

How do we die?

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ABSTRACT. Within the next two decades, the elderly population in the United States will reach its zenith, comprising 73 million individuals, 20 percent of the nation, the baby boomers' final surge. The process of their dying may become contentious. Should policymakers and bioethicists be satisfied with our current approach to dying, or should they begin now to reconceptualize it? We distill end-of-life discussions in the bioethics literature and popular press, paying particular attention to physician-assisted suicide and its uptake where legal. Evidence so far indicates that few of the dying opt for this alternative, suggesting that its role in assuring "death with dignity" cannot be, as may have been hoped, a leading one. The end-of-life literature on the whole lends credence to the fear that most of the dying, along with their families and physicians, will muddle through a morass of uncoordinated options, with futile medical intervention the most prominent outcome — despite more palliative strategies, such as home hospice care, being favorably described. We found no reason to recommend persistence in our current approach to dying and found good reason to urge early, conscientious, and thoroughgoing reconceptualization in policy and practice as well as in theory.

Key words: Assisted suicide, hospice, palliative care, death with dignity, end-of-life care

Occasionally, the question of how we die hits the headlines with a sensationalist splash. In the 1990s, Jack Kevorkian, dubbed "Dr. Death" by the media, provoked animated debate about euthanasia after helping more than 100 patients die using machines of his own invention.¹ Terri Schiavo's death in 2005 precipitated a national dialogue on living wills; she spent 15 years in a persistent vegetative state until, finally, after protracted family and political battles involving multiple courts, Congress, and even President George W. Bush, artificial life support was removed.² In 2014, 29-year-old Brittany Maynard was diagnosed with incurable brain cancer and moved to Oregon to avail herself of that state's right-to-die law, and her actions and activism inspired the implementation of California's physician-assisted-dying law in June 2016.³ In the wake of such spectacles, discussion about how we die recedes from public dialogue. However, along lonely hospital corridors and in moments of quiet anguish,

family members of the dying, and the dying themselves, continue to confront the question. In the 21st century, the process of dying can take anywhere from days to a decade, and most people can expect to face a protracted period of physical decline and some dependency. Thus, it has been argued, death may come "very slowly and too late" for many.⁴

Currently, demographic changes draw attention to the fact that most of us are ill prepared for the indeterminate length and quality of the time preceding death. The aging U.S. population is expected to reach its zenith in 2030,⁵ which means a burgeoning number of us will be facing the process of death and its attendant difficulties in the immediate decades to come. According to the U.S. Census Bureau, the entire baby boomer generation will have joined the ranks of the older population by 2030. By that year, the number of Americans over the age of 65 years will reach 73 million, representing 20 percent of the U.S. population — up from just 14 percent in 2012 (an increase of 30 million aging individuals).⁶ A critical task of policy makers and bioethicists in this coming era will therefore be to consider questions of ongoing ethical import centered

doi: 10.1017/pls.2016.12

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on our experience of death and engage the public at large in this discussion. By dispelling the taboo against talking about death among physicians and the public alike, we can prepare people for the end of life, while improving its quality and mitigating the substantial financial and emotional costs that it exacts. There is much still to be done to enhance the experience, if not the inevitable outcome, of dying, through personal planning and public policy alike.

In recent years, public discussion about how we die has often focused on physician-assisted suicide. Four states (Oregon, Washington, Vermont, and California) have legalized it, and much consideration has been given to the topic in the policy and bioethics literature.^{7,8,9} Certainly, the ethical and legal dimensions of physician-assisted suicide deserve attention. In 2010, the *New York Times* reported that all people in Washington state who died under the auspices of the assisted-suicide law cited “loss of autonomy” as a reason for their choice to seek assistance in taking their own lives before their fatal illness could do so.¹⁰ Indeed, for some individuals, improving the experience of death is closely related to the issue of personal autonomy — in the case of physician-assisted suicide, autonomy involves having the ability to take a legal and active role in deciding when death should come, and thus eschewing the profound disability and decline that often accompany the process of dying.

However, the issue of physician-assisted suicide is arguably not of the greatest relevance to most people’s everyday lives or, in this case, everyday deaths. Although 68 percent of Americans support the idea of physician-assisted suicide and euthanasia in principle,¹¹ many of these people will not, whether for legal or other reasons, choose to pursue it for themselves. Even among the terminally ill individuals who make arrangements for assisted suicide, a substantial proportion ultimately do not choose to pursue this option. For example, in 2014, 105 of the 155 patients who had been prescribed lethal medications under the provisions of Oregon’s Death with Dignity Act (DWDA) actually took them,¹² accounting for less than one-third of 1 percent of all deaths in the state. In fact, in the years 2012 to 2014, more Oregonians (99) died annually of heroin overdoses on average than died from drugs prescribed under DWDA during that same time period, when the average annual number of physician-assisted deaths was 87.¹³ In 2015, the number of DWDA prescriptions written in Oregon jumped to 218, doubling the previous average annual increase of 12 percent; however, only 132

patients opted to take the lethal dose.¹⁴ In Washington state, a similarly small number of terminally ill citizens availed themselves of the legal right to assisted suicide in 2014: 126 of 176 patients took the lethal medications they had been legally prescribed and died as a result.¹² Figure 1 shows rates of physician-assisted suicides in the first years of implementation in Washington and Oregon as well as the most recent annual data that these states have reported.^{15,16}

