



GOLDEN YEARS?

SOCIAL INEQUALITY IN LATER LIFE

THE AMERICAN SOCIOLOGICAL ASSOCIATION'S ROSE SERIES IN SOCIOLOGY

DEBORAH CARR

== Chapter 8 ==

Is Death the Great Equalizer? Disparities in Dying

Theologians, poets, and scholars have proclaimed that death is “the great equalizer.”¹ All people, according to scripture, “share a common destiny . . . the good and the bad, the clean and the unclean . . . will die” (Ecclesiastes 9:2–3). In “Death the Leveller,” the seventeenth-century poet James Shirley observed that death erases the inequities that existed during life:

Death lays his icy hand on kings:
Sceptre and Crown
Must tumble down,
And in the dust be equal made
With the poor crooked scythe and spade.²

Despite such eloquent claims about the inevitability and universality of death, it is not an egalitarian transition. At what age and of what causes a person dies are tightly tied to social, economic, and geographic (dis)advantages over the life course.

Researchers have only recently started to investigate disparities in the quality of dying among older adults. According to bioethicists, death quality encompasses many dimensions, such as whether the dying person takes their last breath at home surrounded by family and friends or alone in a hospital room. Death quality also reflects whether those final days are marked by pain versus comfort, medical care that matches rather than betrays the wishes of the dying, autonomy versus acquiescence in end-of-life decision-making, and family cooperation versus conflict. This chapter provides a historical sketch of death and dying in the United States and suggests reasons why inequalities in older adults’ dying experiences are a uniquely contemporary phenomenon. I describe the core components of good versus bad deaths and show the complex

ways in which these experiences are linked to markers of social inequality and public policies, especially Medicare reimbursement practices.

I also argue that while death is inevitable, a bad death is not—even for older adults whose lives have been marked by persistent disadvantage. I describe strategies and policies that may help older adults die peacefully and on their own terms. These strategies include advance care planning (ACP) and other tools, like physician orders for life-sustaining treatment (POLSTS), that convey a patient's preferences to both loved ones and health care professionals. ACP is available to all adults, in theory, yet in practice these tools are used far less often by African Americans, the poor, and socially isolated older adults than by whites, the wealthy, and socially integrated older adults.³ This lack of ACP, in turn, renders patients less likely to receive treatments they want and more likely to receive futile, costly, and uncomfortable treatments they had hoped to avoid.

A Brief History of Dying in the United States

Death today rarely comes suddenly, quickly, or painlessly. We may cling to the dream that we will die suddenly, doing what we love, like Jane Little, an eighty-seven-year-old bassist with the Atlanta Symphony who collapsed and died while performing onstage in 2016, or seventy-year-old actor-director Orson Welles, who died suddenly of a heart attack in 1985 the morning after discussing his life's work on *The Merv Griffin Show*. Most older adults' deaths are much less dramatic and far more difficult. Of the more than 2.6 million deaths in the United States in 2016, nearly 80 percent were to adults age sixty-five and older, and most of them died of long-term chronic illness, such as heart disease, cancer, respiratory disease, stroke, Alzheimer's disease, or other diseases that slowly destroy the mind and body.⁴ Older patients suffering from chronic illness may survive for months, if not years, following their initial onset of symptoms. The "living-dying interval" that follows is marked by spells of pain, breathlessness, difficulty swallowing, emotional distress, fatigue, frailty, and the gradual fading of cognitive capacities.

This modern phenomenon, where dying unfolds slowly over a protracted time period, is sometimes referred to as "the failure of success."⁵ More people than ever before are surviving into their eighties, nineties, and beyond, and a very long life span is now considered a clear indicator of "success" when evaluating the health of a society. Yet a prolonged life span often is accompanied by compromised quality of life, which is widely considered an indicator of "failure." Today more adults will die slowly from aging-related conditions and be kept alive via technological

interventions that are deemed futile—that is, they do not improve a patient’s health, well-being, comfort, or prognosis.

Difficult, drawn-out deaths from chronic illness are a uniquely modern phenomenon. This shift in how adults die has its historical roots in the epidemiologic transition. From the eighteenth century through the early twentieth century, most deaths were caused by infectious diseases, like diphtheria and pneumonia, and struck quickly after a person fell ill. Infectious diseases were generally egalitarian, striking rich and poor, men and women, young and old.⁶ Take, for example, the deaths of the founding fathers and early presidents of the United States. As Atul Gawande writes in *Being Mortal*, George Washington developed a throat infection and died the next evening.⁷ John Quincy Adams, Millard Fillmore, and Andrew Johnson all died within two days of suffering strokes, while Rutherford B. Hayes died three days after his heart attack. Even those with chronic illnesses died much more quickly than their counterparts do today. Ulysses Grant was diagnosed with throat cancer and, despite treatments, died a year later. James Monroe and Andrew Jackson suffered for several months before succumbing to a condition now believed to be tuberculosis. In stark contrast, Ronald Reagan announced publicly in 1994 that he had been diagnosed with Alzheimer’s disease and then suffered for ten years before dying in 2004.

The Medicalization of Death and Dying

Technological and medical advances are largely responsible for the shift from a short and swift death to a protracted dying process. Throughout the twentieth century, improved sanitation and nutrition, immunizations for communicable diseases, effective treatments for infections, and other medical advances dramatically reduced mortality rates among young people, and life expectancy increased accordingly. These trends were accompanied by an important cultural transformation: the medicalization of aging and dying. Aging and dying were once accepted as natural parts of life. Today aging is seen as something to be cured, and death as something to be staved off. The National Academy of Medicine’s “Grand Challenges” program, along with the proliferation of anti-aging lotions, diets, vitamins, fitness regimens, and magazine articles with catchy titles like “Extending Life: 7 Ways to Live Past 100” and “12 Tips for a Longer Life,” reflect the expectation of the contemporary cultural zeitgeist that we should search for the elusive cure for aging and death.

Medicalization influences how older adults die today in two distinct ways. First, people now die in different locations than they did in the past. In the eighteenth and nineteenth centuries, death happened at

home, where family members, clergy, and community members would provide care to the dying person. In the twentieth century, by contrast, death moved from the home to hospitals and long-term care institutions, where chronically ill older adults receive high-tech medical treatments intended to increase their life span, such as ventilators and feeding tubes, as well as round-the-clock monitoring by skilled nursing professionals.⁸ This highly medicalized death stands in stark contrast with the “good death” to which patients and their loved ones aspire.⁹

Second, medicalization has created a context in which dying patients and their families cede health care decisions to physicians. With the rising prestige of the medical profession in the twentieth century, patients began to believe that their doctors were authorities who should not be challenged.¹⁰ As the Institute of Medicine (IOM) recounts, for most of the twentieth century older adults with advanced chronic illnesses “relied almost unquestioningly on their physicians’ judgments regarding treatment matters, trusting that physicians would act in their patients’ best interests as a matter of professional and personal ethics.”¹¹ This tendency to go along with doctor’s orders rather than assert one’s own preferences or share decision-making varied by race and socioeconomic status, and that remains true today: blacks, Latinos, and older adults with lower levels of literacy and education and less ease in interacting with medical professionals are less likely to assert their own values and preferences when meeting with clinicians.¹²

For older adults today, delegating decisions to health care providers often involves acquiescing to invasive life-extending interventions, even if they would prefer less aggressive treatment. Through much of the twentieth century, medical education emphasized saving and sustaining patients’ lives. As the pioneering palliative care physician and MacArthur Foundation “genius grant” recipient Diane Meier observed in the *British Medical Journal*, “medical students are taught to do things, not how to know what not to do.”¹³ Consistent with this training, physicians often are reluctant to withhold life-extending treatments and may shield patients from dire prognoses.¹⁴ Telling a patient, “I’m sorry, but there’s nothing more we can do,” may be seen as an admission of failure. Physicians’ reluctance to withhold treatment also reflects that, as human beings with emotions, they may not be ready to admit that a patient’s death is imminent. Physicians who have close and warm relationships with their patients may be highly motivated to keep them alive, especially if they believe that the dying patient is not yet ready to say good-bye to his or her family.¹⁵ More cynical interpretations are that costly and aggressive treatments are financially lucrative for health care institutions, and that fears of malpractice lawsuits impel physicians to over- versus undertreat.

