

CONTENT

Civil Discourse	2
How We Die	2
Shared Decision Making and Advance Care Planning	3
Putting Preferences in Writing	3
Barriers to Advance Care Planning	4
Long-Term Care	5
Palliative Care and Hospice	5
Barriers to Palliative Care and Hospice	5
Policy Options to Improve End-of-Life Care	6
Implications of Inaction	8

About the Institute. The National Institute for Health Care Reform (NIHCR) contracted with the Center for Studying Health System Change (HSC) between 2009 and 2013 to conduct health policy research and analyses to improve the organization, financing and delivery of health care in the United States. As a result of the subsequent merger of Mathematica Policy Research (MPR) and HSC, MPR assumed the contract to complete NIHCR projects.



NIHCR
Research Director: Paul B. Ginsburg
c/o Mathematica Policy Research
1100 1st Street, NE, 12th Floor
Washington, DC 20002-4221

Bridging the Disconnect Between Patient Wishes and Care at the End of Life

BY JAMES D. RESCHOVSKY, AMANDA E. LECHNER AND ALWYN CASSIL

Most Americans want to die at home, but most die in hospitals or other facilities. Most people care more about quality of life than prolonging life as long as possible, but many receive invasive, life-sustaining treatments that diminish quality of life. Often, the disconnect between patient wishes and actual care near the end of life reflects reluctance by patients, family members, clinicians and society at large to acknowledge the inevitability of death and openly discuss end-of-life care. Other barriers to high-quality end-of-life care include a fragmented delivery system that hinders care coordination and communication of patients' wishes across care settings and payment policies that discourage clinicians from discussing end-of-life care preferences with patients and instead encourage aggressive treatment. Along with increased public engagement about the issue and broader reforms to foster patient-centered care, policy options to improve end-of-life care include greater use of shared decision making among patients and clinicians, improved care coordination, greater integration of health care and long-term social services, more use of palliative care to relieve pain and other symptoms outside of hospice, better access to hospice services, and training clinicians to discuss end-of-life care preferences with patients and families.

A Snapshot of Death in America

Almost 7,000 people on average die each day in the United States. Sixty-five are infants and about 100 are children or young adults. Nearly a quarter are between 25 and 65 years old, while almost three in four are 65 or older and die from heart disease, cancer or chronic lung disease.¹ Behind each person's death—more than 2.5 million a year across America—is a story. Some end the way people wished—at home, comfortable, surrounded by family and friends. Most do not—in a hospital or other institution, in pain, often tethered to invasive medical equipment.

Although surveys indicate that about 70 percent of people wish to die at home, only 25 percent actually do so—the rest die in a hospital, nursing home or long-term care facility.² Research also indicates that most people nearing the end of life want to maximize quality of life in their remaining days rather than prolong life as long as possible. But many receive invasive, life-sustaining treatments and report unmet needs for palliative care to relieve pain, other symptoms and stress.³

In many cases, the disconnect between patient wishes and care provided at the end of life reflects reluctance by everyone—patients, family members, clinicians, society at large—to acknowledge and accept the inevitability of death

Only a small share of Americans dies suddenly from accidents or acts of violence. Most die of medical conditions, with varying consequences for length of life, medical needs and assistance with daily living activities.

and talk openly and candidly about end-of-life care preferences before it's too late. Other barriers to honoring patients' wishes include uncertainty about the course of terminal diseases, a fragmented health care delivery system that hinders coordination of care and communication of patients' wishes across care settings and providers, along with payment policies that discourage talking with patients about end-of-life care preferences and instead reward aggressive treatment.

And for too many frail, older Americans facing progressively debilitating illnesses with lengthy and uncertain courses, the lack of affordable long-term care options and supportive social services can pose insurmountable barriers to care consistent with their wishes.⁴

Civil Discourse

Respecting that one person's futile care is another's life-sustaining care is critical to fostering more open and productive civil discourse about improving end-of-life care. Too often, the topic is fraught with political hyperbole of "rationing" and "death panels."

Likewise, framing the issue by focusing on the extraordinary costs of medical care at the end of life is unlikely to engender public confidence. Improving the quality of end-of-life care might or might not reduce costs—studies addressing this issue often have methodological limitations and have produced mixed results.⁵ Given policymakers' need to understand the potential savings or costs of interventions to improve the quality of care for patients nearing the end of life, there is a clear need for additional research examining what

models of care can best integrate medical and social services, improve care coordination across settings, and encourage the use of advance care planning and shared decision making.

This policy analysis describes quality issues in end-of-life care and discusses barriers to increased use of advance care planning, palliative care and hospice care. The analysis also outlines policy options to improve end-of-life care, including greater use of shared decision making, improved care coordination, more use of palliative care outside of hospice, better access to hospice services, improved education and training for clinicians, and needed research to identify models of sustainable, high-quality care for people nearing the end of life.

