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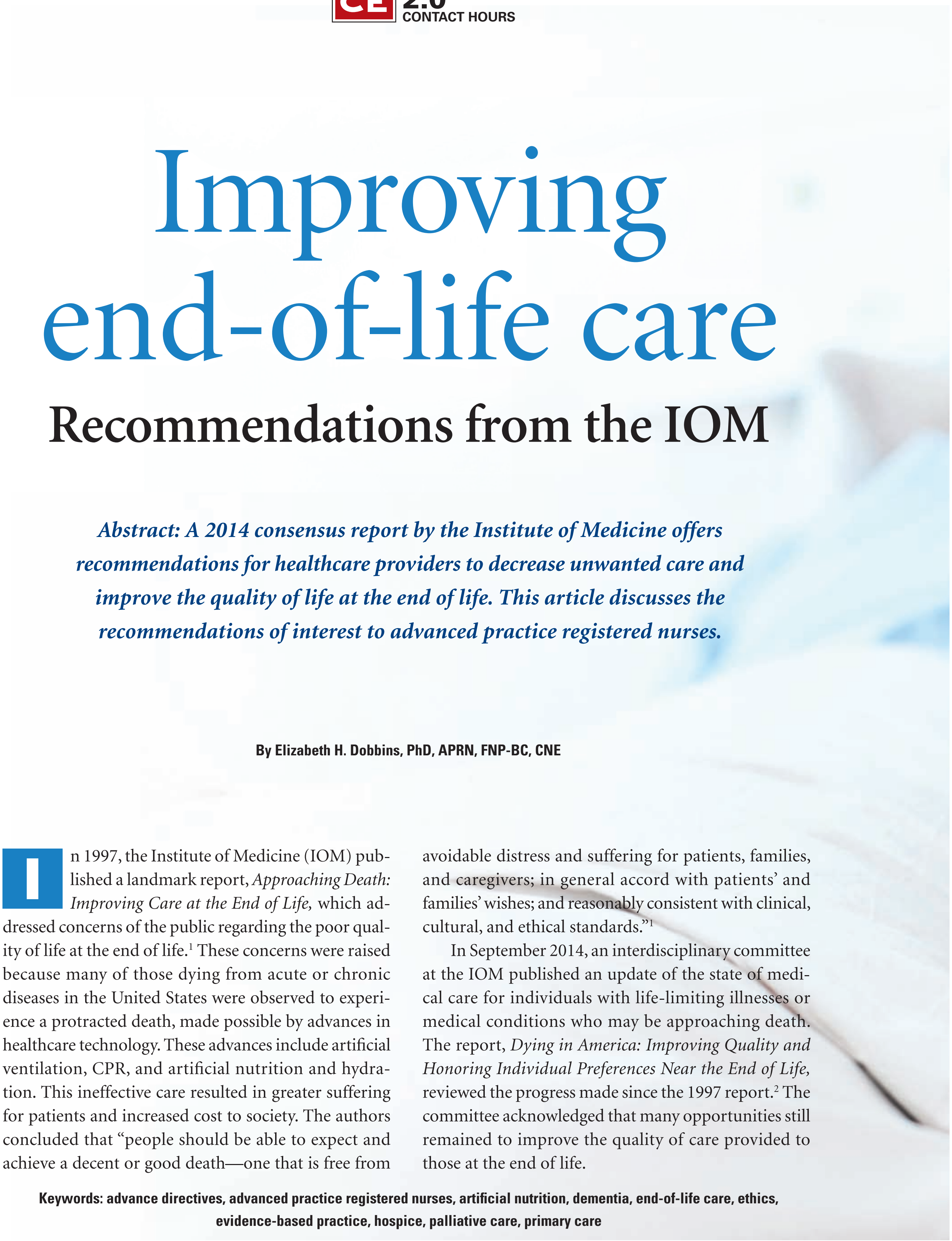

Improving end-of-life care

Recommendations from the IOM

***Abstract:** A 2014 consensus report by the Institute of Medicine offers recommendations for healthcare providers to decrease unwanted care and improve the quality of life at the end of life. This article discusses the recommendations of interest to advanced practice registered nurses.*