Although physicians' training and professional mission support the use of life-extending treatments, national survey data show that patients want the exact opposite. In 2013, Pew Research Center surveyed more than four thousand Americans about their end-of-life treatment preferences.¹⁶ More than 70 percent of those age sixty-five to seventy-four and 62 percent of those age seventy-five and older said that they would want their doctor to "stop treatment so they could die" if they had "a disease with no hope of improvement and were suffering a great deal of pain." Such desires to avoid life-extending treatment are consistent with accumulating evidence about the problems with many life-extending technologies. Medical researchers and practitioners alike recognize that many aggressive treatments are futile and may take an emotional, physical, and financial toll on patients and families.¹⁷

According to a recent estimate, one in five critical care clinicians believe that their patients receive care that is futile.¹⁸ And while reliance on feeding tubes has declined dramatically over the past two decades, their use persists even though they do not prolong patients' lives, sometimes cause infections, and have been strongly criticized by major professional organizations, including the Alzheimer's Association.¹⁹ The economic costs of end-of-life care also pose a substantial burden to older adults, their families, and the federal government. In 2017, an estimated 13 percent of the \$1.6 trillion spent on health care overall, and one-quarter of the \$675 billion in Medicare spending, was for people in their last year of life.²⁰ Together, the epidemiologic transition, the "failure of success," and forces of medicalization have conspired against a good death—especially for older adults who may lack social and economic power.

Attaining a Good Death

The notion of a good death may seem subjective, reflecting highly personal preferences and values, yet survey data show that most Americans share a similar vision of what a good death looks like. A research team led by Karen Steinhauser surveyed two thousand people across four different categories: seriously ill patients, recently bereaved family members, physicians, and other care providers, such as nurses and chaplains.²¹ More than 90 percent of people across the four groups rated twelve out of forty-four possible death attributes as very important at the end of life. These twelve attributes reflected four broad end-of-life goals: being comfortable and free of pain; maintaining one's dignity; being knowledgeable about and prepared financially and emotionally for death; and having positive relationships with care providers. These perceptions map closely onto the Institute of Medicine's definition,

which describes a good death as “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.”²²

Approaches to Studying Inequities in Death and Dying

Is the idealized good death, marked by dignity and comfort, truly attainable? New research on death quality reveals both stark disparities and some universalities. Yet studying dying experiences is difficult and distinct from many other aspects of older adults’ well-being because self-report data are seldom if ever available. In short, dead people cannot report on the care, support, and medical treatments they received at the end of life. Instead of self-reports from decedents, two main types of information are used to study death quality.

The first is interviews with proxies, or people who are knowledgeable about the dying person’s end-of-life experience, typically a widow(er) or adult child. This approach also is referred to as a mortality follow-back method. Surveys like the Changing Lives of Older Couples (CLOC), a study of widowhood, ask widows and widowers how painful or prolonged their late spouse’s death was.²³ Likewise, the National Health and Aging Trends (NHATS) survey asks proxies whether the decedent and family members were treated with dignity and respect, and whether the dying patient’s personal care needs were met during the last month of life.²⁴

These assessments, like most retrospective survey data on emotionally charged topics, may be affected by recall bias. Bereaved family members who are particularly grief-stricken, depressed, anxious, or carrying unresolved anger may describe the death in more critical terms, whereas those who were closely involved in caregiving may offer more positive appraisals, perhaps as a way to affirm their belief that they did all they could to help ensure a peaceful death for their loved one.²⁵ Methodological studies that compare reports from multiple proxies, such as spouses and children, or that compare proxy reports with medical record data find that proxy reports of subjective aspects of the dying process, such as the patient’s level of pain or psychological distress, may be biased. However, their reports are much more reliable in evaluating concrete or observable conditions, such as the services received or whether the patient struggled with breathlessness.²⁶

A second method for assessing death quality is to use formal medical claims data or medical records. The widely used Dartmouth Atlas, a highly respected source of information on objective indicators of death quality such as hospice use, place of death, medical expenditures, length

of hospitalization, specific services used, and intensity of medical care, is based on information on Medicare beneficiaries obtained from the Centers for Medicare and Medicaid Services. These data also include very basic information on the decedent's demographic characteristics, such as age, race, sex, and geographic region. Using these data, researchers can examine patterns like racial and ethnic differences in the number and duration of hospitalizations, intensive care unit (ICU) admissions, hospice use, and whether death occurred at home or in a hospital.²⁷ These two types of data resources can be used to explore disparities (or similarities) in four main dimensions of death quality: place of death, pain and pain management, use of hospice care services, and subjective and interpersonal aspects of end-of-life care, like being treated with dignity. To date, most of this research has focused on race differences rather than socioeconomic differences, owing in part to the unclear meaning of SES among very old and terminally ill patients.²⁸

Most older adults at the end of life are retired rather than employed. Some might have transitioned from a lifetime job such as construction worker or waitress to a less physically demanding job, like store cashier, when their health started to decline. Most rely on Social Security as their primary income source, and many have depleted their savings to pay for medical or nursing home care. The handful of studies that do obtain information on SES may not necessarily capture the socioeconomic position that individuals occupied for most of their adult lives.²⁹ Thus, I focus primarily on race and regional differences in place of death, pain management, hospice use, and a broader range of social factors that might influence subjective death quality indicators, such as social isolation.

Place of Death

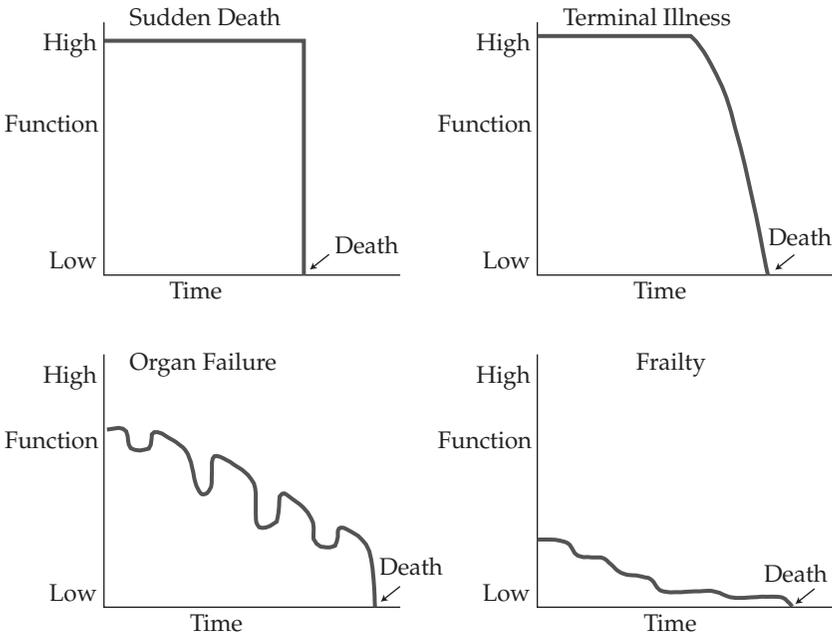
Whenever I give lectures on death and dying—whether to community groups, academic audiences, or even eighteen-year-old college students—I often ask, “How would you like to die?” Without fail, one clear answer emerges from the crowd: “When I’m very old . . . at home, in my own bed, surrounded by loved ones.” The specific details may vary—some would like a Schubert string quartet playing in the background, others want a prime rib feast as their final meal, while others name favorite activities that would fill their final day, like a quiet moment at the beach with their spouse and dog. My informal poll results map closely onto national survey data: 75 to 80 percent of American adults say that they would like to die at home, and similar proportions of older adults with chronic diseases say that they would like to avoid hospitalization and intensive care at the end of life.³⁰ However, statistics on where older

adults die show that the common desire for a home death is seldom realized. In 2009, just one in three died at home, and nearly 60 percent died in an institution, whether an acute care hospital (25 percent) or a nursing home (28 percent).³¹ Even though most Americans say that they do not want to be hooked up to machines at the end of their life, one-third of all recent decedents spent time in an ICU in their final month.³²

Most adults want to die at home for personal and spiritual comfort, to avoid the sterile and impersonal hospital or nursing home environment, and to spend their final moments with loved ones. Caregivers also say that they prefer that the dying person take his or her final breath at home.³³ Experts agree that a home death is better than an institutional death for the patient and family, especially if in-home hospice services are used. One study of cancer patients and their caregivers found that patients who died in an ICU or hospital experienced more physical and emotional distress and poorer quality of life compared with patients who died at home with hospice. For their caregivers, as well, ICU deaths were associated with heightened risk of post-traumatic stress disorder (PTSD) and prolonged grief disorder.³⁴

Dying in an institution can be particularly distressing for older adults who need transfers in care at the end of life and are moved from home to a hospital or nursing home and then to an ICU in their final days. Within the last three months of life, dying patients average 3.1 transfers.³⁵ These abrupt shifts often lead to fragmented patient care when the old and new care teams have limited communication about the patient's health conditions, treatments, and personal history.³⁶ Such moves also can be disruptive and disorienting for dying patients and their families, as they must adjust to unfamiliar surroundings, new treatments, and new teams of care providers.³⁷