Individuals who choose physician-assisted suicide actively make a decision about how to die. However, when approaching death, many people will follow a style of decision making that has more in common with what political scientist Charles Lindblom described as “the science of muddling through”¹⁷ — taking incremental steps based on incomplete knowledge without a comprehensive understanding of whether those steps might lead them to a desired end, which they are unlikely to have clearly defined. In the application of this inexact science, the fields of public policy and bioethics may offer meaningful guidance to individuals and their families who too often needlessly approach the daunting decisions of their dying days unprepared and alone.

To establish a firm foothold from the outset in our journey toward death, bioethical debate must address the perils of various slippery slopes. Many worry about the pernicious potential for the overuse of assisted suicide or euthanasia, but legal restrictions currently hold these practices at bay and our limited experience with the former practice suggests its adoption will not be widespread. A slippery slope of more immediate concern for many people is the continued overuse of treatments that may extend the life of the dying but impose no small measure of misery upon patients and their loved ones. Such treatments, whether overtly aggressive or seemingly routine, can create a condition of incrementally longer life that many would not consider worth the painful cost at which it was purchased. As Atul Gawande writes, “ultimately, death comes, and no one is good at knowing when to stop.”¹⁸

Bonnie Stabile, one of the authors of this article, traversed such a slippery slope when her 81-year-old mother, Laura Brendel, reluctantly had a pacemaker implanted. Laura experienced her first episode of acute delirium upon hospitalization for the procedure, and her heart reliably pumped throughout her subsequent six-year descent into a dementia marked by constant hallucinations and relentless physical and mental deterioration before her death in 2010. For other families, the first faltering steps along the slope are taken when

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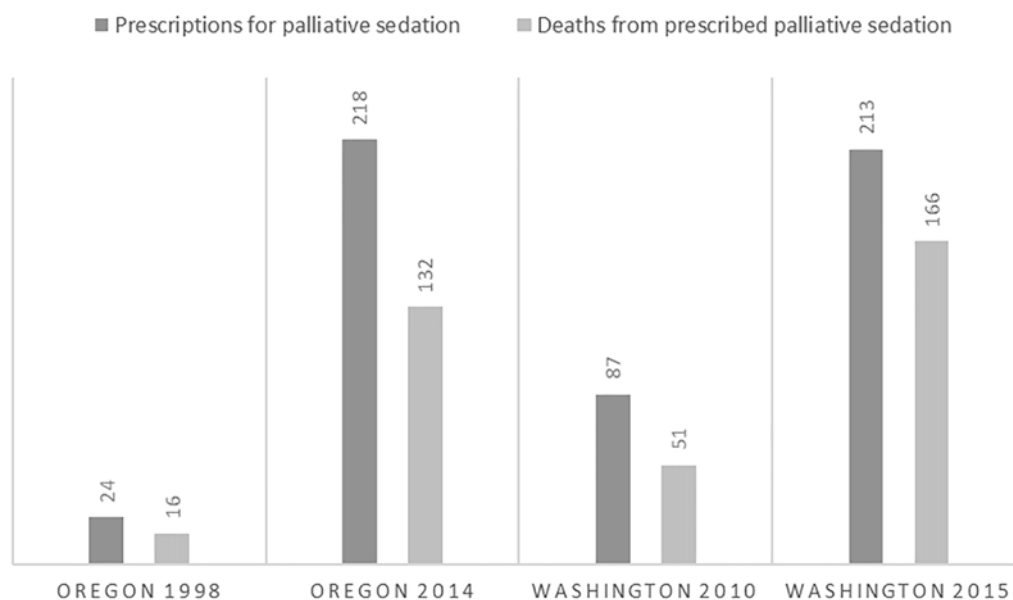


Figure 1. Physician-prescribed palliative sedation and resulting deaths in Oregon and Washington during the first and most recently reported years of legal physician-assisted deaths. For Washington, “Taken” indicates “died after ingesting the medication.” In 2010, 15 people in Washington who were prescribed medication died without ingesting the medication; the ingestion status is unknown for the remaining 6 people who died. In 2015, 24 individuals in Washington who were prescribed medication died without ingesting it; the ingestion status is unknown for the remaining 12 people who died. Sources: Oregon Public Health Division, 2016;¹⁵ Washington State Department of Health, 2015.¹⁶

a “79-year-old man with a 5-year history of metastatic thyroid cancer plus emphysema and chronic obstructive pulmonary disease” receives a gastrostomy tube¹⁹ or when a soon-to-be octogenarian who had a debilitating stroke and developed an inguinal (intestinal) hernia is fitted with a pacemaker to treat his slow heartbeat prior to the operation to fix his hernia.²⁰

Often, physicians are not prepared for end-of-life care discussions with patients and their families. Few medical students receive end-of-life education, although most physicians believe it is the responsibility of physicians to help their patients and families through the end-of-life process (including bereavement services).²¹ A 2003 study on education in American Medical Association-accredited universities found that only 18 percent of students completed a course on end-of-life care.²¹ A substantial minority of medical students in that study identified that they were not well prepared to discuss their patients’ fears of dying. Almost half of the students surveyed (47 percent) felt unprepared to deal with their own emotions concerning patients’ deaths.

