

# End-of-Life Care Issues: A Personal, Economic, Public Policy, and Public Health Crisis

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Advance directive documents are free, legal, and readily available, yet too few Americans have completed one. Initiating discussions about death is challenging, but progress in medical technology, which leads to increasingly complex medical care choices, makes this imperative.

Advance directives help manage decision-making during medical crises and end-of-life care. They allow personalized care according to individual values and a likely reduction in end-of-life health care costs.

We argue that advance directives should be part of the public health policy agenda and health reform. (*Am J Public Health*. 2013; 103:e8–e10. doi:10.2105/AJPH.2013.301316)

## IS END-OF-LIFE CARE A MATTER

of personal values, economics, public policy, or a looming public health crisis? Actually, it is all of these. But when we consider the population's demographic shift to older adults, which is associated with chronic illness and multiple comorbidities, the enormous health care costs consumed in end-of-life care, and complex ethical issues, it is time for the public health community to put this issue squarely on its agenda. Increasing the rate of completion of advance directives is a key step, and specific policy strategies can be identified to accomplish this objective.

Advance directives were created by federal and state law to ensure autonomy of patients who eventually become unable to make decisions for themselves.<sup>1,2</sup> Advance directives are free, legal, and straightforward forms that can be completed in a few minutes. Typically, advance directives address several areas regarding end-of-life care when a person becomes unable to make medical decisions for himself or herself. First, a person defines the amount and kind of care he or she might receive under various medical circumstances. Second, a person designates a health care agent to make medical decisions when the person can no longer do so. Third, advance directives may also address other end-of-life care issues including organ donation, whole body donation to medical schools, funeral and burial arrangements, legacy recordings for posterity, and—in 3 states (Oregon, Washington, and Montana)—assisted dying.

## RATE OF AMERICANS WHO HAVE COMPLETED ADVANCE DIRECTIVES

The question of rate of completion across the general population arose as we worked on public policy questions in the Maryland legislature relating to end-of-life care (the lead author is a Maryland State Legislator).<sup>3</sup> Although data are collected on almost every aspect of health care, this is one area where data were scarce. Previous studies that have investigated the frequency of advance directive completion were focused on selected populations of people already confronting end-of-life care issues: nursing homes, senior centers, or oncology practices.<sup>4–8</sup> Information about the prevalence of advance directives across the general population was lacking, which posed a challenge to the development of evidence-informed policies.

Therefore, we initiated a study to investigate the frequency of advance directives and people's attitudes toward them.<sup>9</sup> Our study focused on Maryland, but because Maryland's population demographics are fairly similar to those of the United States,<sup>10</sup> what we learned has broad application for policymaking in this area.

Our study<sup>9</sup> revealed that more than 60% of individuals aged 18 years and older want their end-of-life wishes to be respected; however, only about a third of them had completed advance directives. People had given thought to the question of end-of-life care, but a majority had not completed the forms. What were the reasons

people did not complete advance directives? About a quarter of those who did not have an advance directive said they did not know about them. Others felt they were too young or healthy to complete them or were concerned about the cost, complexity, or time that might be required to do so.

We also found that people wanted to obtain information on advance directives from their doctors or other health care providers. They preferred this to getting information from attorneys, clergy, or online sources. This means that health care providers have an important role to play. One of us (DM) has written a book, *The Better End: Surviving (and Dying) on Your Own Terms in Today's Modern Medical World*, to help encourage this discussion in families and with providers.<sup>11</sup>

Our study also revealed significant differences among racial and ethnic groups in the rate of completion of advance directives. About twice as many Whites as African Americans completed advance directives. The difference between Whites and African Americans regarding the prevalence of advance directives is likely attributable to several factors, including cultural differences in family-centered decision-making, distrust of the health care system, or poor communication between health care professionals and patients.<sup>12,13</sup>

## ECONOMIC FACTORS

The number and proportion of those aged 65 years and older in the United States is rising steadily.

In 2009, there were an estimated 39.6 million people aged 65 years or older, and by 2030, there will be about 72.1 million older persons.<sup>14</sup> As the baby boom generation continues to age and is impacted by chronic diseases and multiple comorbidities, and as medical technology advances, it is inevitable that health care costs will increase.

Completion of advance directives will very likely reduce health care costs. For most Americans, it is estimated that 25% or more of all the health care dollars spent in their entire lives are spent in the last months of life.<sup>15</sup> Money is often expended to keep people alive far past any hope of reasonable recovery, money that could be spent earlier, when the impact would be much greater in terms of quality and length of life.

