



Final Moments

Perspective on death

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By John M. Benson

Conventional wisdom holds that modern America is a death-denying culture. Elisabeth Kübler-Ross, who pioneered investigation of the psychological stages patients pass through in reaction to fatal diagnoses, said as early as 1969, "We may want to ask ourselves what happens to man in a society bent on ignoring or avoiding death." More recently, Daniel Callahan argued that our society fails to come to terms with the reality of death, that we are a nation obsessed with trying to control and defeat nature, and that this has resulted in the unconscious belief that modern technology will overturn death.

But public opinion data on the topic are far from conclusive. It is perhaps more accurate to say, as Joanne Lynn has put it, that "we are simply unfamiliar with death, at least with the kind of dying most Americans actually face."

Philippe Ariès, in *The Hour of Our Death*, called the twentieth century the period of "death denied." He argued that this is primarily due to feelings of control over nature, a sense of individual worth, longer life expectancy, and a lack of experience with death. The first two criteria are surely hallmarks of the American character. The latter two point as much to

unfamiliarity as to denial, but are just as surely relevant to Americans' judgment of death.

Americans live much longer than they did a century ago. According to a recent Institute of Medicine report, life expectancy at birth in 1900 was less than 50 years; today it is 77. This change is due mainly to a reduction in infant mortality, which declined 93% between 1915 and 1997. In the United States today, only 2% of deaths involve people under age 15, while 73% die at age 65 or over.

Changes in living arrangements from extended to nuclear families, combined with increasing geographical mobility, have meant that many young Americans have little contact with the nation's most elderly in their final days. As a result, most Americans do not experience the death of a loved one until they become adults. A September 2000 *Time/CNN/Yankelovich Partners* poll showed that fewer than half (45%) of Americans under age 50 have experienced the death of a family member or close friend.

Ariès also spoke of "invisible death," that is, death that occurs in institutions rather than at home among family and friends. In 1949, about half of American deaths occurred in institutions. By 1980 that figure had risen to 74%, including 60% in

hospitals. Today, according to the Institute of Medicine, 57% die in hospitals, 17% in nursing homes, and only 20% at home.

Older Americans tend to die of different causes than those who die young. The dying process for most adults is often extended, while the deaths of younger Americans tend to be more sudden and violent. Unintentional injury, homicide, and suicide, along with cancer and congenital abnormalities, are the leading causes of death for Americans under age 20. Because few young Americans see older relatives die, their experience of death through the media and the occasional traumatic death of a peer tends to be with violent and dramatic causes.

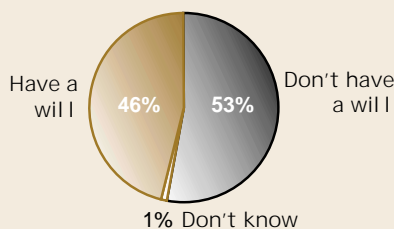
It is not as surprising, then, as it might first seem, that younger adults are more concerned about various aspects of death than older adults are. According to an October 1999 *Los Angeles Times* poll, Americans 18 to 29 years old are significantly more likely (27%) than those 45 and over (17%) to say they often think about death. Interestingly, they are *not* more likely to think about their *own* deaths, according to the *Time/CNN* poll. In fact, here we find the more expected result: Americans 65 and over are more likely (30%) than those under 65 (22%) to think about their own deaths once a week or more.

The *Los Angeles Times* poll shows that young adults are more likely than those 65 and over to be afraid to die (20% to 7%), while simultaneously being more likely to have ever considered suicide (15% to 6%). In the *Time/CNN* poll, younger adults were also far more likely than those 50 years old and over to say they were very fearful of dying in pain (42% to 25%).

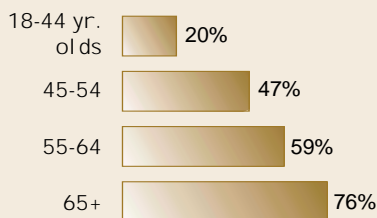
Americans have a generally positive view of medical technology, but they are not interested

Figure 1
Delayed Planning

Question: Do you have a will, or not?



Have a will



Source: Survey by the *Los Angeles Times*, October 20-23, 1999.

in being kept alive if they are incurably ill and have to live in severe pain. In a 1999 Pew Research Center poll, about two-thirds (66%) said they believed medical advances that prolong life are generally good because they allow people to live longer; 29% believed these advances are bad because they interfere with the natural cycle of life. According to a January 1997 *Newsweek* poll, if medical advances in laboratory-made organs became feasible, about half (53%) of Americans would want to live longer, including 24% who would want to live forever, or at least as long as they could. Forty-two percent would prefer to live only about as long as they expect to live now.

But a poll in 2000 by the Harvard School of Public Health and the Robert Wood Johnson Foundation found that if they were terminally ill, 86% of Americans would prefer being kept as comfortable and pain-free as possible, even if it meant not living as long.

