

# Thoughts about *Dying in America*: Enhancing the impact of one's life journey and legacy by also planning for the end of life

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This Perspective offers a summary of the recommendations in the Institute of Medicine report *Dying in America*. How we die is a deeply personal issue that each of us will face. However, the approach to end-of-life (EOL) care in the United States needs improvement. Too frequently, healthcare delivery is uncoordinated and has many providers who are not adequately prepared to have meaningful conversations about EOL planning. This is amplified by payment systems and policies that create impediments, misunderstanding, and sometimes misinformation. *Dying in America* made five recommendations to improve quality and honor individual preferences near the EOL beginning with making conversations with providers and families something that occurs during various phases of the life cycle and not just when one is facing serious illness or possible EOL. It was recommended (i) that public and private payers and care delivery organizations cover the provision of comprehensive care that is accessible and available to individuals on a 24/7 schedule; (ii) that professional societies and other entities establish standards for clinician patient communication and advance care planning and that payers and care delivery organizations adopt them; (iii) that educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and care delivery organizations establish palliative care training, certification, and/or licensure requirements; (iv) that public and private payers and care delivery organizations integrate the financing of health and social services; and (v) that public and private organizations should engage their constituents and provide fact-based information to encourage advance care planning and informed choice.

end of life | EOL | palliative care | death and dying

Whether you are probing the fundamental biological, chemical, or physical dimensions of life, seeking to understand the psychosocial factors impacting behavior or the forces that compose and define our planet or the cosmos, as a scientist you are likely thinking about how you might expand or deepen the scope of your research. You are probably not thinking about how the limits of your life will impact your discoveries. However, at some point and for each of us, our work (and life) will end, sometimes abruptly and without warning or more commonly slowly in a spiral of compromises and transitions.

## Ultimately, We All Will Die

*Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* is the title

of a report conducted by the Institute of Medicine (IOM) (now the National Academy of Medicine) that was published at the end of 2014 (1). I served as the cochair of the IOM Committee that produced this report and was invited to write this Perspective about it.

Whether and how we plan for our own eventual death has important implications for us individually, and as members of families and communities. This awareness and the conversations that ensue can be as important to our legacy as the contributions we make personally and professionally. Indeed, a lack of planning and communication with our health care provider(s) and others to whom we entrust our lives, could preempt the preferences we might have for the extent of the care we receive at the end of life.

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More specifically, failure to communicate our preferences could result in receiving too many or too few interventions, either of which can impact the quality of our death. In the end, the memory of how and where we die will be etched in the minds of those who will live beyond us, making it important to reflect the quality of death as well as the legacy of one's life.

We are also at a cusp in history when longevity is changing the demography of the world. This too impacts the number of individuals who will face end-of-life issues. As a corollary, these decisions will impact the availability, utilization, and cost of medical and social services and resources.

Although we might hope for a "good death," whereby we will work and live productively until the day we die, the current reality is that most of us will experience a chronic decline over months or years, sometimes accompanied by physical, cognitive, and emotional impairments. The choices we make about our medical care and how we communicate our preferences could result in treatments and procedures that impact how and where we live out the last part of our lives, even to the point of compromising our personal dignity. One of the challenges we face is that, except for a couple of medical diagnoses, we do not have good predictors of when death will occur, especially in the setting of chronic disease. This makes planning for a "good death" more challenging for individuals and their families and underscores the importance of discussing end-of-life preferences before the prospect of death is raised, ideally at different occasions and milestones throughout the life cycle.

Although it is understandable to put off thoughts and plans about dying until later in our lives, it is also true that death can occur at any age. Having spent decades as a pediatric oncologist caring for children and adolescents with cancer, and as a pediatric infectious disease specialist focused on pediatric AIDS, I have witnessed directly the impact of death and dying on young people—along with the consequences it presents to their families (2). As noted, we need to think about death as an accompaniment to life throughout the life cycle and to be prepared to discuss it openly throughout the life journey.

The challenges surrounding end-of-life care reflect many of the broader issues and problems of healthcare delivery in the United States where healthcare is still mired in the fee-for-service payment system that rewards a number of perverse incentives that foster overutilization of expensive services and procedures; limits the time that physicians spend with patients; and is oriented toward disease management by specialists who outnumber primary care physicians who often deliver care in silos rather than in a coordinated manner. There is also no doubt that continued healthcare reform is essential in the United States, particularly given the more than \$3 trillion dollars spent on health care, nearly a third of which is unnecessary, including some of that expended for individuals facing the end of life.