The privilege of dying at home, like most other privileges, is linked to race and socioeconomic status. Yet these patterns are complex and closely tied to the severity of one's health condition, the treatments required, the availability of support systems to provide care at home, and public policies that dictate the kinds of treatments and services Medicare will cover. First and foremost, whether an older adult dies at home or in an institution depends on his or her health trajectory—that is, the timing and level of health symptoms. Medical researchers generally agree on three common dying trajectories for older patients with progressive chronic disease. As figure 8.1 shows, terminal illnesses, such as cancer, are distinguished by a steady progression of symptoms and a clear terminal phase. Deaths from organ failure (such as heart or respiratory failure) are marked by a gradual decline punctuated by roller-coaster-like up-and-down episodes of deterioration, recovery, and a seemingly sudden or unexpected death. Frailty refers to deaths from

Figure 8.1 Proposed Trajectories of Chronic Illness and Death

Source: Lunney, Lynn, and Hogan 2002.

dementia or extreme old age: in these cases, the patient experiences a prolonged and gradual decline or “dwindling.”³⁸ A fourth, sudden death, is very rare in older adults and might be due to a sudden heart attack. In general, older adults whose disease progresses in a generally steady and predictable way, like cancer or dementia, are more likely to die at home, often using hospice services. By contrast, patients in the second category, who experience unpredictable up-and-down symptoms, are more likely to die in an institution.³⁹

Second, a home death is more likely for those who have social support and whose caregivers have the schedule flexibility that allows them to carry out their tasks. One study of 350 terminally ill cancer patients found that those whose relatives took at least two weeks off work in the three months preceding their death were more likely to die at home, compared with patients whose relatives took off fewer than three days.⁴⁰ Another study based on 1.5 million patients from thirteen countries found that older adults with a greater number of family caregivers were five times as likely to die at home.⁴¹ Socially isolated older adults with-

out a spouse, children, friends, or other loved ones to provide informal care often have no choice but to spend their final weeks in an institution rather than at home.

Third, location matters. One of the most powerful predictors of where someone dies is whether there is a hospital nearby; older adults who live in an area with a greater concentration of hospitals and nursing homes are more likely to die in one.⁴² In sharp contrast, older adults living in rural areas with few hospitals or nursing homes are more likely to die at home without the services they need.⁴³ Older adults living in rural areas also may need to move into nursing homes prematurely, before they require the full menu of nursing services, because they do not have family caregivers nearby. As their adult children seek promising career opportunities far away from their rustic roots, their aged parents left behind must rely on paid formal care or institutions.⁴⁴

Fourth, race matters. Whites are more likely than blacks to die at home, a gap that has widened since the 1980s. Although rates vary by region and cause of death, about 40 percent of blacks but just 25 to 30 percent of whites die in institutions.⁴⁵ Experts offer three explanations for these racial disparities. The first is cost. To die at home, family members often need to invest in home health aides or other helpers to assist with the tasks of caring for a dying loved one. Blacks and Latinos are less likely than whites to have access to such home health services through private insurance.⁴⁶ Although some Medicare coverage is available, the conditions are strict. If a doctor orders in-home health care, Medicare may pay for only part-time or "intermittent" care from a home health aide. This equals roughly three ninety-minute visits a week during the period of illness. And many of the most common daily needs of frail older adults are not covered. For instance, Medicare does not cover personal care services, such as bathing and dressing, if that is the only care required. In sharp contrast, Medicare and Medicaid provide fairly generous coverage of nursing home care, which contributes to blacks' and Latinos' more frequent use of nursing homes at the very end of life.

The second reason for the race gap in home deaths is that terminally ill blacks are less likely than whites to have a family caregiver who is available to assist with transportation, homemaking services, and personal care. Having a family caregiver is closely tied with demographic factors, such as being married or having children living nearby, as well as economic factors, like having a family member who can afford to take time off work or cut back on work hours in order to provide care. Data from the Assets and Health Dynamics among the Oldest Old (AHEAD) show that white older adults are most likely to turn to a spouse (28 percent) or adult children (41 percent) for assistance with their daily activities and personal care, whereas black adults named adult children

(42 percent) and a nonfamily member (30 percent) as their main caregivers. Hispanics were most likely to rely on family members, with 52 percent relying on children and 20 percent relying on a spouse.⁴⁷ These gaps partly reflect family structure: blacks are less likely than whites and Hispanics to marry and stay married, and they may give rather than receive care from family members, even in later life.⁴⁸

Whether an older adult relies on family members or nonrelatives for personal care matters because the type of tasks each performs differ. Older adults (especially women) generally prefer that close family members assist with dressing, bathing, bedpans, and other very personal tasks, while friends, neighbors, and members of one's religious congregation may be called on to help with less intimate tasks, like giving rides or delivering the occasional meal.⁴⁹ The personal care tasks are essential to helping a terminally ill older adult to remain in his or her own home.

The third reason for the race gap in home deaths is African Americans' and, to a lesser extent, Hispanics' preferences for aggressive care at the end of life—care that can only be delivered in an institutional setting. Ethnic minorities are more likely than whites to say that they want resuscitation and intubation (a breathing tube), and therefore they end up spending more time in the ICU than whites. Yet, as we shall see, blacks' stated preferences for more aggressive care may not capture their actual desires but may instead reflect fear of a health care system that historically has deprived them of treatments they wanted and needed.⁵⁰ Other studies suggest that ethnic minorities, especially those with lower levels of literacy, do not understand what end-of-life treatments entail—often because physicians fail to keep them informed.⁵¹

Pain and Pain Management

Pain is considered one of the core aspects of a bad death, yet most dying older adults experience some pain. One-half to two-thirds of older patients experience some pain during their last month of life, with considerably higher rates among those with arthritis, musculoskeletal conditions, depression, and cancer.⁵² One review of fifty-two studies conducted over a forty-year period showed that one-third of older patients rated their pain as moderate or severe.⁵³ Recent surveys find that 75 percent of older adults have multiple sites of pain and that one in four experience pain that they describe as “dreadful” or “agonizing.”⁵⁴ Shortness of breath, or dyspnea, is another common source of discomfort, with 50 to 60 percent experiencing breathlessness in the final two weeks of life.⁵⁵

Pain and dyspnea are undesirable outcomes in their own right, yet they are also at the root of other psychological and interpersonal difficulties. Pain and breathlessness impair older adults' daily functioning, re-

duce their capacity to socialize or get exercise, increase their risk of depression, and reduce their psychological well-being.⁵⁶ Pain also takes a toll on caregivers; both witnessing loved ones in pain and trying (often unsuccessfully) to soothe that pain are among the most distressing burdens identified by the family caregivers of dying patients.⁵⁷ Family caregivers also may worry that they lack the knowledge or training to help administer pain medications to their loved one and fear making potentially fatal errors.⁵⁸

Severe pain at the end of life is not inevitable, however, and can be treated effectively with medication. Studies of dying patients in their own homes and in nursing homes show that the use of opioids, including morphine, increases the patient's quality of life and does not hasten death unnecessarily.⁵⁹ A recent analysis of NHATS data showed that just 25 percent of proxies reported that their loved one had "unmet need for pain management" and just 21 percent reported "unmet need for dyspnea" in the last month of life.⁶⁰ However, the extent to which pain is appropriately treated varies markedly by race, with blacks experiencing considerably more unmet need (that is, inadequately treated pain) than whites.

One analysis of twenty years of data found persistent black-white gaps in the prescription of analgesic painkillers: blacks were only two-thirds as likely as whites to receive such prescriptions for chronic painful conditions like backaches and migraines, and they were also less likely to receive painkillers for traumatic injuries or surgery.⁶¹ Studies based on Medicare data show that expenditures for older adults' pain medications were lower in geographic areas with high proportions of black residents, whereas studies analyzing workers' compensation claims show that less money was spent on painkillers for injured black versus white workers, and that the duration of the prescriptions (and payment) were considerably shorter.⁶² Many factors account for this disparity, ranging from the implicit prejudices held by care providers to institutional racism such as pharmacies in historically black or poor neighborhoods failing to stock adequate supplies of pain medications.

