

**HEALTH CARE AT THE END OF LIFE**  
*How Realistic and Reverent are Prospects for Cutting Costs?*

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*Author's note.* I started working on this paper in the fall of 2004, but was forced by other projects to break away for several months. In the intervening period, the Terri Schiavo case exploded in Florida, but no less in Washington, DC and across the rest of the nation. The essay that follows was never conceived to focus on the extraordinary issues begged by that episode. It still doesn't aim to do so. Rather, the intent both then and now has been to focus on the many *typical* – albeit, still exceedingly painful and personally unique – dilemmas confronted by dying people and their loved ones every day.

More specifically, my main concerns are not those of fundamental right-to-life debates or family upheavals that degenerate still further into court fights. Piercing questions about euthanasia, likewise, will not be part of this discussion – though even casual readers, I trust, will infer quite the opposite of approbation for physician-assisted suicide and the like throughout the paper. My interest, instead, is on matters much more mundane (if that be the right word), such as finding reverent ways of cutting health care costs at the end of life, plus getting more men and women to sign health directives in the first place. As you may recall, because Terri Schiavo never signed an advance directive or a living will, much of her case pivoted on her husband's claim that she had orally requested, before her illness, "never to be hooked up to machines," or words to that effect. Obviously, had she made her wishes clear on paper, her case likely would have wound up far differently, if a federal case at all.

I say this even though this essay will be replete with maybes and contingencies regarding the effectiveness of legal tools such as advanced directives and living wills. (Definitions are included below.) These qualifiers range from patients changing their minds about the kind of care they want; to their documents' unclear instructions; to family members and physicians not being wedded to provisions previously stipulated by patients; to absurdly simple but nullifying problems such as no one knowing exactly where an advance directive or living will might be – in what draw, file cabinet, or safety deposit box – when it's critically needed.

Still, this paper, appropriately, has come to be informed by the life and terribly sad death of Ms. Schiavo. Those portions of the text should be clear. *MBP*

## (I) Introduction

As you read this essay – and as the U.S. population ages and grows more infirm by the billing cycle – please keep these four, not perfectly consistent quotes in mind.

-- “Most people would ‘spend their last dollar’ to keep their loved ones alive, but would forgo expensive treatments that would prolong their own life.”<sup>1</sup>

-- “The grandmother of one of the authors could not have put it into words more clearly when she remarked that at her advanced age she did not need expensive treatments anymore because ‘these things will only make health care unnecessarily expensive.’”<sup>2</sup>

-- Nonetheless, “[T]he vast majority of Americans who die do not use hospice or advance directives, and even the majority who endorse advance directives in polls find it difficult to actually complete such documents.”<sup>3</sup>

-- And even knowing that: “We know more about the Americans’ preference for cup holders in their minivans than we know about their end-of-life-health-care preferences.”<sup>4</sup>

This paper about health care at the end of life has two main aims.

The first is to consider if there are, not just feasible, but wholly respectful and ethical ways of saving significant amounts of money in the final days, weeks, and months of our lives when almost all of us will require more abundant health care? The answer is yes, but not simply so.

The second goal is to consider how death can be made more bearable, not just for those who are sick, but for their family and loved ones, too. How must public policies change if we are to die in less pain and in deeper peace? More importantly, how must personal behaviors and cultural attitudes change? Against stubborn grains, is the shorthand answer here.

Several points and definitions are needed before going further.

One might ask, exactly what is the presumed connection between a citizen’s “good” death and his or her government? (No reference to the Schiavo case is implied here.) Is such a supposed pairing merely one more – in this instance, an especially grievous – example of Americans looking hopefully to a “Nanny State” for what no state, no matter how large its ambition or profligate its spending, is equipped to deliver?

The short answer is no, as the point to be made here is simply that dying is already financed largely by government – mainly through Medicare – as it has been for decades. This examination is not a pitch for giant new entitlements. Rather, it recognizes that government (and not just Washington) is already intimately involved in how Americans

die and that, without thirsting for major new responsibilities in this area, public agencies can and should do some things differently and better.

Before going on, we also need to define three terms: “palliative care,” “hospice” and “advance directives.”

-- Palliative care is intended to enhance comfort and improve the quality of life during an individual’s last phase of life.<sup>5</sup> Palliative care programs “structure a variety of hospital resources – medical and nursing specialists, social workers, clergy – to effectively deliver the highest quality of care to patients with advanced illness,” with intensive pain and symptom control integrated at every stage of treatment.<sup>6</sup>

-- Hospice is a specialized form of care for patients in the final stages of terminal illnesses, providing support for dying individuals and their families and other loved ones. Hospice emphasizes “the quality of life” in a person’s last months, weeks, or days. It focuses “on the person, not the disease.” And it provides relief from the many types of pain – physical, emotional, and spiritual – that are parcel of terminal illnesses.<sup>7</sup> Hospice care can be offered in various settings: acute care hospitals, nursing homes, freestanding “residential” hospices, and (most frequently) in a patient’s home. Dame Cicely Saunders, a London physician, is credited with being the founder of the modern hospice movement in the 1960s.<sup>8</sup>

Distinctions on the definitional surface, obviously, between palliative care and hospice can be subtle to a confusing fault. In an attempt to clarify, my wife, the Rev. Diane McGowan, who is trained as a hospital and nursing home chaplain, writes that with palliative care, patients “might, in fact, continue receiving active medical treatments, as opposed to hospice care, in which active treatments cease.” Who am I to amend my wife under such circumstances? But I would add that while palliative care and hospice are both *approaches* to end-of-life care, only hospice can refer to a physical *place*. Or, if you will, nurses, clergy and other comforters *do* palliative work, often *in* a hospice.

