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Editorial

Are we appropriately preparing physicians to care for patients throughout their life journeys?

A personal perspective reflected through the lens of the Institute of Medicine

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Introduction

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AΩA's motto is "Be worthy to serve the suffering." When suffering is primarily caused by a disease, using specific and effective treatment may relieve most of the suffering. But, as we all know, many times there isn't an effective, certain, or rapid intervention. This may be most important at the end of life. For dying patients, the care for the patient and the relief of suffering is paramount.

Dr. Phillip Pizzo, Dean Emeritus at the Stanford School of Medicine, was the co-chair of the Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. After I read the report and followed some of the news coverage, I thought about how AΩA and our members could participate in this important discussion on a subject that requires broad and engaged participation and leadership from physicians individually and our profession as a whole.

One of AΩA's important missions is communicating with members and disseminating information so that more of us in medicine learn about important issues. The recommendations in this report are vital to the profession in finding the best approaches in this difficult aspect of patient care and community service. I asked Dr. Pizzo to write this issue's editorial. In his words, "We all will die. As professionals we must be committed to doing all we can to improve quality and honor individual preferences for each other, our loved ones, and the patients we serve when the near the end of life."

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Dr. Pizzo (AΩA, University of Rochester, 1970) is the David and Susan Heckerman Professor and Professor of Microbiology and Immunology, former Dean of Stanford University School of Medicine, and the Founding Director of the Stanford Distinguished Careers Institute. He is the co-chair of the Institute of Medicine Committee on Approaching Death: Addressing Key End of Life Issues, which recently issued its report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*.

It is understandable that most of us do not spend great amounts of time dwelling on our own death, even though we know it is inevitable. Because the experience of death is so personal, when we do think about it, those reflections are shaped by both discrete and aggregate experiences—the loss of a parent, spouse, sibling, friend, and, in the case of physicians, the death of patients and the impact of their loss on their families and loved ones. Regardless of our medical knowledge and expertise, the feelings and thoughts about our own eventual death are also influenced by the biological, psychological, societal, and spiritual forces common to all of us. These views evolve during our life journeys and can vary by the communities we inhabit, the nature of our medical practices, whether we are healthy or have developed an illness that might be serious or life threatening. My views on dying will resonate to some but appear dissonant to others. Even though my thoughts about life and death are not meant to be judgmental, by expressing them, they will be judged. I weighed this carefully when I was asked by the Institute of Medicine to co-chair

a committee on “approaching death.” I was mindful that my personal and subjective perspective would be refracted against a diverse group of individuals, each of whom would be viewing death through their own personal and professional lenses. But it would take all of us to develop an evidence-based consensus assessment about dying in America. I will share the intersections of how my professional journey has impacted my views about death and how those views have been impacted by my work with the Institute of Medicine.

Developing a personal perspective on life and death

While my undergraduate work in philosophy posed many existential questions about the meaning of life, my introduction to death and dying began as a medical student, albeit in a somewhat orthogonal fashion. I had been inspired to pursue a career in medicine by reading books like *The Microbe Hunters*,¹ and fantasized about becoming a doctor who would discover new ways of treating or preventing serious disease. As I began medical school, my goal was focused very much on conquering disease—not yielding to death. Ironically, my very first patient encounter as a first-year medical student was facilitated by my assigned advisor, who was a pediatric hematologist-oncologist, and who brought me to the bedside of a young child with acute leukemia. At that time most children with leukemia died, and I recall wondering how anyone could pursue a career path where the prospect for death was so prominent. It was pretty clear to me that I could never do that.

In parallel I benefited from a medical school curriculum that at the time was unique. Not only was the University of Rochester pioneering the biopsychosocial model of medical education, it also was championing ways of teaching students how to listen to how patients and families communicated their health problems, using their own words to describe the impact of the illness on them, their family, and community. It was a highly humanistic style of teaching and learning and helped to make students comfortable with complexity, including engaging in difficult conversations. We were guided to learn more about what our patients were seeking as they formulated their personal stories, hopes, fears, and views. These skills have proved invaluable to my entire professional life and career—both inside and outside of medicine.