Some researchers have suggested that health care providers may (unwittingly) hold implicit attitudes about race—such as the belief that blacks are more likely than whites to abuse drugs—that make them reluctant to prescribe analgesics to blacks. Others contend that physicians—the majority of whom are white or Asian—are less adept at empathizing with patients who look different from them and less able to accurately gauge their pain. Recent studies suggest that older black and, to a lesser extent, Hispanic patients are more likely to have their pain underestimated by health care providers and are less likely to have pain scores documented in their medical record compared to whites. As a

result, dying African Americans and Hispanics are less likely to receive opioid analgesics and more likely to have their pain untreated compared to white patients.⁶³

One particularly disheartening study suggests that doctors' underestimation of pain in African American patients reflects inaccurate if not outlandish beliefs about blacks' superior ability to tolerate pain. In a study of medical students and residents, Kelly Hoffman and her colleagues found that 14 percent of second-year medical students believed that "blacks' nerve endings are less sensitive than whites," while 42 percent believed that blacks have "thicker skin than whites."⁶⁴ Although the proportions endorsing these beliefs declined considerably by the students' final year in medical school, the researchers argue that these stereotypical beliefs and biases are a crucial mechanism behind the disproportionately high levels of untreated pain among African Americans at every stage of the life course.⁶⁵

Racial disparities in the appropriate use of pain medication for dying older adults also may reflect institutional racism, a form of racism carried out in the practices of social and political institutions. Although the intent of such practices may not be explicitly racist, the outcome is unequal on the basis of race or ethnicity. In the case of pain medications, pharmacies, especially those in poor, urban, and historically African American neighborhoods, may not stock opioids if they believe they are at risk of theft. Yet these practices ultimately keep much-needed medications out of the hands of dying older adults who desperately need them.

One study of 188 retail pharmacies in Michigan characterized a pharmacy as having "sufficient" opioid analgesic supplies if it kept in stock at least one long-acting analgesic, one short-acting analgesic, and one combination opioid analgesic.⁶⁶ The researchers classified neighborhoods as predominantly white or predominantly black based on whether more than 70 percent of residents were white or black, respectively. Pharmacies in the minority zip code areas were fifty-two times less likely to carry sufficient opioid analgesics than pharmacies in white zip code areas, regardless of income. A similar study of New York City pharmacies yielded similar albeit less extreme results.⁶⁷ The researchers examined 176 pharmacies, randomly selected from all pharmacies in the city, and documented whether they stocked morphine and other opioids like fentanyl patches and oxycodone. Just 25 percent of pharmacies in predominantly black neighborhoods had opioid supplies that were sufficient to treat patients in severe pain, compared to 72 percent of pharmacies in predominantly white neighborhoods. The study investigators attributed these patterns to fear on the part of pharmaceutical companies and business owners that these medications would be stolen by local addicts. Yet even when local crime rates were taken into consideration,

the disparities persisted, revealing that perceptions of the kinds of people who lived in the neighborhood were more powerful influences on business decisions than the actual crime rates.

In informal interviews with New York City pharmacists, some pharmacists told the *New York Times* that they did not stock the drugs simply because they did not have sufficient demand.⁶⁸ Others were quick to point out, however, that lack of demand is not the same as lack of need; rather, lack of demand might have reflected either lack of insurance to pay for the medications or the failure of physicians to prescribe painkillers to those who need them. Yet these explanations may mean little to the older adults suffering from untreated pain and dyspnea. Many may go without their pain medications, or their family members may need to devote considerable time and energy traveling to find medications. R. Sean Morrison, the lead author of the New York City study, recounted to the *New York Times* that he was treating a seventy-four-year-old Hispanic woman from the South Bronx with severe pain from a spinal disease, for whom he prescribed morphine. When he followed up with her the next day, she was still in agony. Although her daughter had gone to every pharmacy in their neighborhood, she could not locate the drug. It was only when the doctor intervened that the family located and obtained the medication they needed. The subtle and overt ways in which racism operates in everyday life are at the core of race disparities in pain management at the end of life.⁶⁹

Hospice

The hallmarks of hospice care are the soothing of pain and the provision of comfort care. Hospice care is a comprehensive program that facilitates dying at home with one's family and emphasizes palliation (pain relief) and comfort rather than aggressive treatment at the end of life. Roughly 60 percent of hospice patients receive services in their own homes and the rest in institutions, although these rates vary based on the availability of services in different geographic areas.⁷⁰

Hospice use has increased dramatically over the past two decades, with the number of sites in the United States increasing at about 3.5 percent a year from 2000 to 2010.⁷¹ In 1997, 17 percent of all deaths in the United States occurred under the care of hospice; by 2011, this proportion had more than doubled, to 45 percent.⁷² Roughly half of all Medicare decedents had been receiving hospice care.⁷³ The growing popularity of hospice among dying patients reflects shifting attitudes favoring quality of life over length of life. The movement toward hospice also is due to increased Medicare funding for hospice services as a way to reduce the costs associated with high-tech end-of-life care.

Medicare beneficiaries who are certified by a physician to have a terminal illness and less than six months to live are eligible for the Medicare hospice benefit. If the patient lives longer than six months, then hospice coverage may continue if the primary care provider and hospice team recertify the eligibility criteria.⁷⁴ This benefit provides services not covered under “traditional” Medicare such as nursing care, counseling, palliative medications, up to five days of respite care to assist family caregivers, and bereavement support for family members after the patient has died. Importantly, Medicare does not currently reimburse for hospice services until a patient has agreed to forgo curative care. (This may change, however. Medicare is currently conducting a pilot study that allows terminally ill patients to receive hospice care yet also see doctors and get medical treatments, like chemotherapy or hospitalization, intended to fight their illnesses.)⁷⁵

Hospice is widely praised by the patients and caregivers who use its services, yet many Americans hold strong misconceptions that may frighten them away from hospice. Hospice care typically involves withholding or withdrawing medical treatments that may sustain a patient’s life, but it is not a form of euthanasia or physician-assisted suicide (PAS), whereby patients are directly administered medications that may hasten their death. Despite this profound difference between hospice and PAS, many laypersons misunderstand precisely what hospice is and does. Patients and family caregivers may believe that hospice “starves” patients to death by depriving them of feeding tubes, or that hospice care means giving up all hope that the patient will live.⁷⁶ Even more dire, one study found that more than half of all palliative care physicians had been accused by a distraught family member of “committing murder.”⁷⁷

This misunderstanding is an obstacle to using hospice services and may contribute to poorer-quality deaths among some older adults. Clinical trials have found that patients receiving hospice services have fewer ICU admissions, greater satisfaction with their medical care, and reduced levels of pain, while surveys document significantly better mood and superior quality of life.⁷⁸ The family caregivers of hospice patients also report feeling supported and experiencing fewer symptoms of sadness and anxiety. The benefits of hospice linger even after the patient has died. Bereaved family members whose loved one received hospice care have reduced risks of mortality, depression, and traumatic grief. These positive outcomes are due partly to the fact that the death is less stressful for caregivers, as hospice provides support services to bereaved caregivers in the immediate aftermath of the death.⁷⁹

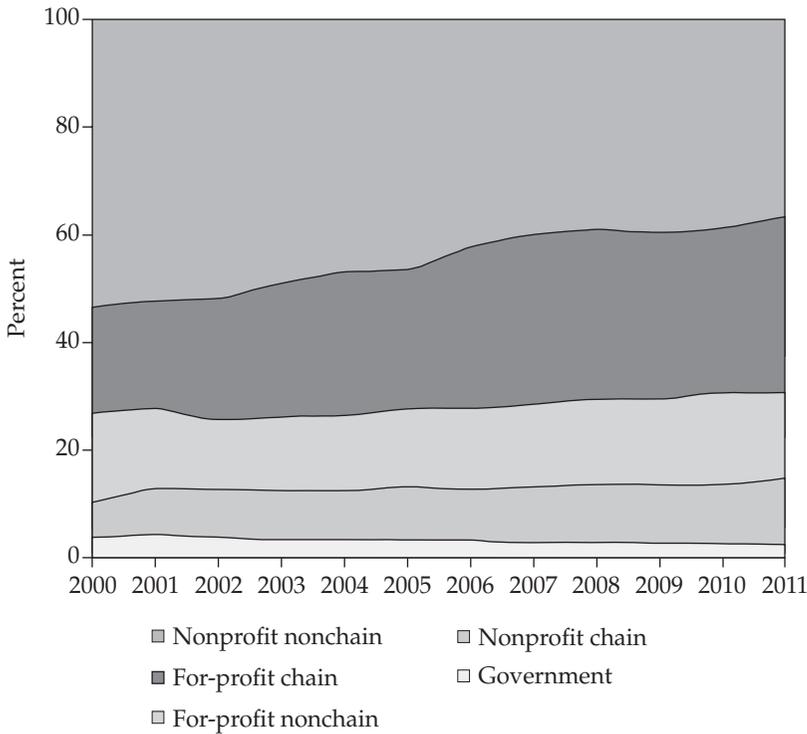
Open-ended interviews, blogs, and personal essays by bereaved family members reveal a tremendous sense of gratitude to hospice for the care it delivers. For instance, Open to Hope Foundation, a nonprofit

foundation with “the mission of helping people find hope after loss,” regularly features on its webpages first-person essays and readers’ reactions. The essays written by bereaved older persons who relied on hospice services are overwhelmingly positive. One widow wrote that “my husband of 42 years passed away in 2009. After a one-year fight to keep him alive, we brought in hospice to our home from which he transitioned . . . I will be forever grateful for their tender care, responsiveness and for the bereavement counseling they provided after my husband’s death.” Another older widower shared that “my wife Patt was put under hospice care [in 2011], due to ovarian cancer. She fought a hard battle for about 2.5 years, but got to the point where her body couldn’t take chemo anymore. We had hospice care at home. . . . Patt only lived for one month. I couldn’t have made it without our hospice people.”⁸⁰