By Elizabeth H. Dobbins, PhD, APRN, FNP-BC, CNE

In 1997, the Institute of Medicine (IOM) published a landmark report, *Approaching Death: Improving Care at the End of Life,* which addressed concerns of the public regarding the poor quality of life at the end of life.[1] These concerns were raised because many of those dying from acute or chronic diseases in the United States were observed to experience a protracted death, made possible by advances in healthcare technology. These advances include artificial ventilation, CPR, and artificial nutrition and hydration. This ineffective care resulted in greater suffering for patients and increased cost to society. The authors concluded that "people should be able to expect and achieve a decent or good death—one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."[1]

In September 2014, an interdisciplinary committee at the IOM published an update of the state of medical care for individuals with life-limiting illnesses or medical conditions who may be approaching death. The report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,* reviewed the progress made since the 1997 report.[2] The committee acknowledged that many opportunities still remained to improve the quality of care provided to those at the end of life.

Keywords: advance directives, advanced practice registered nurses, artificial nutrition, dementia, end-of-life care, ethics, evidence-based practice, hospice, palliative care, primary care

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Advanced practice registered nurses (APRNs) provide care to patients throughout the lifespan in many different settings. APRNs working in primary care, long-term-care facilities, and as hospitalists can expect to see an increase in patients age 65 and older, reflecting the swell of baby boomers in the United States. As the complexity of care increases with patient age, APRNs working with aging patients will find themselves increasingly challenged by a fragmented healthcare system. With those challenges, however, come great opportunities.

To most effectively and efficiently care for these patients, the IOM recommends that care decisions be evidence-based and support the collaborative healthcare choices of patient and provider.[3] Evidence-based practice guidelines have been shown to improve patient outcomes and reduce healthcare costs throughout the lifespan, particularly at the end of life.[4]

Delivering end-of-life care

The IOM recommends a palliative approach to patient care.[2] The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness via early identification and impeccable assessment and treatment.[5]

Patients with dementia and other debilitating chronic diseases frequently experience eating and swallowing problems.

Palliative care principles can be applied in any setting and integrated into disease-specific care. Many larger hospitals now offer formal palliative care programs, which include the specialized services of physicians, APRNs, and social workers.[2,6]

Palliative care has been shown to result in a higher quality of life and increased dignity, emotional and spiritual support, and patient and family well-being. Evidence suggests that patients receiving palliative and hospice care live longer when compared with similar patients who do not receive those services.[7,8] The authors of a study investigating the impact of early palliative care for patients with metastatic non–small cell lung cancer found that the mean survival rate was 3 months longer for patients receiving the intervention.[9] Another group of investigators found that clinic-based outpatient palliative care services implemented before the patient was eligible for hospice admission lived an average of 9 days longer under hospice care.[10]

According to the Center to Advance Palliative Care (CAPC), the prevalence of hospitals (50 or more beds) with a multidisciplinary palliative care team increased 165% from 2000 to 2013.[11] In 2000, less than one-quarter of U.S. hospitals had a palliative care program; by 2013, nearly three-quarters offered palliative care services to their patients.[11] Financial reimbursement to physicians and NPs who provide palliative care consultation services is available under Medicare Part B, Medicaid, and some commercial insurances.[12]

Patients with dementia and other debilitating chronic diseases frequently experience eating and swallowing problems. It is commonly believed that such problems indicate the end of life is near as they frequently lead to life-limiting complications.[13,14] Pneumonitis due to aspiration of solids and liquids was ranked 15th in leading causes of death in the United States in 2013.[15] When 323 long-term-care facility residents were followed for 18 months, researchers found 86% of patients with dementia developed eating problems, which led to infection, malnutrition, and hospitalization.[16]

Patients with dementia and other end-stage chronic diseases often receive invasive care, which may be of limited value. A recent review of the literature concluded that artificial nutrition did not prevent aspiration pneumonia, decrease pressure ulcers, improve functional status, reduce or prevent malnutrition, provide comfort, or reduce mortality.[13,17] Efforts to prevent patients from pulling out tubes also resulted in increased agitation and the use of mechanical or chemical restraints for more than one-third of the patient sample, increasing the burden of suffering.[18]