### Framing the Issues and Scope of Work

The process leading to the publication of *Dying in America* began with Dr. Harvey Fineberg, then President of the IOM, who reached out to me and to David M. Walker, the former Comptroller General of the United States, to cochair the Committee on Approaching Death: Addressing Key End of Life Issues (1). Neither of us as cochairs was an expert in end-of-life care per se, but we benefited from the dedicated work and contributions of 19 other committee members with expertise in aging, adult and pediatric medicine, nursing, palliative and hospice care, mental health, social work, spirituality, finance, health disparities, ethics, health

systems research, communications, and more. Our charge was to produce a comprehensive report that addressed the state of health care in the United States for individuals facing a serious illness or medical condition that would likely result in death and for whom appropriate care and communication could be of value and that extended the recommendations of two previous IOM reports that focused on end of life care for adults (3) and children (4).

The IOM Committee began its work at the end of 2012, and in September 2014, we reported our findings and subsequently produced a 612-page report entitled *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (1). The report was based on extensive literature reviews, six meetings (including three public meetings), site visits, commissioned papers, and a review of online testimony together with a lot of debate and discussion by the committee members. Although we provided substantial documentation of our findings, we elected to distill them into five interrelated recommendations (Table 1). At a high level, the recommendations underscored the need to dramatically improve on how care is delivered and compensated; how communications between clinicians (including physicians, nurses, social workers, clergy, and other providers) and the patients and families they serve. The recommendations highlighted the importance of changing the policy and payment system issues that impede the delivery of high-quality care honoring an individual's preferences and of engaging in a broad and deep public discourse about *Dying in America*.

**Delivery of Care.** Recognizing how fragmented clinical care currently is in the United States, our committee advocated for a model of comprehensive care that is seamless, of high quality, integrated, family centered, and patient oriented, and that is available around the clock. In doing so, we were mindful of the importance of decreasing the use of 911 and emergency room care when a medical provider cannot be accessed, because that often results in overutilization of medical care, especially in the emergency room. To help achieve this, we noted "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." High-quality clinical care needs to consider the evolving physical, emotional, social, and spiritual needs of the patient. Moreover, care should be provided by professionals with appropriate expertise and training who are able avoid or overcome the problems associated with the handoffs that so frequently occur in the specialist-driven provider system. This would benefit from coordinated, efficient, and interoperable information transfer systems across all healthcare providers and settings that are consistent with the values, goals, and preferences of individuals.

Individuals facing advanced serious illness should have access to palliative care (i.e., health professionals who provide supportive care as an adjunct to active treatment throughout the course of a chronic disease) or, when appropriate, to hospice care [which refers to supportive care (e.g., pain management) when active treatment is usually discontinued and when death is imminent—generally within 6 mo]. Ideally, an interdisciplinary team of skilled and trained health care providers should provide palliative and hospice care, either directly or by consultation. Although hospice care remains woefully underused, it should be noted that palliative care, in tandem with ongoing medical treatments, has been shown in a randomized clinical trial to extend the duration of life while also improving the quality of life at the end of life (5, 6).

**Table 1. Key areas of recommendation from *Dying in America***

No.	Area of recommendation
i)	Public and private payers and care delivery organizations should cover the provision for comprehensive care for individuals facing the end of life.
ii)	Professional societies and other entities should establish standards for communication and advance-care planning. Payers and care delivery organizations should adopt these standards.
iii)	Education institutions, credentialing bodies, accrediting boards, state regulatory agencies, and care delivery organizations should establish palliative care training, certification, and/or licensure requirements.
iv)	Public and private payers and care delivery organizations should integrate the financing of health and social services.
v)	Public and private organizations should engage their constituents and provide fact-based information to encourage advance-care planning and informed choice.

High-quality, integrated care will help honor an individual's preference about the care she or he receives. Some people want more care (even if the evidence suggests that it may not be beneficial), whereas others will want less care or interventions when the prospects for life become constrained or limited. There is a disparity in what physicians profess they want for their own end-of-life care and what is offered to their patients (7–9). Based on studies in older as well as younger physicians from different cultural backgrounds, between 80% and 88.3% prefer to receive pain medication but would refuse or forego life-sustaining treatments at the end of life. This contrasts with the care physicians provide to the patients they serve. Although like their physicians 80% of patients say they do not want life support care, over 33% wind up receiving it anyway. This disparity is unfortunate and needs to be addressed by the medical profession.