The benefits of hospice are financial as well as physical and psychosocial. A hospice stay of two to four weeks has been found to save Medicare nearly \$6,500 per patient.⁸¹ Part of the cost savings results from hospice patients’ reduced use of other costly life-sustaining treatments and services, including ER visits and hospital admissions in the last month of life and chemotherapy within the last two weeks of life.⁸² However, some policy analysts worry that these savings are starting to erode—and will continue to do so—as growing numbers of for-profit hospice providers engage in practices that boost their corporate bottom line yet potentially hurt patients (and overwhelm the Medicare payment system).⁸³

Despite its many benefits, experiences with hospice are not uniformly positive. Both scientific studies and personal narratives suggest that hospice is most beneficial to the patients and family members receiving services for fairly long periods. A well-documented limitation of hospice is that patients may receive these services only very late in their illness. One-third of hospice patients receive these services for one week or less; the median duration in hospice is nineteen days.⁸⁴ Patients who receive hospice care only at the very end of life—for three or fewer days—are more susceptible to major depression relative to those who receive longer-term care.⁸⁵ These statistics cohere with the laments of an Open to Hope blogger and widow, Paula, who had recently lost her husband of thirty-five years to cancer. After struggling with his illness for many years, Paula’s husband died less than one week after he entered in-hospital hospice care. As Paula wrote: “If I could go back in time and make that decision [to place her husband in hospice] over again, I would have chosen not to have hospice care. I know that many people speak highly of hospice and the care that is given; this was not my experience. Perhaps if you are home and the care is being provided there it is different. But in-hospital hospice care seemed to be just another layer in

Figure 8.2 Medicare Hospice Enrollees, by Ownership of Hospice Provider, 2000–2011



Source: Stevenson et al. 2015.

Note: Data are from Medicare cost reports, which must be submitted annually by all Medicare-certified hospice agencies and are publicly available from the Centers for Medicare and Medicaid Services.

the system. What could they have done differently? Perhaps, the hospital administration could have explained the process more thoroughly.⁸⁶ In general, hospice works best when patient and family members are told what to expect and they receive services for longer durations to help transition them toward the death.

Another potential threat to the quality of hospice care is the rapid increase in the number of for-profit hospice providers, who differ from nonprofit providers in important (and troubling) ways. While just 5 percent of hospice providers were for-profits in 1990, by 2000 this share had reached one-third, and by 2011 one-half (see figure 8.2).⁸⁷ This shift in the composition of hospice providers carries potential problems for

patients and their families. In general, for-profit hospices exist within larger corporate systems and are motivated to run as efficiently as possible. Regardless of whether a hospice provider is for-profit or nonprofit, they are all reimbursed by Medicare at a flat daily rate. The daily per diems vary slightly by state, and by place and duration of care, but averaged around \$160 to \$200 per day in 2018.⁸⁸

Federal watchdog groups like the Medicare Payment Advisory Commission (MedPAC) have cautioned that because of this flat-rate reimbursement system, some for-profit hospice providers may be selectively enrolling patients in an effort to maximize their profit margins. Patients who remain in hospice for a long time yet have less complex health care needs are the most profitable, whereas patients at the very end of life with short, service-intensive stays are the least profitable.⁸⁹ In short, if all hospice providers are going to receive roughly \$180 a day, regardless of what services they provide, the “rational” decision would be to focus on patients whose needs are modest and avoid those patients whose care needs are time- or labor-intensive. Consequently, for-profits tend to fill their patient rosters with those suffering from conditions that are less onerous to treat, leaning toward dementia and heart disease patients rather than cancer patients, who require intensive pain treatments.⁹⁰

These processes affect patient care in several ways. First, for-profits generally offer a narrower range of services, leaving out potentially valuable services like bereavement care for family members once the patient dies. They also offer fewer community benefits such as charity care or training sites for care providers. Second, for-profits are more likely to provide care to patients in nursing homes or hospitals rather than in their homes. It is simply more efficient for hospice workers to see multiple patients in a single institution, especially when basic routine tasks like bathing have already been taken care of by the nursing home staff. Home-based patients, by contrast, may require extensive travel to far-off homes and neighborhoods, and the caregiving tasks may be especially time-consuming, as the patient’s family members cannot pick up the workload in the way that paid nursing home workers can. What that means is that more patients are dying in institutions, which betrays their desire to die at home.

Third, in an effort to run “mean and lean,” for-profit hospice providers tend to maintain lower staff-to-patient ratios, and with less professionalized staff, care may be rushed or inadequate.⁹¹ The dire consequences of understaffing were vividly recounted in Karen Brown’s 2018 *New York Times* op-ed, where she details how her dying father’s final night was marked by excruciating untreated pain because of a long delay in an overworked hospice provider arriving at his bedside. As Brown recalls, “At the end of life, things can fall apart quickly, and nei-

ther medical specialist nor hospice worker can guarantee a painless exit. But we were told a palliative expert would be at my father's bedside if he needed it. We were not told this was conditional on staffing levels." Individual hospice workers may be every bit as kind, compassionate, and dedicated to their patients in for-profit as nonprofit hospice organizations, yet organizational constraints prevent them from delivering the high-quality care they would like. Some experts believe that these gaps in quality of care may be particularly troublesome for black and Latino hospice patients, who are more likely than whites to be recruited by and enrolled in a for-profit hospice.⁹²

Finally, for-profits are slightly more likely than nonprofits to disenroll patients at the very end of life, when they require more frequent visits and more intensive support.⁹³ The difference is quite small; 6 percent of nonprofits and 10 percent of for-profits disenroll hospice patients when they are still alive. In some cases, patients request it after having a change of heart about their care. In other cases, hospice providers have little incentive to care for the most challenging patients when they can receive the same per diem reimbursement for easier and less time-consuming patients, thus enabling larger (and more profitable) case-loads.⁹⁴ Yet when patients leave hospice, regardless of the reason, they may end up costing Medicare more money, as these patients may resort to high-cost medical treatments in emergency rooms and ICUs. As a result, they are more likely to die in hospitals, a setting that is widely considered part of a "bad death."⁹⁵

Disparities in Hospice Use Hospice was designed as a program that should be available to all, although in practice, it may be out of reach for many who need it. In the preamble to its formal *Standards of Practice*, the National Hospice and Palliative Care Organization states that hospice "offers palliative care for all individuals and their families without regard to age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay."⁹⁶ Yet despite NHPCO's well-intended philosophy of egalitarianism, some individuals face obstacles to hospice use.

The first obstacle is hospice policies that disproportionately affect those with fewer social and economic resources, such as patients without a family caregiver at home. The first-ever national survey of enrollment policies at nearly six hundred hospices found that 78 percent of hospices had at least one enrollment policy that could restrict access to care. For example, 12 percent of hospices required that the patient have a family caregiver at home and would not provide services to those without a caregiver present.⁹⁷ On the one hand, this policy is defensible: the hospice philosophy emphasizes the importance of family in provid-

ing support and care to dying patients. On the other hand, this policy is implicitly biased against those who are unmarried, childless, or socially isolated, as well as those whose family members cannot afford to take time off work. Low-income and black older adults, being less likely to be married and thus more likely to lack a coresidential spouse caregiver, are particularly affected by such requirements.