Despite the initial reaction to my first patient encounter, I wound up gravitating to a career in pediatrics and ultimately one that combined pediatric oncology with infectious disease. My work in pediatric oncology coincided with a time of tremendous progress in treating childhood cancer—which remains one of the great success stories of the twentieth century in clinical and translational research. While my orientation was always about trying to improve outcomes, many children still died. It was imperative to learn how to deal with death and dying in children and the impact of their loss on families. Because these experiences developed long before hospice and palliative care became part of our lexicon and care system, it was

imperative for physicians caring for children who might die to become knowledgeable about how to discuss death with parents, children, and adolescents, and how to modify or alter the communications depending on the psychosocial factors impacting the child and family. Having sat by the bedside of many children who ultimately died, I learned the limitations of what could be done to control pain and enhance comfort and, to be blunt, was horrified by the poor quality of the death of a number of my patients. At the same time, it was clear that listening to my patients, and developing deep and caring relationships with their parents and families, was important and essential. These experiences forged interdisciplinary collaborations with fellow physicians as well as with nurses, social workers, teachers, clergy, and others. We learned from each other and helped each other to care for children through the lives of our patients and at the time of their death. Because much of this work was conducted in the Clinical Center of the National Institutes of Health, we had the time to care for our patients and were not affected by the perverse incentives that have guided fee-for-service medicine. These experiences affirmed that caring for dying children was as important as focusing on their medical treatment, and that providing multidisciplinary, team-based care was beneficial and allowed us to understand and honor the choices of our patients and families. Some children (and their parents) wanted to know about death, whereas others only wanted to focus on treatment. Some would never give up the next treatment possibility, whereas others recognized when it was time to stop. These decisions were made respectfully and after lengthy and informed conversations.

For a while I assumed that this is the way all patients experienced decisions about life and death—whether the child had cancer, AIDS, or other serious disorders, and regardless of their social or economic strata. It seemed clear that when physicians were honest, engaged, willing to discuss the limitations and boundaries of treatment, and able to make the time to do so, that life and death with dignity was achievable. For a while I even assumed that this was the norm in American medicine.

Witnessing the approach to life and death through the lens of a leader in academic medicine

My perspective on how doctors and institutions approach end-of-life care changed significantly when I left the NIH and assumed two institutional leadership roles, one on the East Coast and another on the West Coast. While I never doubted that health care providers and medical institutions care deeply for the patients they serve, I was surprised to see how little attention was given to preparing young physicians about end-of-life care. There was no real curriculum, few role models, and the focus of these medical institutions was almost always about doing more—additional treatments, including stays in the ICU—even for patients whose prospect for recovery was limited at best. Because many physicians, whether they are working in tertiary centers or in primary care offices, are

increasingly harried and tasked to see more patients in shorter periods of time, the opportunity to take the time and listen to patient's hopes and expectations are all too frequently blunted. It is simply not possible to shoehorn a serious discussion about the prospect of death into fifteen-minute visits. Coupled with this is the reality that fee-for-service medicine, which still very much characterizes American medicine today, incents doing more procedures as something more highly compensated than spending quality time with patients. Medicare, for example, supports hospice care, but only for patients who have less than six months to live and if they forego concurrent medical treatments. This forces a Faustian bargain that leads doctors and patients to underutilize hospice services. In fact the average length of a hospice stay is less than eight days, and this is often preceded by unnecessary and even unwanted stays in the ICU.

Politics have also impacted our approach to end-of-life discussions since the uproar over the egregious allegation that the Affordable Care Act (ACA) would result in "death panels." This resulted in the administration pulling out of the law the provision that would have paid for advance directive planning conversations between patients and doctors at the time of Medicare enrollment. The highly siloed organization of American medicine and the multiple handoffs that occur among the many specialists caring for patients with advanced serious illnesses also makes it difficult for patients to know whom to call when they have a medical emergency or problem. As a consequence, many patients, and especially those on Medicare, wind up using 911 calls and being taken to emergency rooms, where medical interventions often take precedence over patient's prior wishes and even advance directives. All of these events reduce the quality of the dying process for patients. Furthermore, they both directly and indirectly result in overutilization of medical services, almost at the exclusion of social services, thus contributing to the rising cost for care in the United States.