#### **Conversations, Communications, and Advance Care Planning.**

In addition to improved medical and social services, an important component of quality care is that patients and clinicians engage in conversations about their preferences for end-of-life care when they are well and at various junctures of the life cycle (e.g., when they get a driver's license, get married, have children, take on new responsibilities, become eligible for Medicare) and not just when they are facing a serious illness or the prospect of death. These discussions should be high quality, evolve and change over time, and be communicated to all providers of the health care team.

However, simply stating that these conversations should take place is insufficient. Accordingly, we recommended that "professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence based." Furthermore, we recommended that "payers and healthcare delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of healthcare quality." To more fully operationalize this, we recommended that "payers should tie these standards to reimbursements and professional societies should adopt policies that facilitate tying the standards to reimbursement, licensing, and credentialing." For example, this could include payment for physicians for the time taken to have end-of-life discussions with individuals enrolling in Medicare. Of importance, after our report *Dying in America* was published, the Centers for Medicare and Medicaid Services (CMS) announced in July 2015 that it would begin paying doctors to have end-of-life conversations with patients enrolled in Medicare beginning January 2016. This reversed an earlier decision by CMS not to offer these payments and thus is a major step forward, making these conversations more likely to occur. This is important given that there are currently 55 million Medicare beneficiaries, a

number that will increase to over 70 million by 2030. Moreover, because more than three-quarters of all deaths in the United States occur in individuals 65 or older, this policy can have a major impact on end-of-life conversations and planning.

**Professional Education and Development.** Recognizing that end-of-life conversations within families and with healthcare providers is a cornerstone of making one's preferences known and hopefully realized, it is also important to acknowledge that making these conversations meaningful requires significant changes in the education of clinicians. To that regard, the IOM recommended that "Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life."

More specifically, it is important for all clinicians (including physicians, nurses, social workers, psychologists, clergy) who care for people with advanced serious illness to be competent in at least basic skills of palliative care—notably their communication skills (e.g., ability to engage in "difficult conversations"), as well as symptom management (e.g., pain, nutrition, etc.). This requires medical schools, teaching hospitals, and continuing medical education programs to include palliative care training directly in the curriculum at the various stages of the learning trajectory—something that is not well done today. Because this requires regulation and oversight, the IOM Committee commented on the need to make changes in requirements for accreditation, certification, medical staff privileges, and licensure as well as in the need to train and educate more palliative care specialists from all medical disciplines (including physicians, nurses, social workers, clergy, etc.).

**Policies and Payment Systems.** Whatever progress is made within the healthcare community in improving care delivery models and clinicians' skills, we still face a number of policies and health system impediments that negatively impact end-of-life care and that also must be addressed. Because of that, the IOM recommended that "Federal, state, and private insurance and health care delivery programs should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life. To the extent that additional legislation is necessary to implement this recommendation, the administration should seek and Congress should enact such legislation. In addition, the federal government should require public reporting on quality measures, outcomes, and costs

regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers (e.g., Medicare, Medicaid, the Department of Veterans Affairs). The federal government should encourage all other payment and health care systems to do the same."

As noted above, in addition to the decision by CMS in 2016 to pay doctors when they have end-of-life conversations with Medicare enrollees, another important advance could come from the increased use of electronic medical records (EMRs) as one way to better integrate and coordinate care across different settings and geographies. Assuring that patients' information about advance care planning are documented in the EMRs and that the systems are interoperable is an important way for documenting patient preferences and making them accessible to all providers. These preferences can be enhanced by the increased use of physician orders for life-sustaining treatment (POLST), which is designed to facilitate an advance-care planning conversation between healthcare professionals and patients and those close to them, to help them determine which treatments they do or do not want based on their personal beliefs and current state of health. Currently, the POLST paradigm is being applied in some states and our committee encourages other states to develop and implement a POLST paradigm program in accordance with nationally standardized core requirements.

**Public Education and Communications.** Finally, the IOM committee recognized the need to change the national discourse and dialogue on life and end of life. It is all too easy for fear to dominate the agenda, thus sabotaging thoughtful discussion. We know we will die one day, and although it is understandable that many are fearful of the prospect of death, the recognition that one's preferences about dying will be honored can help to offset and even abate fears. With that in mind, the IOM recommended that "Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals."

### Convergences and Catalysis

When *Dying in America* was announced at the end of 2014, it converged with the publication of Atul Gawande's compelling book *Being Mortal: Medicine and What Matters in the End* (10). Through his unique storytelling narratives, Gawande provided a readable and accessible resource about the life journey, end-of-life issues, and death, and it became a national best seller. In some ways, *Being Mortal* can be viewed as a complement to *Dying in America*, but, more importantly, the broad interest and remarkable welcoming of this publication provides evidence that many Americans are willing to engage with the topic of death and dying.