Only 10% preferred to have their lives extended as long as possible, even if it meant more pain and discomfort.

Most Americans do not believe modern medicine can cure all illnesses. In a 1994 survey by the Harvard School of Public Health and the Robert Wood Johnson Foundation, only one-third of Americans agreed that with advanced technology modern medicine can cure any illness, while 64% said that many illnesses cannot be cured by any treatment.

When asked in a May 1999 Harvard/RWJ poll which one disease or illness they fear most, a majority (53%) of Americans named cancer and 21% cited AIDS. Both diseases tend to involve a great deal of pain or prolonged suffering. Heart disease, the biggest cause of death, was a distant third (9%), perhaps because it is seen as more sudden. In the *Time/CNN* poll, about two-thirds (65%) of Americans said they were very or somewhat fearful of dying in pain. In the 2000 Harvard/RWJ poll, more than half (54%) expressed the belief that many or most terminally ill people are in severe pain most of the time.

The *Time/CNN* poll showed that nearly three-fourths (73%) of Americans would rather die at home than in a hospital or nursing home (14%). But in a 1995 poll by Harvard/RWJ, less than a third (31%) said if they were terminally ill, it would be very important to them to die at home. In the *Time/CNN* poll, 43% thought they would most likely die at home. While it is unlikely that this many Americans will actually die at home, the trend is moving away from hospital death. The expectation of many that they will die at home may be one sign of denial.

A stronger indication of denial (or at least lethargy) is the relatively small proportion of Americans—even those

age 65 and over—who have wills or living wills. In the *Los Angeles Times* poll, about half (46%) of Americans said they have a will (see Figure 1), although only 36% have updated it to reflect their current wishes (see Figure 2). Not surprisingly, having such a will is largely a function of age. Only one-fifth (20%) of Americans 18 to 44 years old have them, compared to three-fourths (76%) of those 65 and over. But even among this oldest age group, only 60% have updated wills.

In both the *Time/CNN* and *Los Angeles Times* polls, about a third of Americans (30 to 34%) said they have a living will or advance treatment directive that states how doctors should treat them if they can no longer communicate their wishes. In the latter poll, only 19% of Americans 18 to 44 said they have a living will, compared with 54% of those 65 and over.

Albert Camus once wrote, “There is but one truly serious philosophical problem, and that is suicide.” The 1990 Gallup World Values Study found that on a ten-point scale, where 1 meant suicide was never justified and 10 meant it was always justified, 69% of Americans chose points 1 or 2, indicating that they thought it was almost never justified.

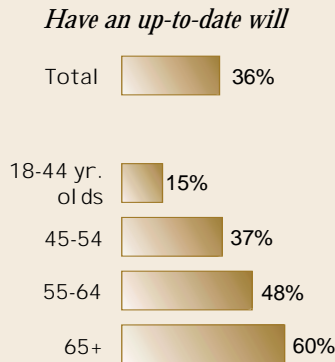
Americans, however, are not totally averse to suicide in cases of terminal illness. About six in ten Americans (61%), according to the 1998 General Social Survey, believe that a person has a right to end his or her own life if that person has an incurable disease. This represents a significant change since 1977, when only 38% supported a right to commit suicide in such cases.

The change probably reflects two developments in American society. One is that during the 1980s and early 1990s, Americans increasingly adopted what might be called a secular human-

Figure 2

Final Wishes Out of Date

Question: ...Has [your will] been updated to reflect your current wishes?



Source: Survey by the *Los Angeles Times*, October 20-23, 1999.

ist view of compassion in this area. The upward trend may also represent an increasing desire by Americans for the availability of choices in difficult situations, even if the respondent might never want to exercise that choice. But rising support for the right to suicide in this particular case should not be confused with a mindless pro-death view, since acquiescence with suicide for other reasons tested in the General Social Survey has not risen appreciably.

According to the *Los Angeles Times* poll, about one in eight Americans (12%) have considered suicide. In a January 1997 Gallup/CNN/*USA Today* poll, about one in four (27%) said they would consider suicide if they had a disease that could not be cured. A March 1999 Gallup/CNN/*USA Today* poll found 40% saying they would consider it if they had an incurable disease and were in severe pain.