Careful hand-feeding is an evidence-based palliative approach foregoing caloric intake and focusing on patient comfort. Many professional organizations support this feeding technique, including the National Hospice and Palliative Care Organization (NHPCO), American Board of Internal Medicine, American Geriatrics Society, and Canadian Geriatrics Society.[19-22]

Food and fluids can be offered as long as the patient has an interest in "recreational eating."[23] Evidence shows, however, that even if oral feedings are consistent and tolerated, they will not improve function or cognition or decrease the mortality for individuals with moderate-to-severe dementia.[14]

Hospice services extend palliative care principles to the end of life (see *The continuum of palliative care*). Patients are eligible for hospice care if they have a projected life expectancy of 6 months or less and have decided to forgo curative disease-directed therapies. In addition to a medical director, nursing staff, and social workers, hospice care providers may also include chaplains, hospice aides, dietitians, and therapists.[24] Mirroring the growth in palliative care programs, the number of agencies offering hospice services has also grown. According to the NHPCO, of all Medicare decedents in the year 2001, 18.1% accessed hospice services for 3 or more days; by 2013, that percentage rose to 47.3% with over 1.5 million patients receiving care.[25] Hospice care is funded by the Medicare Hospice Benefit, which provides hospice-related services and supplies related to the patient's care.[2,26]

Clinician-patient communication and advance care planning

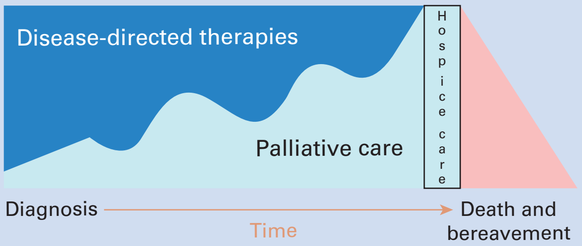
The IOM emphasizes that all individuals should have the opportunity to actively participate in their healthcare decisions throughout their lives.[2] Advance directives (living wills and durable powers of attorney for healthcare) provide a means for patients to communicate to their healthcare providers what they want for themselves at the end of their lives. This information is especially important for cases in which patients are unable to speak for themselves.

Included in advance care planning, but not intended as a replacement for advance directives, the Physician Orders for Life-Sustaining Treatment (POLST) are medical orders written for patients with serious illnesses who may die within the next year. Intended to stay with the patient across care settings to prevent unwanted emergency interventions, the form is prepared by the patient's healthcare provider and documents the patient's preferences with respect to treatment and preferred site for receiving care and death. Although variations of the form are used in many states, the POLST may not be recognized if the patient moves into a jurisdiction that does not utilize the form, such as Alabama, Arkansas, or South Dakota.[27,28]

The IOM identifies primary care providers as being in an ideal position to begin end-of-life conversations with their patients.[2] Advance care planning can begin at any patient-care interaction, regardless of age or health status. Communication between the healthcare professional and the patient and family should be clear, open, and respectful to facilitate the development of a therapeutic relationship and negotiate and complete the advance care plan documents.[2,29]

The Centers for Medicare and Medicaid Services (CMS) and the American Bar Association recommend that original copies of the advance directive documents be kept where they can be easily found and that copies be provided to healthcare proxies, providers, hospitals or long-term-care facilities, family, and friends. Carrying a wallet card and reviewing the documents annually are also recommended.[30,31] Advance care planning has been found to be the strongest and most consistent modifiable factor that can help patients avoid unwanted or unnecessary treatments.[14] Nonetheless, researchers continue to find that most individuals in the United States have not prepared these documents.

The continuum of palliative care



Adapted from *Illness Progression Graph*, Center to Advance Palliative Care © 2015. Used with permission.

Historically, communication between clinicians and patients has been poor, particularly when discussing prognoses and concerns in cases of serious advanced illnesses.[2] According to Bernacki and Block, physicians surveyed regarding this blamed time constraints, personal discomfort in discussing end-of-life issues, lack of training in communicating those issues, and uncertainty about prognosis accuracy.[32]

Reasons reported for patients not completing advance directive documents included a lack of awareness, not wanting to think about death or dying, not realizing they had a terminal disease, or waiting for the provider to initiate the conversation.[2,33] Additional reasons that patients did not complete advance directives were not knowing about advance care planning, being too young, and having concerns about the process being too costly.[34]

The IOM recommends that primary care providers initiate advance care planning discussions long before a medical crisis is expected.[2] Patients with dementia or other cognitive disorders pose challenges to providers of end-of-life care, as capacity to understand, retain, and evaluate information can be difficult to assess.[35]

To have capacity, individuals must understand information related to the decision, retain the information, be able to evaluate the risks and benefits of the information, and communicate their decision.[36] In the absence of advance directives, patients who have lost capacity to make decisions (patients with dementia) default to family members who may be unable or unwilling to speak on their behalf.[29] Therefore, it is imperative that the discussion of patient preferences begins as early as possible in the course of the disease and be updated on an ongoing basis.