To further the national dialogue, since the publication of *Dying in America*, the IOM hosted a National Action Conference in March 2015 to foster a continuing dialogue and stimulate implementation of the recommendations emanating from the report related to policies and payment systems. This included reaching out to a wide array of public and private institutions and agencies to solicit and share their plans for improving end-of-life care. These and related efforts have paid off by the aforementioned decision by CMS to

reimburse physicians for end-of-life counseling of Medicare beneficiaries, stimulating CMS to raise payment rates for hospice, skilled nursing, and rehabilitation facilities for individuals receiving end-of-life care through the Advance-Care Planning payment. Further actions by CMS to explore new models of care through Accountable Care Organizations, the Comprehensive Primary Care Initiative, and engagement of the Innovation Center are important steps forward. In addition to federal initiatives, a number of states have also developed important initiatives including the Massachusetts Coalition for Serious Illness Care and coalition between the California Health Care Foundation and the Coalition for Compassionate Care of California that resulted in *Dying in California: A Status Report on End-of-Life Care* (11). A number of professional societies and organizations (e.g., American Nurses Association, American Geriatrics Society, American College of Physicians, the Cambia Health Solutions, National Hospice and Palliative Care Organization), universities, foundations, and think tanks, including Aspen Health Strategy Group, have initiated programs to follow up on the report's recommendations and advance the field further. The National Academy of Medicine also hosted a follow-up stakeholder meeting on May 23, 2016, to assess progress and evolving opportunities and to also nucleate the initiation of a new Roundtable on Quality Care for People with Serious Illness that will continue work in this important area over the next 3 y. Clearly, the progress made on *Dying in America* is far from reaching the end of its life.

### Additional Opportunities

Some of the work to-date has been more operational and tactical, and although the recommendations offered by the IOM are based on available evidence, it is clear that additional research is needed to further refine the understanding of the biopsychosocial issues and intersections that relate to end of life. With that in mind, following the publication of *Dying in America*, members of the IOM Committee met with leaders at the NIH to explore questions and issues that might be explored based on the limitations and opportunities delineated in its report. One glaring need is the development of tools and diagnostics that would permit greater precision around when "end of life" is beginning. Although this is currently viewed through a retrospective lens, reliable and predictive measures of whether death is imminent or likely to take place in months or years would be a major advance for individuals, providers, and communities.

In addition, the Committee recognizes the need to develop evidence-based models to better assess how to deliver care that is seamless, high quality, integrated, patient centered, culturally appropriate, and consistently available. From a behavioral and operational perspective, we need to understand why the type of services physicians typically use themselves at the end of life vary from those administered to the individuals they care for and how this relates to implicit bias, knowledge differences, and medical literacy.

We also need to improve knowledge about the major symptoms that impact individuals with serious chronic disease who are approaching the end of life (e.g., pain, nutrition, etc.) as well as to develop new and more effective management strategies and interventions.

We need to develop and evaluate models and metrics of improving clinician-patient/family communication, including communication with children, individuals with disability, individuals with low literacy, from different cultures, etc. We further need to determine whether "conversations" through the life cycle help

prepare individuals for end-of-life planning and whether they improve quality and honor individual preferences and to study how to integrate effective communication strategies into existing practice. Coupled with this, we need to develop more effective and successful approaches to the education and training of all healthcare providers about how to manage advanced serious illness and end-of-life planning. Furthermore, we need to develop metrics to assess success for individuals and for the education and training institutions.

From a policy perspective, we need to better assess the impact of current and future payment systems on the management of individuals with advanced serious illness and who are approaching the end of life and determine which models and financing policies and payment systems improve outcomes. This should include the management of individuals with complex conditions, including multiple morbidities. We also need to assess ways to eliminate inappropriate barriers and provide appropriate incentives for high-quality, compassionate, and cost-effective end-of-life care that includes both health and social services.

Finally, in its discussion with NIH leaders, the Committee highlighted the need to develop and create new approaches to public education that dispel misinformation that may impede informed decision-making. This includes the development of new approaches to use and use new communication strategies and media that serve culturally and geographically diverse communities and that enable individuals to make informed choices that improve quality and honor individual preferences at the end of life.

### What This Means to All of Us

Knowledge and responsibility about end-of-life issues, concerns, and plans is something we all should embrace—in our communications with individuals, colleagues, professional societies, and communities. In our various roles, we have the ability to help dispel misinformation and promote a dialogue that puts these important issues in a context that dispels fear and promotes decision-making. As scientists, professionals, and members of the national community, we should all be part of the solution.

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