Over the past decade, the number of medical fellows completing palliative care rotations has increased;

however, more than 25 percent of the hematology and oncology fellows who participated in a 2013 survey “reported not being taught to assess prognosis, when to refer a patient to hospice, or how to conduct a family meeting to discuss treatment options.”²² Many physicians continue to indicate that they lack of exposure to palliative care and that little emphasis placed on end-of-life care during medical school.²³ It seems as though medical professionals are forced to learn and become comfortable with their end-of-life care while on the job, as their encounters and discussions with patients and family members increase. Physicians’ level of comfort with end-of-life care is important, as it likely affects their willingness to adhere to patients’ wishes. A 2013 survey found that a physician’s willingness to comply with patients’ end-of-life care requests increased with years of experience.²⁴

Even individuals who are educated, famous, and otherwise seemingly savvy about life’s journey are often at a loss for how to proceed in the face of impending death. Bioethicist John D. Lantos described his own sense of impotence and indecision in making end-of-life decisions for his physician father, despite having an

advance directive in hand and a lifetime of experience with medicine and ethics.²⁵ Susan Sontag was the insightful author of *Illness as Metaphor* and many other lauded works, but she nevertheless died badly — as recounted by David Rieff in *Swimming in a Sea of Death: A Son's Memoir*, she suffered unduly in her final days, unable to discern that further treatment for her lethal blood cancer could bring her only pain and offered no meaningful hope for survival.²⁶ In the latest of her *Passages* books, Gail Sheehy chronicled her caregiving struggles during her husband's 17 years of living with cancer. After too many futile procedures and visits to the emergency room, Sheehy finally gave up the fruitless fight and “wheeled him out of there with the needles still in his arms.”²⁷

The widespread discussions of the end of life in the bioethics literature and the popular press suggest that we have not yet hit upon a satisfactory way to die. We feel great anxiety when choosing between our personal autonomy in death and time spent with family. Some of us will approach death with our eyes wide open and our sense of humor intact. Columnist Art Buchwald, who checked himself into hospice, recorded his own video obituary and quipped “I never realized dying was so much fun.”²⁸ But most of us do not want to make decisions about end-of-life care, or even talk about dying.²⁹ Even at the end of a life well lived, our ability to rationally accept death can be limited, even though we know it is coming. After all, saying goodbye can be profoundly, achingly sad, and holding on until the bitter end — surviving — is a natural instinct. Making that inevitable end less bitter — some would say more dignified^{30,31,32} — is the goal before us.

For a few, dignified death might involve autonomously deciding on its appointed hour. For a multitude of others, a dignified death could be achieved in the presence of a community of care that embraces us in our dying and dependency with the same tenderness that welcomes us in our vulnerable state at life's beginning. As Ira Byock, director of the Palliative Care Service at Dartmouth-Hitchcock Medical Center, has rightly pointed out, people who are dying are possessed of their own inherent dignity, by virtue of being human.³³ The process or means of dying neither denies nor confers dignity. Rather, those who are dying are deserving of deaths in circumstances that treat them with respect and compassion. Of course, the palliative care movement has made progress toward achieving such conditions, but more must be done before the dying days of the baby boom detonate with full force.

It has been suggested that better marketing of hospice and palliative care could help more people to make “a good finish.”³⁴ Indeed, the first rule of marketing is to educate consumers — let them know why they need your product. The demand for and availability of hospice programs have grown as public awareness of these programs has expanded. In 1974, there was only one hospice program in the United States, in Branford, Connecticut;³⁵ by 2014, the number of programs had risen to more than 6,100 nationwide.³⁶ If more people knew about the options and implications of palliative and hospice care earlier in the process of reaching life's end, many could avoid muddling through a morass of uncoordinated, aggressive interventions. Instead of stumbling onto the slippery slope toward an overly medicalized death, patients could exercise the autonomous choice to end their days in an environment of comfort and support.

However, selling this seemingly sensible approach to a larger market may not be easy. Because a prevailing metaphor for illness and death has been that of an enemy to be conquered at any cost, people may resist palliative measures if ostensibly curative therapies are imaginable. Also, because Americans have rarely approached medicine with a “less is more” attitude, we may suspect that some recommendations for holding back hospital-based interventions could be motivated by concern for the financial bottom line of the family, insurance company, or government. Who can we trust? When should we begin to consider palliative measures? Who will coordinate balkanized views of patient care to help discern the best path for each individual?

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