For older adults living in urban or suburban areas with many hospices nearby, such a restriction may be of little consequence; they may choose another hospice program that does not have it. Yet older patients living in remote rural areas may have few if any alternatives. A case in point is ninety-five-year-old Wyoming rancher Bill Kolacny, who wanted to die peacefully at his log home with his wife Beverly by his side. After he suffered heart failure, Bill and his family looked into hospice services. The hospice closest to his four-hundred-acre ranch on the Clarks Fork River was located in Red Lodge, Montana, and was not licensed to care for patients over the state line in Wyoming. Yet the closest Wyoming hospice could not afford to send its staff to the Kolacny ranch, more than sixty miles away.⁹⁸ Ultimately, Bill's son and two daughters each traveled more than an hour each way to care for their ailing father.

A second obstacle is lack of awareness of what hospice does. This is one of the main reasons why blacks and Latinos are less likely than whites to use hospice and more likely, when they do, to enroll at more advanced disease stages and thus have shorter spells of care. Analyses of Medicare beneficiary records show that roughly half of white but only one-third of black older adults used hospice services in the last week of life.⁹⁹ Yet informational barriers to African Americans' use of hospice are potentially modifiable and can be minimized with patient education and outreach programs. One small study of two hundred community-dwelling older adults found that 19 percent of blacks yet just 4 percent of whites had never heard of hospice, while 72 percent of whites and fewer than half of blacks said that they knew a lot about hospice. Among both blacks and whites, greater knowledge about hospice is a predictor of holding favorable attitudes toward it.¹⁰⁰ Health care providers and institutions could develop targeted educational programs to increase knowledge of, preferences for, and ultimately enrollment in hospice among blacks.

A third barrier is fear or skepticism about what the program entails; these beliefs are particularly common among blacks and have deep roots in the historical mistreatment of blacks by the U.S. health care system.¹⁰¹ As Maisha Robinson, a palliative care physician at the Mayo Clinic, told the *New York Times*: "You have people who've had a difficult time getting access to care throughout their lifetimes" because of poverty, lack

of health insurance, or difficulty finding a medical provider, “and then you have a physician who’s saying, ‘I think that we need to transition your mother, father, grandmother to comfort care or palliative care.’ People are skeptical of that.”¹⁰² This skepticism is compounded by the Medicare reimbursement rule that hospice patients must forgo curative treatments. Blacks who have had to fight and advocate for quality health care throughout their lives may not be comfortable actively forsaking these treatments.¹⁰³

Some older adults believe that hospice is at odds with their religious beliefs. African Americans in particular may view hospice as a challenge to beliefs such as “God will decide when it’s my time to die,” or that miracles may occur if one is kept alive long enough.¹⁰⁴ The miracle might be a dying parent reuniting with an estranged child, a patient rediscovering his or her faith as death nears, or, on rare occasions, recovering from terminal illness and exiting hospice care. To withhold treatment, some African Americans believe, “would get in the way of God’s will” or be antithetical to the belief that suffering can be redemptive or a “test from God.”¹⁰⁵ Yet promising new interventions and educational programs conducted in partnerships between health care systems and religious leaders aim to increase rates of hospice among older blacks. The National Hospice and Palliative Care Organization has produced a guide for older African Americans and their community leaders, to explain what hospice does and challenge pervasive myths about the service.¹⁰⁶ One early example of success was the establishment of the Caring Touch Ministry, a church-based hospice education and coordination program started by Cassandra Cotton, a church leader, certified nursing assistant (CNA), and community relations coordinator at a local hospice. Cotton says, “Providers must find ways to educate faith communities and engage faith leaders in end-of-life care conversations. The congregation must have an informed, trained leader who has an understanding of the range of hospice services and how these services are delivered.”¹⁰⁷ These programs have high potential to create a context in which blacks and whites alike may die with dignity.

Death with Dignity: Subjective End-of-Life Appraisals Surprisingly little research has explored subjective aspects of end-of-life experiences, in part because of the methodological challenges involved. Subjective end-of-life assessments must be provided retrospectively by a proxy because the decedent cannot report the care he or she received in the last few days of life. Yet proxy assessments are often of questionable validity. If they are obtained too soon after the death, the proxy reporter’s assessments may be biased by symptoms of grief, depression, or anxiety. But if the assessments are done long after those initial symptoms have

passed, the proxy may not recall all the details of the death.¹⁰⁸ The handful of studies done in this area suggest few race or socioeconomic differences in subjective aspects of death quality.

One of the richest resources for exploring proxy assessments of death quality is the NHATS, which asked survivors of older adults who died between 2011 and 2013 to rate the quality of nine objective and subjective aspects of death. Although these data reveal high levels of dissatisfaction with pain (67 percent) and shortness of breath (56 percent), the proportions reporting interpersonal or spiritual concerns are much lower: fewer than one in five recalled that the dying patient was treated without respect, decisions were made without enough input from the decedent or family, the decision went against what the decedent would have wanted, or the family was not always kept informed.¹⁰⁹ Also using NHATS data, the sociologist Elizabeth Luth found that blacks were more likely than whites to report unsatisfactory pain treatment.¹¹⁰ She found no differences, however, regarding more subjective concerns, like being kept informed, being treated with respect, and having spiritual concerns met.

Similar patterns were detected in three other data sets: the Changing Lives of Older Couples, a prospective study of spousal bereavement in the 1980s and 1990s; the Wisconsin Longitudinal Study, a longitudinal study that tracked white Wisconsin high school graduates from their senior year in 1957 through old age in 2011; and the New Jersey End of Life Study, a sample of 305 black, white, and Hispanic terminally older adults.¹¹¹ Although blacks reported less satisfaction with pain management, no race differences emerged for other subjective measures of death quality, like the patient's awareness of and acceptance of death, positive family interactions at the end of life, and the survivor's belief that the decedent led a full life.¹¹² These results are consistent with a key theme of fundamental cause theory: social and economic resources are protective only in situations where they can be used to gain an advantage.¹¹³ Although money, status, and power may help in advocating for appropriate medical care and pain medication, those resources may be of little value as family members prepare emotionally and spiritually for the death of their loved one.

Agency in Dying: Advance Care Planning

Death may be inevitable, but a bad death is not. In an effort to combat highly medicalized, costly, protracted bad deaths, policymakers and practitioners are working to give patients and their families greater latitude in decision-making. In 1990, the U.S. Congress passed the Patient Self-Determination Act (PSDA), which requires all health care facilities

receiving federal funds “to ask patients whether they have advance directives, to provide information about advance directives, and to incorporate advance directives into the medical record.”¹¹⁴ An advance directive has two main components: a living will and a durable power of attorney for health care (DPAHC) designation. A living will is a legal document specifying the medical treatments a person would like to receive if he or she is not healthy or aware enough to make those decisions at the moment they are required. A DPAHC permits a person appointed by the patient to make decisions about health care if the patient is incapable of doing so.

The benefits of advance care planning are well documented. Older adults with advance directives in place are much more likely to experience several core components of a good death, including greater use of hospice or palliative care, reduced use of invasive or futile treatments such as feeding tubes or ventilators, a stronger belief that they have some control over the end-of-life process, a greater chance of dying at home rather than in an institution, and fewer instances of receiving treatments that are discrepant with their wishes.¹¹⁵

ACP also eases the experiences of family members. It reduces their decision-making burden, thus minimizing their anxiety and depressive symptoms. New findings from the Wisconsin Study of Families and Loss (WISTFL) reveal how ACP minimizes the decision-making burden.¹¹⁶ The WISTFL is a study of 750 bereaved family members of recently deceased Wisconsin Longitudinal Study participants. The survivors were asked whether their loved one had done ACP, and whether it helped, hurt, or had no effect on the quality of the loved one’s death. The survivors then described in their own words precisely how the ACP helped or hurt. Most noted that the decedent’s planning had helped, and that the living will eased decision-making in five ways. First, it provided family members with knowledge of the end-of-life process. As one bereaved spouse recalled, “We had discussed how everything was supposed to work so when time got closer everyone knew where we stood.”¹¹⁷

Second, it clarified family members’ responsibilities. A bereaved son reported, “Us kids knew who it [the DPAHC] was so there was no bickering . . . it was never an issue as to who should make decisions.” Third, survivors felt affirmed that the decedent’s preferences were heeded. One daughter found comfort in the recognition that “we knew that my mom could make the decisions that she wanted.” Fourth, the formal designation of power reduced ambiguity. A widower believed that the living will helped because it provided “the security in knowing you had that power ability.” Finally, family members felt supported when making a difficult choice. A son responsible for making the decision regarding his

elderly father's care recalled, "I was the one that said 'well, we will not prolong his life' and that was it. The nurses and the director knew the same thing; they are the ones that finally helped me let it go. . . . You have to make a decision and you have to do it rather quickly. If people are wishy-washy about it, the living will takes that away. At least it did for me."¹¹⁸

Despite the many positive consequences of ACP, it cannot guarantee a good death. The limitations of living wills are widely documented.¹¹⁹ The treatment preferences stated may not be relevant to the patient's condition at the very end of life, especially for those who drafted their living wills years earlier. Physicians may not have access to the document at the critical decision-making moment. The living will might be stashed away in a safe deposit box, or it might be sitting in a desk drawer in a Wisconsin home when an older adult is unexpectedly hospitalized while wintering in Arizona. Many advance directives begin with the statement: "If I have a terminal condition, then . . ." This statement requires that a physician evaluate whether the patient's condition is terminal. Until that determination is made, the content of the advance directive does not hold, despite what the patient and family had hoped.