How We Die

Only a small share of Americans dies suddenly from accidents or acts of violence. Most die of medical conditions, with varying consequences for length of life, medical needs and assistance with daily living activities. As described by Joanne Lynn, M.D., most deaths follow one of three relatively predictable paths (see Figure 1).⁶ On the first path, people are reasonably well despite an underlying fatal condition and then experience a short period—perhaps weeks or months—of rapid decline leading to death. This trajectory is most commonly associated with forms of incurable late-stage cancer, although other conditions, such as heart attacks and strokes, might follow it as well. About one in five deaths follows this course.

The second path is characterized by a slow decline in physical capabilities disrupted by serious complications typically resulting in hospitalizations. If patients survive, they may return home and go on much as before until the next crisis. Ultimately, rescue attempts fail, and the person dies. While many conditions follow this course, the most common include congestive heart failure and emphysema. About 25 percent of Americans follow this path to death.

Finally, the largest portion of Americans, about 40 percent, experiences long-term dwindling of physical function and growing frailty. About half experience serious cognitive declines, often from such conditions as Alzheimer's disease. Death is often the result of an acute condition—such as influenza, urinary tract infections, broken bones—that would not be life threatening to a less frail person. People on this path to death typically lose the ability to conduct the normal activities of daily living—dressing, bathing or preparing meals—and require long periods, often many years, of personal or assistive care from family members or in assisted-living facilities or nursing homes.

Awareness that patients with different conditions and trajectories toward death have different needs—both medical and otherwise—is central to improving the quality of end-of-life care. For instance, hospice care may be most pressing for cancer patients in the first group, while home care and other

About the Authors

James D. Reschovsky, Ph.D, is a senior fellow at Mathematica Policy Research; Amanda E. Lechner, M.P.P., is a health research analyst at Mathematica Policy Research; and Alwyn Cassil is a principal at Policy Translation, LLC. The authors thank Joanne Lynn, M.D., for her thoughtful and helpful review of the paper.

long-term care to assist with activities of daily living are typically the greatest need for the last group.

Shared Decision Making and Advance Care Planning

An important component of patient-centered medical care is shared decision making, which should occur—but often doesn’t—when more than one medically acceptable treatment option is available. Shared decision making involves patients and clinicians together making “health care decisions in the context of current evidence and a patient’s needs, preferences and values.”⁷ Shared decision making is particularly important for patients nearing the end of life, whose preferences will vary for life-sustaining medical interventions. Some patients may prefer all measures to prolong life, while others decline treatment in light of poor prospects or lack of acceptable quality of life going forward. Research suggests that a majority of patients prefer a natural death to intensive medical interventions,⁸ although studies have found some differences in preferences across racial and religious groups.⁹

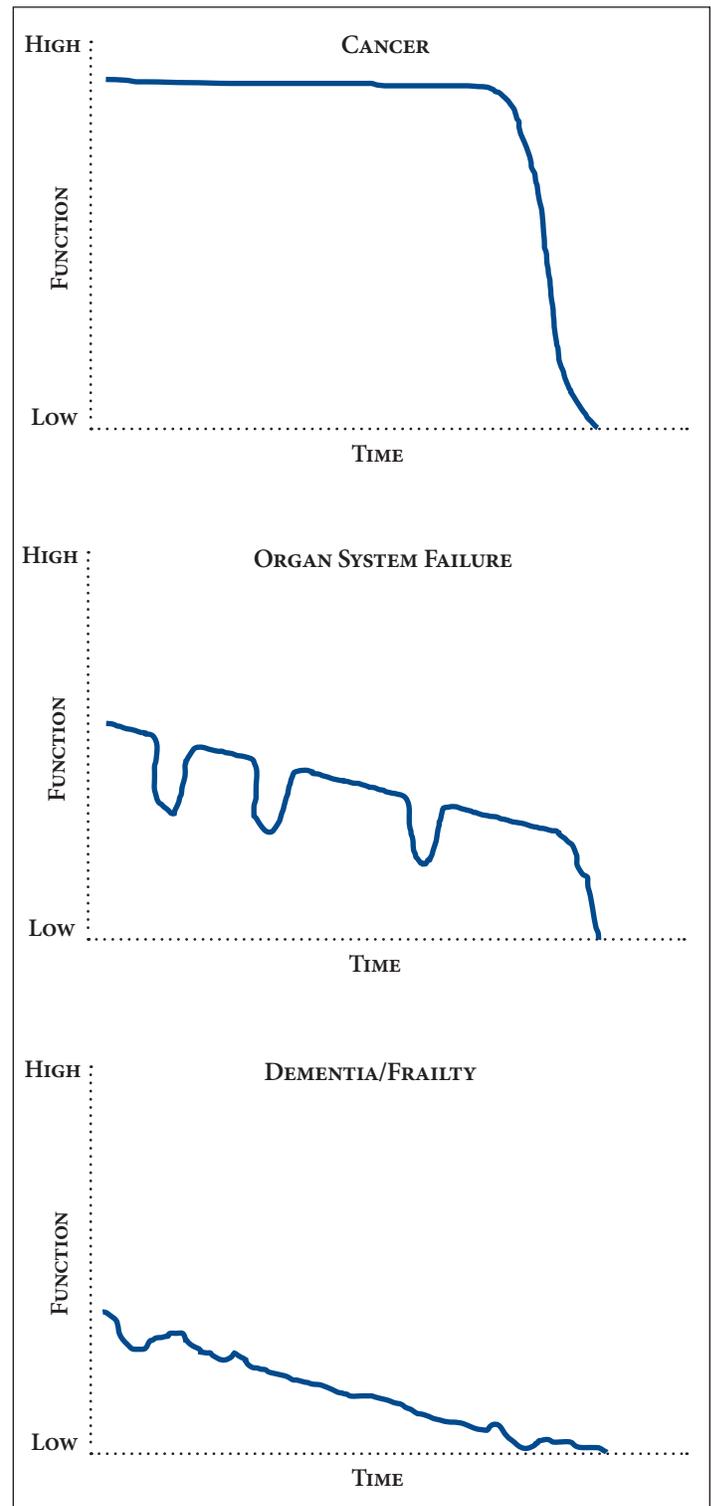
One type of shared decision making, known as advance care planning, allows people to consider and formally express preferences for end-of-life care, typically through an advance directive and designation of a surrogate decision maker to act on their behalf if they are incapacitated.¹⁰ Research shows that advance care planning increases the likelihood that patients’ wishes are known and followed by clinicians, improves patients’ and families’ satisfaction with care, and decreases stress and depression among bereaved family members.¹¹

