate expectations about care options, the needs of caregivers, and the hallmarks of high-quality care; and
- the individual level, to motivate and facilitate advance care planning and meaningful conversations with family members and caregivers.

Although Americans' values and opinions about end-of-life care will necessarily differ, the committee emphasizes the importance of disseminating accurate information so that individual care decisions and public dialogue, as much as possible, are based on an informed understanding of facts.

Conclusion

The IOM committee believes a person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life should be a national priority. *Dying in America* provides a comprehensive assessment of the knowledge gaps, structural problems, and financial disincentives that hamper delivery of optimal care and makes cross-sectoral recommendations to achieve compassionate, affordable, sustainable, and effective care for all Americans. 🌱

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