According to the Congressional Research Service, more of us are dying in the hospital (58%) or nursing homes (20%) than at home (22%).<sup>1</sup> Expenses in institutions are always greater than those at home. One question to address is what portion of deaths in institutions would be more reasonably managed at home? The Congressional Research Service reports that family members of loved ones who died at a private home with hospice services were more likely to report “a favorable dying experience.” Of patients in a hospice program, more than 70% chose to die at home.<sup>1</sup>

Who pays for this care? Costs for end-of-life care may be paid by private insurance, Medicare, or Medicaid, and these may be self-paid. In fact, nearly 30% of all Medicare spending is for the last year of life, and more than 50% of that is in an acute care hospital.<sup>15–18</sup> In the final analysis, we,

as taxpayers, employers, and individuals are all paying for this.

Ten states have advance directive registries to assist clinicians in getting appropriate access to advance directive information in an accurate and timely manner. Expanded use of electronic health records, which was included in the 2010 Patient Protection and Affordable Care Act, should facilitate this.

In the health care reform debate, the term “bending the cost curve” is used. Perhaps new systems, such as accountable care organizations, electronic health records, and “aligning incentives” will help reduce expenses without causing undue harm to patients and providers. In some instances, even standard terminology is changing.

To the extent that expensive, futile, and often painful “care” is forgone, money will be saved in the system. But it will be saved the right way: by respecting the wishes of individual patients, not by paying providers less to do more or by erecting barriers for patients to obtain needed care. For example, a number of hospital systems are now replacing the term “Do Not Resuscitate” with “Allow Natural Death.”

### END-OF-LIFE CARE DECISION-MAKERS

Advance directives are critical to designating when, where, how, and how much care a person wants at the end of life. We believe this care is or should be primarily determined by individuals, and not by government, insurance companies, hospitals, or other outside entities.

Americans are concerned about end-of-life care.<sup>9</sup> Health care professionals should be involved in discussing these issues with their

patients and honoring advance directives when presented with them. This aspect of medical practice needs to be supported and should be viewed as another aspect of preventive care. It is ironic that this was the intent of the so-called “death panel” clause in the 2009 health care reform debate. The clause would have given physicians modest but fair compensation for discussing this important issue with Medicare patients upon their request.

The reality is that the subject of advance directives is not yet a standard part of most medical examinations. It is important that advance directive discussions become routine between doctors, nurses, and other key health providers and their patients, because the more normal the topic is, the less scary it will become.<sup>11</sup>

### IMPLICATIONS FOR POLICY

Increasing the low rate of completion of advance directives in the United States needs to become part of the public health agenda. The prime reason to do this is humanitarian: empowering individuals and families to be actively involved in care decisions at a critical time. In addition, reducing needless or unwanted end-of-life care expenses would allow those funds to be diverted to other pressing public health needs.

There are policies that might address this. Physicians, nurses, social workers, and other key providers should obtain fair reimbursement for having end-of-life care discussions with patients. The rate of completion of advance directives should be a routine part of patient encounters and used as a metric of quality care. Advance directive registries

should be universally available, and the information presented, with proper access, in electronic format. The role of advance directives should be part of medical education and training and incorporated as an aspect of cultural competency. End-of-life care issues could be discussed, as appropriate, at other venues such as the workplace or at faith-based institutions. We would like to see our political and cultural leaders be part of a coordinated campaign effort to promote use of advance directives. For these ideas and others, we believe that the public health community is a critical stakeholder, and efforts should be made to update the American Public Health Association policy statement related to advance directives.<sup>19</sup>

Though we Americans strive to control nearly every aspect of our lives, many of us abandon control of life’s final passage. But the realities of 21st-century medicine will allow most of us to have a say in how, when, and where we die. We are the first generation in human history afforded this unique circumstance, and the implications are far-reaching.

As public health professionals, our job is to find the best, positive, and most effective ways to empower Americans to take full advantage of their options. In the final analysis, it is a matter of individual responsibility, and we hope that having an advance directive on file becomes as routine as getting a driver’s license or a Social Security number. The cost is small, but the payoff is substantial. These complex issues involve personal, spiritual, and cultural values combined with family dynamics and health care economics. Addressing this must become part of the public health agenda. ■

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### Contributors

D. K. Morhaim conceptualized the article and led article writing. K. M. Pollack provided critical review to the article during its draft and final stages.

### Human Participant Protection

Human participant approval was obtained from the Johns Hopkins Bloomberg School of Public Health institutional review board for the survey discussed in the article; however, approval was not needed to write this brief.

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