Advance care planning is important for two key reasons. First, important care decisions sometimes must be made during moments of crisis, when the full range of treatment options and ramifications may not be fully understood. In such cases, patients or their families may acquiesce to unwanted treatments intended to extend life because they don’t fully understand the prognosis or their options. Advance care planning allows patients to formally communicate their care wishes to family members and providers before such crisis moments. Second, physicians are more likely to opt for more aggressive life-sustaining treatments for incapacitated patients near the end of life when there is no clear statement of patient preferences to do otherwise. Likewise, without explicit orders to do otherwise, hospitals are required to resuscitate patients in such situations as cardiac arrest or respiratory distress.

Putting Preferences in Writing

There are several ways advance care planning can take place. The process typically involves generating signed documents—such as a living will, advance directive or durable medical power of attorney—that state an individual’s general wishes for

Figure 1
Three General Trajectories of Function and Well Being over Time in Eventually Fatal Chronic Illnesses



Source: Lynn, Joanne, “Living Long in Fragile Health: The New Demographics Shape End of Life Care,” in Jennings, Bruce, Gregory E. Kaebnick and Thomas H. Murray, editors, *Improving End of Life Care, Why Has it Been So Difficult?*, The Hastings Center, Garrison, N.Y. (2005).

end-of-life care and designate a surrogate or proxy to make decisions if the patient is incapacitated. Advance directives provide opportunities for terminally ill patients to express care preferences, for instance, about whether they want feeding tubes and artificial respiration to prolong their life if they are incapacitated and unable to make their own decisions.

There are limitations to the benefits of advance directives. Advance directives may not be able to address key clinical decisions when the prognosis and impact on quality of life are uncertain and difficult to quantify for an incapacitated patient. These uncertainties can lead to the impression that decisions concerning medical interventions are inconsistent with patient preferences. Moreover, considerations and preferences may change from a time when a person is healthy, to onset of a disease, to a point where imminent death appears likely and care decisions are more clearly definable, underscoring that advance care planning should be ongoing.

Other tools are available to help people ensure that their preferences for care are honored. Physician Orders for Life-Sustaining Treatment (POLST) complement advance directives and are standardized forms signed by physicians and sometimes patients—or their proxies—indicating what specific treatments a patient does or does not want. As a physician

.....

While most people believe that advance care planning is important, many are reluctant to think about and discuss preferences for end-of-life care.

.....

order, a POLST directs other medical personnel, including paramedics and other first responders, to follow a patient’s care preferences and is intended to follow patients across providers and medical settings.

Advance care planning, however, can fall short in ensuring patient preferences are followed because of the fragmented nature of the health care delivery system, with patients seeing many providers across multiple settings.¹² For example, when a patient enters an emergency department or is admitted to a hospital, treating physicians may not have access to the patient’s advance directive or be able to communicate with their regular clinician about care decisions. Gaps in continuity of care resulting from such care transfers can increase the likelihood that providers make treatment decisions without understanding patient preferences, leading to unwanted care and greater treatment costs.