It is important to remember that attitudes about “death” issues (or, as they are more often called, “life” issues) can be quite diverse, even apart

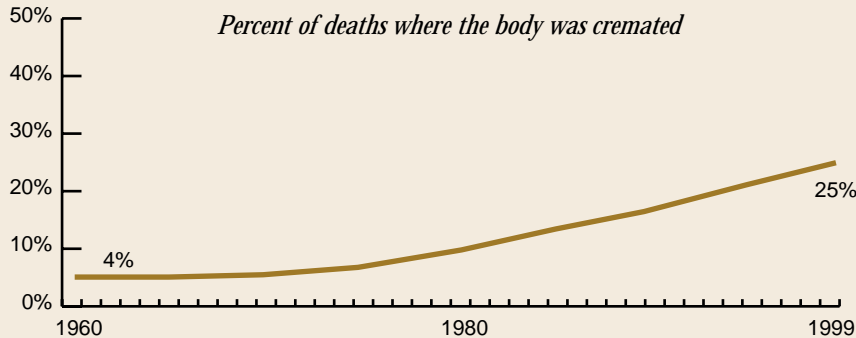
from age. Three issues—euthanasia, abortion, and capital punishment—are part of what Pope John II has called “The Culture of Death,” and which the late American Cardinal Bernardin called the “seamless garment” of the Catholic Church’s teachings on the sanctity of life. But a concern for the sanctity of life is not solely the domain of the Catholic clergy. Highly religious Americans, regardless of their religious preference, are far more likely than the less religious to oppose euthanasia and abortion. Born-again or evangelical Christians are among the most likely to oppose both practices.

Americans also maintain widely differing views on such crucial issues as the nature of death, necessary rituals, expectations of the afterlife, and whether folk medicine or faith healers should be involved in medical practices. A 1997 study by the Gallup Organization for the Nathan Cummings Foundation and the Fetzer Institute is an extraordinary effort to investigate Americans’ spiritual needs at the end of life.

One reason many Americans are able to cope with death is that they have a positive view of what happens afterward. The Gallup/Cummings/Fetzer survey showed that two-thirds (67%) believe they will exist in some form after their death. Of this group, 83% think that experience will be positive (1% negative). Similarly, 72% believe in heaven, and among those who believe or are not sure, 78% think they have an excellent or good chance of going to heaven. Only 3% believe their chances of going to hell are good. According to the 2000 *Time/CNN* poll, most Americans get a great deal (58%) or some (25%) comfort from their religious beliefs when they think about death. Younger adults (18 to 34 years old) are significantly less likely than others (49% to 63%) to say they derive a great deal of comfort.

Figure 3

Growing Preference for Cremation



Source: Cremation Association of North America.

One indication of the diversity in our approach to dying is the increase in cremations in the US. Partly due to religious considerations, such as the Christian belief in the resurrection of the body, burial was historically the dominant means of disposal for dead bodies in this country. But the past two decades have witnessed a rapid growth in cremation as an alternative. According to the Cremation Association of North America, as late as 1965 only 4% of bodies were cremated. The proportion grew to 14% in 1985, and now stands at 25% (see Figure 3).

A 1990 Gallup poll seems to have been a leading indicator, as it found that 65% preferred burial and 26% preferred cremation. A 1999 Wirthlin poll found the main reasons for preferring cremation were that it was less expensive (24%) and uses less land, along with other environmental considerations (17%); but many cited reasons that might be considered primarily religious.

Denial of death is neither uncommon nor necessarily bad. Americans are known to be in denial about other scary vistas, like retirement security and provision for long-term care. Moreover, Ernest

Becker argued in his Pulitzer Prize winning book *The Denial of Death* that human personality and behavior has its deepest roots in our denial of our own death, including the horrors associated with it. In this light, neurosis is seen to be at least partly a result of being unable to construct adequate defense mechanisms.

What we have outlined here are the attitudes of a populace that has largely been sheltered, by historical happenstance or conscious choice, from regular contact with death. Demographic and social changes over the next generation are likely to affect these attitudes.

In the short term, several groups are making an effort to raise consciousness about death and dying. A handful of foundations have devoted ample resources to improving care for the dying. Increasing attention is being paid to the concept of a "good death," one that is free from avoidable distress and suffering for patients, families, and caregivers; in accordance with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical norms.

Most media coverage of death involves its most dramatic and sudden

forms: murders, suicides, car accidents. But recently certain news outlets have begun to look at more common, more prolonged, and less dramatic kinds of dying. These efforts include major series on dying by NPR and the *Boston Globe*, as well as the Bill Moyers PBS special, "On Our Own Terms."

Somewhere between 2020 and 2040, as the Baby Boom generation reaches the end of its lifespan and puts an enormous strain on our nation's medical and social support systems, we are likely as a society to have quite a lot more personal contact with death. We are already witnessing a move away from hospital death toward nursing homes and hospice care that is likely to accelerate. But the nation will find it difficult to pay for institutional long-term care for such a vast number of elderly. As a result, more of the elderly will have to depend on family support, often from children who are themselves old. As Joanne Lynn puts it,

Within the first quarter of the millennium, we will nearly double the aggregate challenge of disability by old age. Death will once again come back home, as we will not use hospitals for most of our old and dying.

Such changes will make it more difficult to "deny" death in the sense that term is usually employed. And certainly we will become more familiar with death. ●

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