From the vantage of an institutional leader, my colleagues and I sought ways to more appropriately address medical utilization, especially for patients with advanced serious illness, but it was also clear that our health care system is poorly designed to provide care for patients with advanced serious illness, including those nearing the end of life.

Viewing the end of life through the lens of the Institute of Medicine

At the end of 2012, the Institute of Medicine assembled a twenty-one-member panel 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 and who require coordinated care, appropriate personal communication (or communication with parents or guardians for children), and individual and family support. The com-

mittee will assess the delivery of health care, social, and other supports to both the person approaching death and the family; person-family-provider communication of values, preferences, and beliefs; advance care planning; health care costs, financing, and reimbursement; and education of health professionals, patients, families, employers, and the public at large.²

I co-chaired this committee with David M. Walker, the former U.S. Comptroller General. We had very different life journeys and perspectives, but we benefited from the knowledge and insights of committee members with exceptional 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 work included extensive literature reviews, six meetings (including three public meetings), site visits, commissioned papers, and a review of on-line testimony. We approached our work with the recognition that our nation is at the cusp of the most significant demographic shift in its history, with a growing and ever more diverse population of elderly Americans, who will represent twenty percent of the U.S. population by 2030.

Our report entitled *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*³ focused on five interrelated recommendations. Remarkably, these recommendations were closely aligned to the personal and professional assessment of death and dying that I described above. But when viewed through the lens of the IOM, these recommendations reflect the need for a major transformation in how the United States approaches the care of individuals with advanced serious illness, including those nearing the end of life. The recommendations focus on how to improve care, including how it is delivered and compensated; how communications between clinicians and patients take place with quality and excellence; the need to educate and train clinicians on how to engage patients about advance directives and end-of-life care; and the importance of addressing the policy and payment system issues that impede the delivery of high-quality care that honors individual preferences. In addition, the recommendations emphasize the importance of engaging the nation in a broad and deep public education and discourse about dying in America—one that is evidence based and that dispels the misinformation when "death panels" became the operative, albeit politically driven, phrase defining the ACA.

Our committee focused on the provision of quality care throughout life and at the end of death. Recognizing how fragmented clinical care currently is, we recommended a model of comprehensive care that is seamless, of high quality, integrated, family-centered, and patient-oriented that is available around the clock. This is particularly important to help patients to avoid 911 and emergency room care when they can't access a medical provider—since that often results in overutilization

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of care. Importantly, high-quality care needs to consider the evolving physical, emotional, social, and spiritual needs of the patient. Moreover, this care needs to be provided by professionals with appropriate expertise and training. To avoid the handoffs that so frequently occur in our current specialist-driven provider care system, our committee underscored the importance of developing and implementing coordinated, efficient, and interoperable information transfer across all providers and settings, and to do so in a manner that is consistent with the values, goals, and preferences of individuals. To assure that these important changes in delivery of care are accomplished, the committee recommended

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.^{3p3}

The committee went even further in its recommendations regarding comprehensive care by stating that all people with advanced serious illness should have access to palliative care, or when appropriate, to hospice care. This should ideally include care provided by an interdisciplinary team of skilled and trained palliative care providers, either on-site or by virtual consultation. At the same time, we underscored the importance of individual choice and noted that patients should also have the right to decline medical and social services if that is their preference.

A critically important component of quality care is that patients and clinicians engage in health care decisions not only when they are facing a serious illness or the prospect of death, but also that these conversations happen at key milestones throughout their lives. These discussions should be high quality, evolve and change over time, and be communicated to all providers of the health care team. To help assure that these conversations take place, we recommended that professional societies and other organizations that establish high quality standards should develop standards for advance care planning that are measurable, actionable, and evidence based. Further, payers and health care organizations should adopt these standards and integrate them into assessments, care plans, and reporting of health care quality. Importantly, payers should tie these standards to reimbursements—and thus overcome the negative decision that was made when CMS withdrew payment of advance care planning discussions for Medicare patients.