Moreover, an incapacitated patient’s preferences, as expressed in advance planning documents, may be inconsis-

tent with family wishes, placing clinicians in difficult positions about whose wishes to honor. Some providers may place the family’s values and care preferences above those of the patient. Also, fear of malpractice suits may reinforce decisions to order aggressive life-sustaining medical interventions when faced with inconsistent patient and family preferences for care.

Despite their limitations, the importance of advance directives should not be discounted. Rather, they are only one component in a broader approach to advance care planning as an ongoing process where patients think about and express their wishes for care to clinicians, individuals designated as proxy decision makers and family members.

Barriers to Advance Care Planning

Less than a third of Americans—and slightly more than half of Americans 65 and older—have a written advance directive, though two-thirds of Americans 65 and older have discussed end-of-life care wishes with their children.¹³ Although high proportions of patients with such conditions as cancer have discussed care preferences with their physicians, advance care planning discussions are less common among non-cancer patients. Barriers to advance care planning include patients’ reluctance to discuss difficult end-of-life decisions—often compounded by clinicians’ lack of training and reluctance to engage patients in such discussions.

While most people believe that advance care planning is important, many are reluctant to think about and discuss preferences for end-of-life care. According to one study, more than 80 percent of California adults said that putting their wishes in writing is important, but only 23 percent had actually done so.¹⁴ The same study found that 56 percent of Californians had not discussed end-of-life wishes with a loved one, with the top reasons being that they were worried about other priorities, did not want to think about dying, or their loved one did not want to talk about the possibility of their death. And, only 13 percent of elderly Californians reported that a doctor had asked them about their preferences for end-of-life care. Physicians and other providers may be uncomfortable initiating and conducting such conversations, and few have received explicit training.¹⁵

An added barrier is that insurer payment for clinicians’ time to explain and discuss end-of-life options with patients and encourage preparation of advance care planning documents is either nonexistent or insufficient. Political hyperbole surrounding end-of-life issues has stymied some legislative and regulatory measures to address this issue. For example, a provision in the Affordable Care Act (ACA) of 2010 intended to allow Medicare payment for physicians to discuss end-of-life care preferences with patients was dropped after widespread alarm that such counseling would constitute govern-

ment rationing of health care through so-called death panels. A subsequent rulemaking effort to allow for such payment was attempted by the Obama administration but dropped in the face of opposition. In October 2014, the Centers for Medicare and Medicaid Services announced Medicare will consider paying doctors in 2016 to counsel patients about their options for end-of-life care.¹⁶

Long-Term Care

As noted previously, about two out of five Americans' trajectory toward death will involve declining physical and/or cognitive function and growing frailty over an extended period. While advance care planning is important for these patients, an even more serious concern is access to affordable and patient-centered long-term care, ranging from in-home support with the daily activities of living to care in assisted-living or skilled-nursing facilities.

Patients traveling this course need comprehensive care planning that addresses housing, caregivers, finances, food, transportation and medical needs. Traditional medical providers are often ill equipped to assist patients with these needs, reflecting the larger lack of societal commitment to funding for supportive social services and long-term care for frail elders.

Medicare does not provide long-term care, and Medicaid home and community-based or institutional long-term care are only available for those with limited incomes and resources. Consequently, addressing the needs of this population involves difficult trade-offs that balance cost, time, emotional, and other burdens on family caregivers, quality of care and the patient's quality of life. While addressing long-term care is beyond the scope of this analysis, it's clear that inaction on this issue will continue to preclude access to high-quality, patient-centered care for many frail elders on this trajectory to death.

Palliative Care and Hospice

Palliative care refers to care aimed at providing any seriously ill patient—not just one near death—with relief from symptoms, pain and stress. Palliative care can be provided along with curative treatment, and the goal is to improve quality of life for both the patient and family. Palliative care typically is a team-based approach to care that includes physicians, nurses and other providers with special training in palliative care, along with psychological and spiritual counseling and other support services.

Unlike palliative care, hospice care is focused on dying patients—typically those with six months or less to live—who choose to forgo curative treatment. Hospice organizations specialize in providing palliative care—most often in patients'

homes but also in hospitals, nursing homes and other settings.

The majority of patients receiving hospice care in the United States—83 percent—do so under Medicare's hospice benefit, though most private insurers also offer hospice benefits, typically modeled after Medicare.¹⁷ The Medicare hospice benefit offers comprehensive palliative care to beneficiaries certified by two physicians as having less than six months to live, provided they forgo medical interventions intended to extend life. There is no upper limit to the length of time patients can receive Medicare hospice benefits, although patients periodically must be recertified by physicians or advanced practice nurses as having less than six months to live.