Professional education and development

Although exposure to palliative care content in medical, nursing, social work, and chaplaincy programs has increased

End-of-life resources

Organization	Description of services provided	Website
American Academy of Hospice and Palliative Medicine	Offers education and practice information to members. Serves as an advocate for health policy change. Nominates Fellows of the American Academy of Hospice and Palliative Medicine (over 300 have been inducted).	www.aahpm.org
Center to Advance Palliative Care	Provides tools, training, and technical assistance needed to establish and maintain a palliative care program.	www.capc.org
End-of-Life Nursing Education Consortium	Administered by the AACN, based at the City of Hope National Medical Center. Live train-the-trainer program teaches palliative care skills to nurses serving a variety of patient populations (more than 20,100 nurses and other healthcare professionals trained worldwide).	www.aacn.nche.edu/elnec
Education in Palliative and End-of-Life Care Project	Based at Northwestern University Feinberg School of Medicine. Train-the-trainer multidisciplinary program teaches palliative care skills to those serving in a variety of settings using live conference and distance-learning platforms (more than 2,000 trainers are actively teaching).	www.epec.net
Hospice and Palliative Nurses Association	Offers continuing-education activities to members. Offers Advanced Certified Hospice and Palliative Nurse exam through Hospice and Palliative Credentialing Center (nearly 1,000 APRNs certified).	www.hpcc.advancingexpertcare.org
National Hospice and Palliative Care Organization	Offers education and training opportunities to healthcare professionals. Advocates for social change through their Hospice Action Network.	www.nhpco.org

over the past decade, the amount of time allocated to formal study remains limited. Medical schools, on average, offer only 17 hours of end-of-life care content during the 4 years of medical education.[2,37] Baccalaureate nursing programs offer less than 15 hours.[2] A survey of 714 practicing oncology nurses found that 25% did not believe they were sufficiently prepared to care for a dying patient, suggesting inadequate continuing-education opportunities.[38]

The IOM cites the limited number of palliative care specialists as a major deficiency in access to quality end-of-life care. The American Board of Medical Specialists approved the subspecialty of Hospice and Palliative Medicine, but the number of trained specialists remains small. Although there are nearly 100 hospice and palliative medicine fellowship programs in the United States, there were only 6,356 physicians representing 10 medical practice areas who were board-certified in hospice and palliative medicine in 2014.[2] Given the expected swell in the number of patients over age 65, an estimated shortage of 6,000 to 18,000 hospice and palliative medicine specialists is predicted.[39]

The IOM recommends continuing-education opportunities in palliative care for all healthcare professionals working with patients at the end of life.[2] A number of organizations now provide end-of-life information and training opportunities in a variety of formats (see *End-of-life resources*).

The American Association of Colleges of Nursing's (AACN) End-of-Life Nursing Education Consortium Project is dedicated to educating healthcare professionals in the principles of palliative care and uses a modular format to teach end-of-life content.[40] Modules in this train-the-trainer program include palliative nursing care; pain and symptom management; ethical and legal issues; cultural considerations; communication; loss, grief, and bereavement; and what to expect in the patient's final hours.

The IOM recognizes the importance of hospice and palliative nurse specialists.[2] Specialization and certification validate the experience, knowledge, and skills possessed by the certified individual and communicate professionalism, competence, and a commitment to lifelong learning.[41] The Hospice and Palliative Credentialing Center administers certification exams to healthcare providers working at different levels of care. APRNs working in palliative care settings who meet published criteria are eligible to sit for the Advanced Certified Hospice and Palliative Nurse exam.