Physicians also may be reluctant to follow the orders stated in the living will for fear of legal liability; physicians believe that their liability risk is greater if they do not attempt resuscitation than if they provide it against patient wishes.¹²⁰ Family members may not know (or agree with) the document's content, or they may not know how to translate vague preferences into specific clinical practices. A statement like, "If I'm ever a vegetable, pull the plug," has no clinical meaning and provides no clear instructions for providing or withholding treatments. For these reasons, some states are encouraging the use of physician orders for life-sustaining treatment.¹²¹ POLSTs are completed by a patient in consultation with health care providers during a clinical encounter. The document is signed by a physician and kept in the patient's record. Unlike a living will, a POLST is a formal "order," so health care providers are required to follow its content.¹²²

DPAHC appointments also have practical limitations. The designated DPAHC is granted decision-making authority, yet may make decisions that create distress or disagreement among family members. The WISTFL data reveal that, according to some family members, the DPAHC designation created problems and conflict at the end of life.¹²³ Problems typically arise when the appointed decision-maker tries to carry out the patient's preferences and other family members disagree with that decision. One bereaved daughter recounted the difficulty of serving as DPAHC after her mother's recent death: "My father was unable to make the decision to pull life support, which fell to me. [I knew]

it was the right thing to do, not letting her live like that, but my brothers wanted her alive. It helped that one person was responsible for the decision, but it caused issues with the family." In other cases, problems arose because aggrieved family members believed that they themselves should have been chosen for the job, rather than the person named as DPAHC. One widow recalled that her late husband's son from a prior marriage tried to contest her decision: "We had both been married before and had children. His oldest son felt that maybe he should make decisions for his dad instead of myself."¹²⁴

A further difficulty is that the appointed decision-maker may not actually know what the patient wants; multiple studies document that the decision-maker's knowledge of the patient's preferences is usually no better than chance. Often believing (incorrectly) that they and the patient hold the same preferences, proxies often assume that their own preferences should guide the end-of-life decision.¹²⁵ As one study concluded, "surrogates are not perfect ambassadors of patient preferences."¹²⁶ Older adults themselves, in the mistaken belief that their loved ones intuitively understand their preferences, often do not see a need to explicitly inform the legal proxy of their views.

For some patients, their proxy's limited knowledge is unproblematic. Some older adults prefer to have a family member do what he or she feels is best, rather than abide by their own stated preferences.¹²⁷ Others may trust their physicians to make decisions for them. Still, the patient's deference to a specific decision-maker's wishes may create distress or conflict for concerned family members who do not hold legal decision-making power and who may also create additional problems and conflict. Clinicians often share anecdotes of what they call the "daughter in California" phenomenon. In this common scenario, a family member who resides far away from the dying patient and has had little involvement in the patient's end-of-life care jets into town at the eleventh hour, swoops in, and tries to redirect the family conversation and decision-making at the patient's final stage of life. These individuals may try to undo or undermine the decisions made by local family members who were engaged in the care and decision-making process from the start. These family disagreements, in turn, make it difficult for health care teams to provide quality end-of-life care.¹²⁸

Given these limitations of formal ACP, some practitioners suggest that informal discussions with loved ones and care providers are the most critical component of end-of-life planning. Analyses of data from married couples in the WLS show that discussing end-of-life issues with one's spouse increases the chances of correctly identifying his or her end-of-life treatment preferences.¹²⁹ Even though these discussions are not formal or legally binding, they can help to facilitate care consistent

with the patient's wishes; Laraine Winter and Susan Parks conclude that "those who avoid . . . end-of-life conversations are the least likely to have treatment wishes respected, because their proxies are unlikely to know their wishes."¹³⁰

Conversations about an older adult's values also may be useful because very few of us know precisely how and of what cause we will die, making it difficult to specify particular medical interventions that we would want (or not want) at the end of life, such as feeding tubes or chemotherapy. A general conversation about values ("I don't want to be a vegetable") and global preferences ("I don't want to be hooked up to machines") may provide family members with a road map for representing their loved one's wishes even in the absence of a formal living will. Discussions may facilitate decision-making in cases where the patient has not legally appointed a DPAHC. Most states have established default systems for authorizing proxy decision-makers. State laws vary, but such lists prioritize the immediate family—starting with the spouse, followed by an adult child, a sibling, and other relatives.¹³¹ Frank conversations about a patient's values may empower and inform state-authorized proxies when making difficult decisions about their loved one's care.

The timing of these discussions is crucial, however, as some discussions may be too little too late. Conversations regarding end-of-life issues often are triggered by a patient's health-related crisis, such as a heart attack or hospitalization. When discussions occur following such trigger events, the patient and family often are too distressed or frightened to make an informed or levelheaded decision about imminent care needs. Growing recognition of the importance of timely, in-depth conversations between dying patients and their family members and health care professionals was one impetus for the 2016 ruling by the Obama administration that clinicians are to be reimbursed for the time they spend discussing end-of-life issues with Medicare-beneficiary patients and their families. Although this benefit, provided as part of the Affordable Care Act, has an uncertain future under the current political administration, it has high potential to make advance care planning more common, especially among ethnic minorities, persons with fewer socioeconomic resources, and other older adults who face serious obstacles to ACP.

Advance Care Planning: Trends and Disparities

Professional recommendations from organizations like the American Medical Association, public awareness and education campaigns, popular books, and public policies like the PSDA—all aim to increase rates

of ACP, yet these efforts have been met with only moderate success. Only one-third to one-half of all adults in the United States have completed an advance directive, although rates are as high as 70 percent among older adults.¹³² ACP rates have increased sharply since 1990: the proportion with a written advance directive has more than doubled, from 16 percent in 1990 to 35 percent in 2013.¹³³ This trend is partly attributable to the passage of the PSDA in 1990; high-visibility cases of contested end-of-life decisions, such as the fifteen-year legal case of Terri Schiavo; public awareness campaigns like Respecting Choices and the “Five Wishes”; and media programs such as Bill Moyers’s PBS series *On Our Own Terms*.¹³⁴ The Five Wishes, for example, is a user-friendly advance directive written in nontechnical language that includes identification of a proxy and preferences for medical and nonmedical treatment and comfort.¹³⁵

Race Disparities Although ACP rates are steadily inching upward, stark racial disparities persist. Dozens of studies, based on national, regional, and clinical samples, all point to the same finding: blacks and Latinos are less likely than whites to do advance care planning, despite its well-documented positive consequences for death quality. Studies generally show that whites are two to three times as likely as blacks and Latinos to have an advance directive; the gap is much narrower for end-of-life discussions. These gaps persist even when education, income, health literacy, health, and other social factors are controlled.¹³⁶ Explanations for these differentials include: ethnic minorities’ limited access to the medical and legal professionals who may provide assistance in preparing such documents; literacy or language barriers; cultural beliefs that such documents are unnecessary because family members will make decisions collectively on behalf of the patient; historically rooted distrust of physicians and medical institutions; and adherence to religious beliefs like “God will decide” when it is time for a patient to die and “those who believe in God do not have to plan for end-of-life care.” Some research suggests that blacks and Latinos believe that they do not need a living will because they tend to want all possible interventions at the end of life and think that living wills limit their ability to request treatment.¹³⁷

Blacks and Latinos may view ACP as unnecessary because they believe that their family members already know their end-of-life preferences. I analyzed open-ended data from the New Jersey End of Life Study, a study of ACP among a racially diverse sample of dying older adults. The most common reason given by blacks and Latinos for not having an advance directive was: “I don’t need to, my family knows my preferences.” This response, along with the explanation “I’ve never

thought about it," were the top two reasons offered by ethnic minorities, with 69 percent of blacks and 78 percent of Latinos offering these two answers. Whites differed dramatically: only 18 percent said that ACP was unnecessary because their families knew their views. Rather, more than 50 percent attributed their lack of ACP to procrastination, saying things like, "I just haven't gotten around to it yet," and, "I know I need to do this, it's been on my to-do list for a long time."