In recent years, there has been growing recognition of the need for increased palliative care outside of the hospice context. The number of hospitals with palliative care teams has grown rapidly.¹⁸ About 60 percent of hospitals now have such teams, which provide care directly or offer consultations with other providers. Yet, research suggests that palliative care is still underused, especially among patients with chronic rather than acute conditions.¹⁹

Barriers to Palliative Care and Hospice

Reasons for the inadequate provision of palliative care include providers' lack of awareness and training and inadequate payment for some palliative services. Most physicians are not trained to provide care in this manner and lack the infrastructure, allied care providers and referral network to provide this more patient-centered care efficiently. In the case of symptom relief, physicians may be reluctant to prescribe certain pain medications, such as morphine, out of fear that patients will experience harmful effects, develop dependencies, medications will be misused, or that their prescribing patterns will come under scrutiny by authorities.²⁰

The Medicare hospice benefit, as currently structured, is not well suited for patients with long-term conditions, such as congestive heart failure or dementia. Many of these patients do not qualify for hospice under Medicare because they are not necessarily at imminent risk of death or are unwilling to forgo curative or life-sustaining treatment.²¹ When the hospice benefit was enacted in 1982—under the premise that hospice would provide less costly end-of-life care by allowing patients to die at home with greater quality of life—it was primarily seen as providing community-dwelling cancer patients with more care options in line with their wishes.²² Since then, the use of the hospice benefit has grown substantially. Cancer patients are still most likely to use the hospice benefit, but they now comprise only about three in 10 hospice patients.²³

Patients with long-term conditions, such as dementia or chronic obstructive pulmonary disease, have increasingly

Options to improve the quality of end-of-life care include policies that promote use of advance care planning and palliative care through increased provider education and improved payment incentives.

sought care under the hospice benefit. However, many of these patients may not qualify for hospice because what constitutes curative services is less clear, and the ability to predict that death will likely occur within six months is more limited. These patients typically suffer from multiple chronic conditions rather than a terminal illness and have care needs that are quite different from those with cancer or other acute illnesses. These patients, when not in hospice care, often receive inadequate relief from symptoms and limited psycho-social support that hospice patients and their families receive.²⁴ Though traditional Medicare does pay for most palliative services outside of hospice, many services remain underused.

Policy Options to Improve End-of-Life Care

Options to improve the quality of end-of-life care include policies that promote use of advance care planning and palliative care through increased provider education and improved payment incentives. These policies will be most successful if combined with delivery system reforms that better align payment incentives toward more broadly improving care coordination and overall quality of care.

Encouraging advance care planning and shared decision making. To date, federal and state policy efforts to encourage use of advance planning have had limited success. The Patient Self-Determination Act (PSDA) of 1990 requires hospitals, long-term care facilities and home health agencies that receive Medicare and Medicaid payments to ask patients on admission whether they have an advance directive and inform patients of their rights under state law to participate in treatment decisions and refuse care. Compliance with the PSDA, along with its effectiveness, has not been widely studied, but the law does not appear to have had a significant impact on end-of-life treatment in hospitals.²⁵

States have adopted a variety of policies to codify and encourage use of advance directives. Apart from providing sample documents, at least nine states have registries

of advance directives that are accessible by families and physicians, but participation in these registries is voluntary and impact on informing providers and affecting care for patients likely is minimal.

Smaller, more concerted efforts at the local level have been aimed at enhancing either patient or provider education regarding advance care directives and shared decision making on end-of-life issues. These have generally been unsuccessful in affecting treatment patterns or patient experiences.²⁶

There are exceptions, however, such as the Respecting Choices program in La Crosse, Wis., which has increased use of advance care planning through patient education and training of physicians and community facilitators, such as clergy members. The program also has improved availability of advance directives in patients' medical records and documented how advance directives have aligned treatment decisions with patient wishes.²⁷ The success of Respecting Choices, however, is attributable partly to its location in a small community and association with a large integrated health care delivery system.

More recently, wider efforts have been launched that appeal directly to the public to break what has been called the "conspiracy of silence" surrounding death and dying in America.²⁸ One such effort is called The Conversation Project, a national campaign founded by Pulitzer-Prize-winning journalist Ellen Goodman who struggled with decisions about her mother's care at the end of life. In collaboration with the Institute for Healthcare Improvement, The Conversation Project provides a "starter kit" to help people talk with family and friends about end-of-life care.

Ultimately, there may be little policy makers can do directly to foster more public awareness and dialogue about planning for end-of-life care because the issue often gets caught up in political hyperbole. Instead, foundations and other private entities may be more effective in fostering constructive public engagement and discussion.