Having meaningful conversations with patients or engaging in the competent care of individuals with advanced serious illness or nearing the end of life requires significant changes in the education of clinicians. To that regard the IOM recommends

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.^{3p4}

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.). Accomplishing this requires medical schools, teaching hospitals, and CME programs to include palliative care training directly in the curriculum at the various stages of the learning trajectory. It is simply not enough to focus on disease treatment. Attention must also be directed to caring for patients for whom supportive care management should be coupled with disease treatment—and particularly for end-of-life care. While good intentions by medical educators are important, having this education and training truly established will necessitate changes in requirements for accreditation, certification, medical staff privileges, and licensure. In addition, we need to train and educate more palliative care specialists from all medical disciplines. With reductions in funding for Graduate Medical Education through Medicare likely in the future, health care delivery systems, academic medical centers, and teaching hospitals should commit institutional resources to increase the number of training positions.⁴ Such investments are appropriate to improve patient care, help with the education of non-palliative care clinicians, and potentially decrease unnecessary utilization of medical services. These will stabilize or potentially reduce health care expenditures—especially for the growing population of aging Americans with advanced serious illness and nearing the end of life.

Even if we commit to 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. With that in mind, the IOM recommends

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.^{3p4}

While the committee recognizes that some of these changes will take time, it is imperative that they occur. The current fragmentation of the system and frequent handoffs from one physician to another make it difficult for most people to navigate the health care system. They also foster a setting in which emergency services and advanced medical care are used in place of the more appropriate combination of both medical and social services needed to assist patients with advanced illness. The ACA has called for the increased use of electronic medical records as one way to better integrate and coordinate care across different settings and geographies. Assuring that patients' advance directives are documented in the EMR 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, which is applied in some states currently but should become a national program in the near future.

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 and even sabotage thoughtful discussion, as occurred when "death panels" and related political hyperbole were used to characterize aspects of health care reform. While we all know we will die one day, it is also true that many are fearful of the prospect of death and, in particular, that their individual preferences will not be honored. Accordingly,

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.^{3p5}

This is a responsibility we all should embrace—in our communications with individuals, colleagues, professional societies, and communities. As professionals we have the ability to help dispel misinformation and promote a dialogue that puts patients and families first—throughout their lives and at the end of their lives.

An unexpected but appreciative convergence of views

During my personal and professional life, I have learned much about life and death. There is no doubt this knowledge has shaped the care I have provided to my patients, what I have taught to my students and trainees, how I have interacted with professional colleagues, and how I have engaged with leaders to make our medical systems more responsive to the needs of individuals facing the end of life. What I didn't anticipate is how these views were mirrored, enriched, and enhanced by the wisdom that came from the twenty other members of the IOM committee that produced the report *Dying in America*. Looking at life and death issues through their individual and collective lens affirmed some of my views and changed others. It was an informative albeit challenging process. Reaching consensus when there were so many different viewpoints, agendas, and self-interests was remarkable in its own right—but was most important because patients and families were placed in the center of all our deliberations. The skills I learned at the beginning my medical career—listening to patients and learning how the human condition is impacted by biopsychosocial interactions—has helped me appreciate the complexity of the forces that shape each of our reactions to end of life. The work of our IOM committee gave evidence to different experiences but one commonality. We all will die. As professionals we must be committed to doing all we can to improve quality and honor individual preferences for each other, our loved ones, and the patients we serve when they near the end of life.

References

1. De Kruif P. *Microbe Hunters*. Orlando (FL): Harcourt, Brace; 1926.
2. The National Academies. Project: Approaching Death: Addressing Key End of Life Issues. <http://www8.nationalacademies.org/cp/projectview.aspx?key=49481>.
3. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. National Academies Press; 2014. <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>.
4. Institute of Medicine. *Graduate Medical Education That Meets the Nation's Health Needs*. National Academies Press; 2014. <http://www.iom.edu/Reports/2014/Graduate-Medical-Education-That-Meets-the-Nations-Health-Needs.aspx>.

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