Yet this lack of ACP among black and Hispanic older adults may prevent them from receiving the treatments they desire. One national study found that among older cancer patients who want aggressive treatments, blacks are one-third as likely as whites to receive such treatment.¹³⁸ Other research shows a substantial racial gap in end-of-life health care costs: in 2001, the average cost of care in the last six months of life ranged from \$20,166 among whites to \$26,704 among blacks and \$31,702 among Latinos.¹³⁹ Fully 85 percent of the race gap in expenditures is accounted for by blacks' and Latinos' greater usage of costly and invasive treatments. Low rates of ACP, in turn, are a key mechanism contributing to a racial gap in quality of death, because lack of end-of-life planning is linked to the use of costly and intrusive treatments, the failure to receive desired treatments, more pain, fewer home-based deaths, and less use of palliative care services.

Socioeconomic Disparities Surprisingly few studies explore social class differences in ACP, yet recent work shows that older persons with lower levels of education, income, and assets and lower homeownership rates have lower rates of formal ACP relative to their wealthier counterparts, although SES is only weakly related to discussions of treatment preferences. Older adults with greater net worth and homeowners are nearly twice as likely as renters and those with no or few assets to do ACP.¹⁴⁰ Wealth may be linked to health care planning in an indirect way, in that older adults with more assets to protect are more likely to do estate and financial planning than are their less wealthy counterparts. A visit to a lawyer to do financial planning may trigger the completion of related documents, including living wills and DPAHC appointments. If a person or couple is completing their will, they may decide to draft their living will at the same time.

Planning is not linked to financial resources alone. Older adults with more education are more likely to plan, whereas those with lower levels of literacy are less likely to do so. One recent study of patients age fifty-five to seventy-four found that rates of ACP were 12.5, 25, and 50 percent for those with low, marginal, and adequate literacy, respectively.¹⁴¹ Low literacy may be linked to limited knowledge about specific health conditions and possible treatments at the end of life. This lack of knowledge

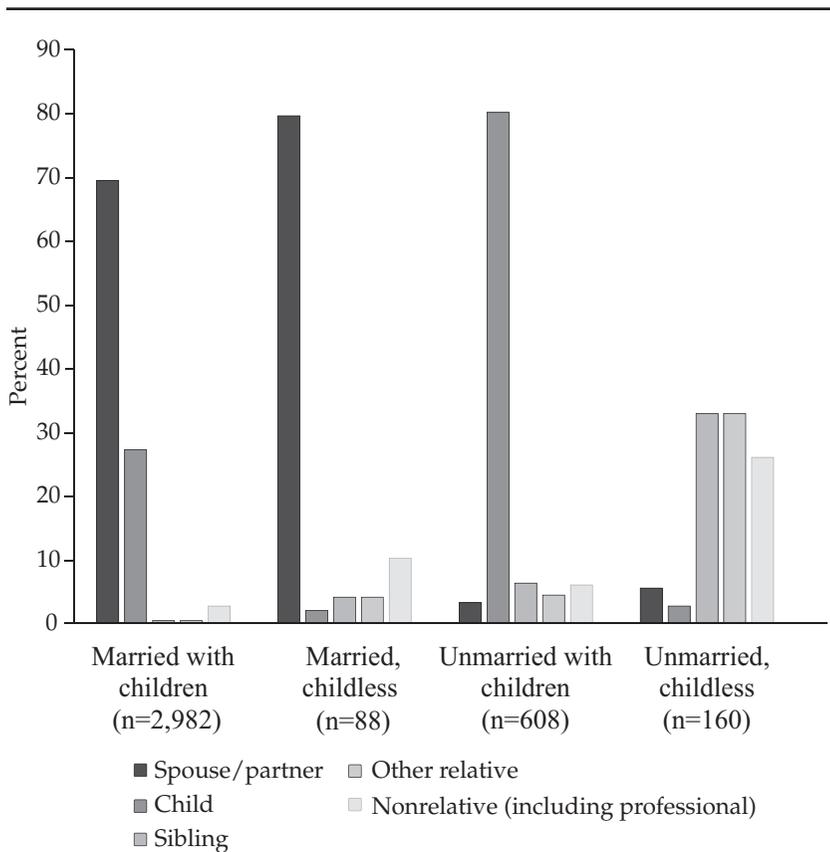
and uncertainty may impede ACP, as older adults often are reluctant to make decisions about treatments they do not understand.

Social Isolation or Integration The bleak platitude that “we die alone” has been attributed to everyone from director Orson Welles to contemporary folk singer Loudon Wainwright, to seventeenth-century philosopher Blaise Pascal’s *Pensées*. In reality, very few people die alone, and ACP helps to ensure that family members know, understand, and feel empowered to carry out the end-of-life treatment preferences of their loved one. Not surprisingly, both whether one does ACP and its effectiveness are tightly linked to one’s social integration and connectedness. People with close-knit and harmonious relationships are more likely than those with troubled relationships to prepare an advance directive. Married older adults whose marriage is marked by high levels of warmth and low levels of conflict are more likely to appoint their spouse (versus an adult child or someone else) as their DPAHC.¹⁴²

For older adults who do not have close family members, however, ACP is either left undone or delegated to individuals who have less intimate knowledge of their values and preferences. This is particularly the case for unmarried and childless older adults. Single, separated, and divorced people are much less likely than their married peers to discuss end-of-life issues with friends or extended family—presumably because they do not have a close confidant with whom to share such highly personal and potentially intimidating conversations. They also tend to name as proxies more distant family members who may not be as well informed about their preferences.¹⁴³ As figure 8.3 shows, among WLS respondents, nearly all married parents (96 percent) chose a spouse or child as their DPAHC; 69 percent selected their spouse, while 27 percent named a child. Fewer than 2 percent of married parents chose another relative, a friend, or a professional. Among married childless persons, the majority named their spouse (80 percent), while a similar proportion of unmarried parents named a child as DPAHC. Very different patterns emerge among unmarried, childless older adults. Equal proportions named a sibling or another relative (33 percent each), while another 16 percent chose a friend or coworker, and a handful named a romantic partner, such as an ex-spouse, or a professional, such as clergy, as their DPAHC designee.

At face value, these choices may not be problematic. Yet in practice, older adults have more frequent contact and meaningful communication with their spouses and children compared to other relatives, friends, and professionals. And given the very low rates of end-of-life discussions among unmarried older adults, it is likely that their DPAHC designees are not as well informed and thus less capable of effectively con-

Figure 8.3 Durable Power of Attorney for Health Care Appointments Among Wisconsin Longitudinal Study Respondents, by Marital and Parental Status, 2003–2004



Source: Carr and Khodyakov 2007.

veying the older patient's preferences to health care providers. These results underscore the powerful ways in which social isolation undermines all aspects of older adults' experiences in both life and death.

Diverse obstacles—economic, informational, structural, and interpersonal, as well as public policies, including Medicare and Medicaid reimbursement structures—may impede older adults' access to pain medication, hospice care, the opportunity to die at home, and other benefits that accompany a good death. Given the large and growing numbers of older adults who will require end-of-life care in the coming decades, practitioners and policymakers have been especially intent on develop-

ing cost-effective strategies and policies to enhance the quality of end-of-life care. Placing decision-making responsibility in the hands of older patients and their families, regardless of their personal resources, has been facilitated by developments like increasing reliance on POLSTs and reimbursing physicians for conducting an ACP consultation session with their Medicare beneficiary patients. However, these practices require careful monitoring to ensure that they are effective. The Institute of Medicine has called for developing quality-of-care metrics and tying insurance reimbursement to these metrics.¹⁴⁴ Ideally, these indicators would capture an alignment of the patient's goals, values, and preferences, as articulated in a living will or POLST, the documented treatment plan, and the treatment ultimately delivered.

An equally important goal is raising awareness and utilization of hospice care, given its widely documented benefits. Yet experts recognize that the expansion of hospice care and the rapid growth of for-profit providers carry potentially negative consequences for patients and their families.¹⁴⁵ Innovative solutions include changes to how Medicare reimburses hospices; considerably higher reimbursements could be offered for those patients who have more complex medical conditions or who do not have family members or the support system necessary to help with less intensive daily care, which thus becomes the responsibility of hospice care workers.¹⁴⁶ Other approaches would be developing more refined measures of the quality of care delivered and keying Medicare reimbursements to quality as well as types of hospice services offered. These practices might allow older adults, regardless of their family ties, economic resources, or knowledge of end-of-life policies and procedures, to die comfortably, peacefully, and on their own terms.