Improving care coordination and delivery system integration. Replication of the Respecting Choices model might succeed on a broader scale if the recent policy focus on integrating the delivery system to foster improved care coordination is successful. For example, the ACA includes demonstrations of patient-centered medical homes that encourage care coordination and shared decision making. The ACA also encourages care integration by providing financial incentives for physicians, hospitals and other providers to form accountable care organizations that are responsible for both the cost and quality of care provided to Medicare patients. Other reforms also may encourage greater integration. Though not currently in regulations, quality metrics that address specific aspects of care for seriously ill patients—for example, surveys of patient and family satisfaction—might motivate improvements in shared decision making.

Moreover, the American Recovery and Reinvestment Act of 2009 encouraged expanded use of health information technology. Along with Medicare or Medicaid payment incentives for adoption and use, the law includes meaningful use and interoperability standards that health care providers must meet. Although these requirements are evolving, promoting inclusion of advance directives into electronic health records and interoperability, particularly across physician office and hospital settings, could assist in informing hospital-based physicians about patient end-of-life care preferences.

Increasing access to hospice care. While there are many issues concerning the burgeoning cost of the Medicare hospice benefit and options for reforming the benefit, policy options to increase use of palliative care include allowing patients to enroll in the Medicare hospice benefit without forgoing curative treatments, incorporating greater use of palliative care into delivery of medical care beyond hospice, and increasing provider education.

Two provisions in the ACA are aimed at allowing patients to receive hospice care and curative services concurrently. One allows children in Medicaid- or Children's Health Insurance Program-funded hospice care to receive curative treatment, and the other mandates a demonstration of a similar approach for Medicare beneficiaries receiving hospice care.

Eliminating the requirement that patients forgo curative treatments to receive hospice benefits may improve quality of care and help ensure patients' care preferences are followed. Patients may be willing to enter hospice earlier if they do not need to give up hope of a cure. Earlier introduction of hospice not only may alleviate physical symptoms but also help patients and family members cope with emotional stress and make more-informed decisions about medical care. One recent random control trial of lung cancer patients found that early palliative care offered soon after diagnosis led to improved quality of life and that patients choosing less aggressive treatment at end of life lived longer than those receiving standard treatment, including, for some, later provision of palliative services.²⁹ Although allowing hospice benefits concurrent with the option of curative treatment can improve quality through greater provision of palliative care to very ill patients, it does not address the broader problem that palliative services often are not provided to seriously ill patients who may not meet the six-month life expectancy standard.

Broader palliative care use outside of hospice. The Medicare hospice benefit is ill designed for patient populations with serious conditions but more uncertain life expectancies than the typical hospice patient. For these patients, integrating palliative care into the normal delivery of medical care is likely a more appropriate approach. One option would be to require hospitals and other health care facilities to provide informa-

tion about palliative care to seriously ill patients. New York has already enacted such a law, the Palliative Care Access Act, which requires hospitals, nursing homes, home care agencies and other facilities to inform patients with advanced, life-limiting conditions and illnesses about palliative care options, and other states are considering similar legislation.³⁰

To the extent that accountable care organizations develop and succeed in altering care delivery, they may be motivated to initiate new systems of treating patients believed to be near the end of life that reduce hospitalization rates and lengths of stay. Key delivery system improvements include improving primary care, greater shared decision making, greater access to and integration of palliative care, and using team-based care

.....

The Medicare hospice benefit is ill designed for patient populations with serious conditions but more uncertain life expectancies than the typical hospice patient.

.....

approaches for complex patients. Likewise, quality metrics concerning provision of palliative care—some of which have been endorsed by the National Quality Forum—tied to provider payment incentives might accelerate changes in practice. And, altering payment incentives to encourage the provision of palliative services by both physician and non-physician providers could be implemented in concert with payment reforms to encourage more-integrated, patient-centered care delivery models.

Educating clinicians. A handful of states, including California, Iowa, Massachusetts, Rhode Island and West Virginia, require physicians to complete continuing medical education related to pain management and end-of-life care. More broadly, efforts to incorporate shared decision making into medical education could help improve physicians' skills and willingness to adopt shared decision making. Similar training efforts for other types of caregivers—for example, nurses and clinical social workers—might be useful. Development of clinical guidelines and quality metrics specific to assessment of patient discomfort and palliative care needs also might spur clinician learning.

Research to identify models of sustainable, high-quality care for people nearing the end of life. Given conflicting research findings about the causes of health care spending variations at the end of life, there is a clear need for additional research to estimate the costs or possible sav-

Engaging clinicians, patients and family members, and society in advance care planning requires that they first accept the inevitability of death and then navigate the difficult and politically charged terrain of end-of-life care

ings of various policy interventions to improve care at the end of life. Ideally, studies should be prospective in nature, identifying patients at high risk of death, rather than retrospectively looking at utilization patterns for those who died. This would allow interventions, such as paying providers for discussions with patients about end-of-life preferences, routine inclusion of advance care planning documents in truly interoperable electronic medical records, and earlier palliative care assessments and interventions, to be assessed for effectiveness in improving patient experiences, clinical quality and outcomes, and costs.