Policies and payment systems

The IOM recommends financial and policy reform by public and private insurance and healthcare delivery programs to support high-quality end-of-life care for patients with advanced serious illnesses.[2] End-of-life care is expensive: Medicare benefit payments totaled $597 billion in 2014 or 14% of the total federal budget.[42]

Currently, financial incentives to provide care are built into Medicare and Medicaid reimbursement guidelines, often resulting in fragmented care, which increases the risks of unwanted and unnecessary care services. The current medical model is life-promoting and life-sustaining; in an emergency situation, care providers unfamiliar with the patient often default to aggressive interventions, resulting in unnecessary suffering and costs. Medicare fee-for-service payments give healthcare providers incentives to offer high-intensity care and high-cost services, consult multiple subspecialties, order tests and procedures, and hospitalize patients.[2]

Because they are frequent consumers of medical services, the personal expenses of healthcare at the end of life are out of control for many older adults. Insurance plans are often confusing, overwhelming, and do not cover the total cost of medical care. In a study using data from the Health and Retirement Study, the out-of-pocket expenses for over 3,200 Medicare beneficiaries were analyzed.[43]

High hospital readmission rates among long-term-care residents also contribute to the high cost of dying.

Researchers found that total out-of-pocket expenses for the 5 years prior to death amounted to $36,688 for individuals and $51,030 for couples in which one spouse had died. Spending for patients with Alzheimer disease was higher, averaging $66,155. For 25% of those studied, the healthcare spending exceeded their baseline total household assets.[43] Evidence now suggests that a coordinated healthcare system that applies palliative care principles to patient care and facilitates appropriate admission to hospice programs has decreased hospital usage and medical costs, reduced rates of unnecessary diagnostic tests, and extended life overall.[2,6,44]

High hospital readmission rates among long-term-care residents also contribute to the high cost of dying. According to the CDC, 1.4 million residents are living in 15,700 long-term-care facilities in the United States.[45] Resident illness or injury often results in a transfer from the skilled nursing facility (SNF) to the hospital for acute care. When Medicare statisticians examined the circumstances surrounding patient transfers, they found that 25% of transferred residents were rehospitalized within 30 days of discharge. A closer review of the circumstances leading up to the transfer revealed that 66% of the hospital transfers were potentially avoidable.[46]

Each readmission results in more tests and treatments, higher healthcare costs, and increased patient suffering. To motivate hospitals and SNFs to address the “bounce back” problem, the CMS lowered payment rates for all Medicare discharges if a hospital experiences higher-than-average readmission rates for certain diagnoses, including pneumonia and heart failure.[46] This situation has led to the development of programs such as Interventions to Reduce Acute Care Transitions, which was developed to promote interaction between SNFs and hospitals, primary care physicians, residents, and their families to best manage care in the long-term-care facility.[46]

Evidence-based care paths are used by SNF staff to recognize and address symptoms as early as possible. Communication tools such as situation/background/assessment/recommendation improve information transfer between levels of care and decrease the possibility of medication and treatment errors.[46]

Although medical care is important, social service programs can make the difference between a patient remaining at home or going to a long-term-care facility. At the present time, Medicare makes no provision for 24/7 home care and support except for short periods of continuous home care provided by hospices during crisis situations.[24] Caregiver “burnout,” defined as physical, emotional, and mental exhaustion, is common. The Alzheimer’s Association reports that 15.5 million individuals in the United States provided unpaid care to a person with Alzheimer disease or related dementias in 2013. Sixty-five percent of caregivers were women, and 21% were age 65 and older. Fifty-nine percent of caregivers reported their emotional stress as a “good amount” or a “great deal,” particularly in areas of finance and family relationships.[47]

Programs providing home-delivered meals, nutrition counseling, transportation, and family respite and support are grossly underfunded.[2] Unfortunately, the federal government has planned reductions in most Medicare spending over the next few years, perpetuating the challenges of providing home support.[25]

In a recent positive step, CMS announced plans to reimburse physicians, APRNs, and physician assistants for end-of-life conversations to encourage advance care planning. After the original discussion in 2009 ended with an uninformed reactionary public outcry against "death panels," refocused attention resulted in the decision to offer reimbursement to providers addressing advance care planning beginning in January 2016.[48]

The required use of electronic health records provides the opportunity to incorporate advance planning documents into the patients' records to improve communication of this important information between disciplines and across treatment settings.[8] In addition to decreasing the likelihood of unwanted care and unnecessary cost, the use of electronic records facilitates public reporting of quality measures, outcomes, and costs of care.