Identifying and evaluating models of care that integrate medical and social services, improve care coordination across settings, and encourage the use of advance care planning and shared decision making for people nearing the end of life could spur both greater public engagement, more informed discussion and ultimately policies that help ensure patient preferences are honored.

Implications of Inaction

Most agree that the quality of end-of-life care can be improved through greater emphasis on patient-centered care, such as improved coordination, team-based care and shared decision making. The Institute of Medicine's September 2014 consensus report—*Dying in America*—concluded 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 also contribute to a more sustainable care system.”

Engaging clinicians, patients and family members, and society in advance care planning requires that they first accept the inevitability of death and then navigate the difficult and politically charged terrain of end-of-life care. For many, death is an uncomfortable topic and one easy to avoid. However, the consequences of avoiding such conversations can be serious and result in unwanted care and prolonged suffering near the end of life. ■

Notes

1. Hoyert, Donna L., and Jiaquan Xu, *Deaths: Preliminary Data for 2011*, National Vital Statistics Report, Vol. 59, No. 1, National Center for Health Statistics, Hyattsville, Md. (Oct. 10, 2012).
2. Cloud, John, “A Kinder, Gentler Death,” *TIME Magazine* (Sep. 18, 2000).
3. Teno, Joan M., et al., “Medical Care Inconsistent with Patients’ Treatment Goals: Association with 1-Year Medicare Resource Use and Survival,” *Journal of the American Geriatrics Society*, Vol. 50, No. 3 (March 2002); Ahronheim, Judith C., et al., “Treatment of the Dying in the Acute Care Hospital: Advanced Dementia and Metastatic Cancer,” *Archives of Internal Medicine*, Vol. 156, No. 18 (Oct. 14, 1996); and Teno, Joan M., et al., “Family Perspectives on End-of-Life Care at the Last Place of Care,” *Journal of the American Medical Association*, Vol. 291, No. 1 (Jan. 7, 2004).
4. Institute of Medicine, *Dying in America: Improving Quality and Honoring Patient Preferences Near the End of Life*, National Academy Press, Washington, D.C. (2014).
5. Much of the empirical literature analyzing end-of-life care uses retrospective data that observe costs or patterns of care among the deceased in their last months or years before death. See Goodman, David C., et al., *Quality of End-of-Life Cancer Care for Medicare Beneficiaries: Regional and Hospital-Specific Analyses*, The Dartmouth Atlas (Nov. 16, 2010); and McCarthy, Ellen P., et al., “Hospice Use Among Medicare Managed Care and Fee-for-Service Patients Dying with Cancer,” *The Journal of the American Medical Association*, Vol. 289, No. 17 (May 7, 2003). These studies attribute disparities in the cost and quality of retrospectively defined end-of-life care to such causes as the local supply of specialists or ICU beds. While some useful insights concerning variations in treatment patterns emerge from this work, results are of limited usefulness because the studies reflect “selection bias” and do not include data on quality and cost of care for persons at risk of death who did not die. See Bach, Peter B., Deborah Schrag and Colin B. Begg, “Resurrecting Treatment Histories of Dead Patients,” *The Journal of the American Medical Association*, Vol. 292, No. 22 (December 2008); and Neuberger, Gerald W., “The Cost of End-of-Life Care: A New Efficiency Measure Falls Short of AHA/ACC Standards,” *Circulation: Cardiovascular Quality and Outcomes* (March 2009).
6. Lynn, Joanne, “Living Long in Fragile Health: The New Demographics Shape End of Life Care,” in Jennings, Bruce, Gregory E. Kaebnick, and Thomas H. Murray, editors, *Improving End of Life Care: Why Has It Been So Difficult?*, Special Report, Hastings Center, Garrison, N.Y. (November-December 2005).
7. O’Malley, Ann S., et al., *Policy Options to Encourage Patient-Physician Shared Decision Making*, Policy Analysis No. 5, National Institute for Health Care Reform, Washington, D.C. (September 2011).
8. Lake Research Partners (LRP) and The Coalition for Compassionate Care of California (CCCC), *Final Chapter: Californians’ Attitudes and Experiences with Death and Dying*, Snapshot, California HealthCare Foundation, Oakland, Calif. (February 2012); and

- Pew Research Center, *End-of-Life Decisions: How Americans Cope*, Washington, D.C. (Aug. 20, 2009).
9. Pew Research Center (2009); Smith, Alexander K., et al., “Racial and Ethnic Differences in Advance Care Planning Among Patients With Cancer: Impact of Terminal Illness Acknowledgement, Religiousness, and Treatment Preferences,” *Journal of Clinical Oncology*, Vol. 26, No. 25 (Sep. 1, 2008); and Barnato, Amber E., et al., “Racial and Ethnic Differences in Preferences for End-of-Life Treatment,” *Journal of General Internal Medicine*, Vol. 24, No. 6 (June 2009); and Gordon, Michael, “Ethical and Clinical Issues in Cardiopulmonary Resuscitation (CPR) in the Frail Elderly with Dementia: A Jewish Perspective,” *Journal of Ethics in Mental Health*, Vol. 1, No. 1 (Nov. 15, 2006).
 10. Kass-Bartelmes, Barbara L., and Ronda Hughes, *Advance Care Planning, Preferences for Care at the End of Life*, Research in Action No. 12, Agency for Healthcare Research and Quality, Rockville, Md. (March 2003).
 11. Detering, Karen M., et al., “The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial,” *British Medical Journal*, Vol. 340 (March 23, 2010).
 12. Pham, Hoangmai H., et al., “Primary Care Physicians’ Links to Other Physicians Through Medicare Patients: The Scope of Care Coordination,” *Annals of Internal Medicine*, Vol. 150, No. 4 (Feb. 17, 2009); and Carrier, Emily, Tracy Yee and Rachel A. Holzwart, *Coordination Between Emergency and Primary Care Physicians*, Research Brief No. 3, National Institute for Health Care Reform, Washington, D.C. (February 2011).
 13. Pew Research Center (2009).
 14. LRP and CCCC (2012).
 15. U.S. Department of Health and Human Services (HHS), Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, *Advance Directives and Advance Care Planning: Report to Congress*, Washington, D.C. (August 2008).
 16. “Medicare weighs paying for end-of-life counseling,” *The Associated Press* (Oct. 31, 2014). Accessed Jan. 30, 2015 at: http://news.yahoo.com/medicare-weighs-paying-end-life-counseling-210208781--politics.html;_ylt=AwrBEiKfh1VUV0IAUzLQtDMD.
 17. National Hospice and Palliative Care Organization, *NHPCO Facts and Figures: Hospice Care in America*, Alexandria, Va. (September 2010).
 18. Morrison, R. Sean, et al., “Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries,” *Health Affairs*, Vol. 30, No. 3 (March 2011); and American Hospital Association, *AHA Hospital Statistics*, Health Forum, Chicago, Ill. (2007).
 19. Gore, Joel M., Christopher J. Brophy and Michael A. Greenstone, “How Well Do We Care for Patients With End Stage Chronic Obstructive Pulmonary Disease (COPD)?: A Comparison of Palliative Care and Quality of Life in COPD and Lung Cancer,” *Thorax*, Vol. 55, No. 12 (2000); and Goodridge, Donna, et al., “Health Care Utilization of Patients With Chronic Obstructive Pulmonary Disease and Lung Cancer in the Last 12 Months of Life,” *Respiratory Medicine*, Vol. 6, No. 102 (June 2008).
 20. Glajchen, Myra, “Chronic Pain: Treatment Barriers and Strategies for Clinical Practice,” *Journal of the American Board of Family Medicine*, Vol. 14, No. 3 (May-June 2001).
 21. Under provisions in the 2010 Accountable Care Act, Medicare will conduct a three-year demonstration project that allows about 30,000 Medicare beneficiaries to receive both hospice care and curative care. See Forlini, Janet H., and Lee Goldberg, *Concurrent Palliative and Curative Care: The Next Step in Evolution of Medicare Hospice Care*, Health Policy Brief No. 12, National Academy of Social Insurance, Washington, D.C. (November 2014).
 22. Medicare Payment Advisory Commission, *Report to the Congress: Medicare Payment Policy*, Washington, D.C. (March 2009).
 23. Medicare Payment Advisory Commission, *Report to the Congress: Medicare Payment Policy*, Washington, D.C. (March 2011).
 24. Lynn (2005).
 25. Leahman, Dee, “Why the Patient Self-Determination Act Has Failed,” *North Carolina Medical Journal*, Vol. 65, No. 4 (July/August 2004); and Yates, Jeffrey L., and Henry R. Glick, “The Failed Patient Self-Determination Act and Policy Alternatives for the Right to Die,” *Journal of Aging and Social Policy*, Vol. 9, No. 4 (1998).
 26. HHS (2008).
 27. Hammes, Bernard J., Brenda L. Rooney and Jacob D. Gundrum, “A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem,” *Journal of the American Geriatrics Society*, Vol. 58, No. 7 (July 2010).
 28. Lazar, Kay, “Campaign Aims to Spur End-of-life Conversations Within Families,” *The Boston Globe* (Aug. 8, 2012).
 29. Temel, Jennifer S., et al., “Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer,” *The New England Journal of Medicine*, Vol. 363, No. 8 (Aug. 19, 2010).
 30. Ollove, Michael, “In New York Palliative Care Adds a Layer of Support for the Seriously Ill,” *Stateline* (March 4, 2013).