The IOM recommends the use of accurate, reliable, and valid quality measures for assessing care delivery and assigns accountability to the federal government for the delivery of quality care in all federal government programs it funds or administers. The development of organizational policies and professional standards, which would be tied to reimbursement, is also recommended.[2]

Public engagement and education

The IOM acknowledges the need for culturally appropriate public education about end-of-life choices.[2] Opportunities for education and engagement are found at the societal, community, family, and individual levels.

At the societal level, the IOM identifies public officials, professional organizations, religious leaders, and community groups as bearing the greatest responsibility for bringing the discussion about death and dying to the population at large. These groups have the greatest potential to affect public policy changes related to the organization and funding of "high-quality, compassionate, and sustainable care" in institutional and practice settings.[2]

Advocacy and educational activities sponsored by professional organizations, which facilitate end-of-life discussions between patients, families, and caregivers have been shown to be successful. A coalition between insurance groups, consumers, healthcare professionals, and others was found to increase awareness of the value of advance care planning and resulted in an increase in document completion.[2,49] Honoring Choices Minnesota, a project that began in 2008 and involved eight large healthcare systems, increased the number of hospitalized individuals with advance directives in their electronic medical record from 12.1% to 65.6%.[50] Organizations (including the NHPCO and CAPC), insurers, private foundations, and others have also sponsored public awareness campaigns regarding what constitutes good end-of-life care and how to obtain it.

Websites for consumer information regarding advance directives

Organization	Description of services provided	Website
Aging with Dignity/Five Wishes	Advocates for quality end-of-life care and advance care planning. Provides free information and guidance to individuals, families, and organizations in the area of advance care planning. Also includes an online program to create advance directive documents (fee required).	https://agingwithdignity.org
National Hospice and Palliative Care Organization: Caring Info	Provides information about advance directives and instructions on how to write them.	www.caringinfo.org/i4a/pages/index.cfm?pageid=3287
The Conversation Project	Works in collaboration with the Institute of Healthcare Improvement. Promotes end-of-life conversations and the writing of advance care plans.	www.theconversationproject.org
The State of Tennessee Department of Health	Provides downloadable advance directives forms for residents of Tennessee, including the POLST form. Provides consumer information in English and Spanish.	www.tn.gov/health/article/advance-directives

At the community and family level, the IOM reports a growing interest in regard to death and dying, with public discussions becoming acceptable in America's previously death-denying society.[2] Public education and engagement campaigns address concerns about end-of-life care, disseminate relevant information, and correct misconceptions that may impede informed decision making, public support, and reform.

On an individual level, the IOM recommends meaningful conversations regarding patient values, goals, and preferences of care, which can lead to advance directive completion.[2] Most patients are not aware of the choices they have at the end of their lives. Healthcare providers should use the information and materials available to inform and advise their patients of possible options.[51] (See *Websites for consumer information regarding advance directives*.)

Moving forward

The IOM's *Future of Nursing* report identifies nurses as the ideal providers of palliative care, as it is "the essence of nursing—care and caring."[52] Nurses are recognized as skilled clinicians who interpret patient responses to diseases and treatments, advocate for holistic and effective care, facilitate relationships with other care providers, and provide biopsychosocial and spiritual care. APRNs serve as primary care providers, hospitalists, and administrators. They function as educators, advocates, and researchers. They are ideally positioned to improve the quality and availability of medical and social services for patients and their families, enhancing quality of life through the end of life.

APRNs and other healthcare providers caring for patients at the end of life are encouraged to read the entire IOM report to learn more about improving the care of dying patients. These, along with current evidence-based best practices, better prepare healthcare providers, families, and caregivers to deliver compassionate, affordable, sustainable, and high-quality care to a growing population of patients facing the end of their lives.[8]

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Elizabeth H. Dobbins is a professor of nursing at Walters State Community College, Morristown, Tenn.

The author and planners have disclosed that they have no financial relationships related to this article.

DOI: 10.1097/01.NPR.0000490388.58851.e0

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