(Just to complicate matters a bit more, I refer later in the paper to a bill proposed by U.S. Sen. Ron Wyden of Oregon that would give Medicare patients the right to receive hospice care and curative treatments simultaneously.)

-- An advance directive (and variations on the term) is a written document that guides health care decisions in the event a person becomes unable to communicate such matters on his or her own. It enables individuals to do one or both of the following: Name a person or persons to make critical health care decisions on his or her (i.e., the patient’s) behalf; and/or state his or her wishes about the kind of care he or she wants.

“Health care directives” (Minnesota’s preferred locution) combine the general purposes of living wills and durable powers of attorney for health care.<sup>9</sup> Typical language includes provisions such as: “If I am unable to decide or speak for myself, my agent has the power to: “Consent to, refuse, or withdraw any health care, treatment, service, or procedure”; and “Stop or not start health care which is keeping or might keep me alive.”<sup>10</sup>

The term “advance directives” is sometimes used interchangeably with “living wills.” Likewise, terms such as “health care power of attorney” and “durable power of attorney” are also sometimes mentioned in the same implicit breath. Technically, though, and as noted shortly below, advance directives are not synonymous with living wills and durable powers of attorney. Rather, advance directives contain and subsume the purposes of living wills and durable powers of attorney.<sup>11</sup>

Linked to this essay are a sample “Minnesota Health Care Directive” and a sample Health Care Instructions Worksheet,” both courtesy of the University of Minnesota Extension Service and the Minnesota Board on Aging. Also linked is similar information from a joint publication of the American Association of Retired Persons, the American Bar Association Commission on Legal Problems of the Elderly, and the American Medical Association.

## **(II) Numbers**

The discussion also needs a statistical frame and context. Here are a dozen sets of key and sobering data.

-- Spending on health care in the United States is the highest of any industrialized nation in the world, making up almost 15 percent of our gross domestic product.<sup>12</sup>

-- Government directly pays for health care for more than one-quarter of the U.S. population. This translates into approximately 44 percent of all medical care consumed in the country.<sup>13</sup> If one takes into account tax exemptions for insurance premiums and out-of-pocket spending, government is directly and indirectly on the hook for about 75 percent of all medical care in the United States.<sup>14</sup>

-- In 1950, 9 million Americans (7 percent) were older than 65. In 1990, 31.7 million Americans (12.3 percent) were over 65. Over the first decade of the current century, the over-65 population will grow by 13-14 percent.<sup>15</sup>

-- Between 2010 and 2030, the over-65 population will double. By 2030, approximately 20 percent of Americans, or 70 million men and women, will be 65 years of age or older.<sup>16</sup> Medicare and Medicaid will “bear the brunt of this strain.”<sup>17</sup>

-- Medical care at the end of life consumes about 10 percent to 12 percent of total health care spending in the United States, and 27 percent of Medicare budgets.<sup>18</sup>

-- More than two million people die in America every year, with Medicare serving more than 80 percent of them.<sup>19</sup>

- In 2005, the federal government will spend \$481 billion on Medicare and Medicaid (including the State Children’s Health Insurance Program, which is an offshoot of Medicaid). This will be more than the \$478 billion that Washington will spend on national defense and homeland security combined.<sup>20</sup>
- Large disparities exist in the number of days Medicare patients spend in the hospital during the last six months of their lives, ranging from a low of 4.4 days in Odgen, Utah to a high of 22.9 days in Newark, New Jersey.<sup>21</sup>
- Hospice costs represent only 1 percent of Medicare spending annually.<sup>22</sup>
- The average premium for a family health insurance policy is more than \$9,000. This represents 21 percent of the national median household income of \$42,409. We spend about \$5,540 per person on health care annually in the United States.<sup>23</sup>
- The number of people without health insurance in the nation is about 45 million.<sup>24</sup>
- On the brighter side, there is “plenty of evidence to suggest that these health care investments have paid handsome dividends,” as life expectancy in the United States has increased from 47 to 77 over the last century.<sup>25</sup>
- One in four people in the United States now dies in a nursing home. By 2020, the ratio is expected to increase to nearly one in two people.<sup>26</sup>
- Medical Assistance spending on skilled nursing facilities and home care represented almost one out of every ten dollars spent on health care in Minnesota in 2000.<sup>27</sup>
- Only about 18 percent of Americans (presumably adults), in one study, reportedly have living wills or advance directives.<sup>28</sup> The proportion was less than 15 percent in another study.<sup>29</sup>

### (III) Money

One of the more intriguing problems in the debate over health care costs at the end of life is discerning how big is big and how small is small.

A Canadian health care organization, for example, recently argued that the “perception” that the costs of treating the dying “drives up” medical budgets is longstanding, but it has been “debunked” by 30 years of research in North America and Europe. In fact, according to the Canadian Health Services Research Foundation, end-of-life costs “tend to account for a *minority* of total costs to health care systems . . . .” More precisely, one of the foundation’s regular “Mythbusters” reports says, “healthcare costs during the last

year of life account for *only* about 10 to 12 percent of total healthcare budgets (emphases supplied).”<sup>30</sup>

Please recall that 10 to 12 percent is the exact range I cited a few pages ago for end-of-life health care costs in the United States specifically.

Beyond noting that a “minority” of health care costs could be as high as 48 or 49 percent, permit me to pose a respectful question: Given that average life expectancy in the United States is a lengthy 78 years,<sup>31</sup> and that we are getting close to spending \$2 trillion annually on health care,<sup>32</sup> is it really fair and proportionate to suggest that devoting, on average, 10 to 12 percent of health care dollars to the final dozen months of life can be said to qualify for the prefix “only”? Or is fairer to assume that approximately \$200 billion (one-tenth of \$2 trillion) is a reasonably hefty sum no matter how humanely it’s spent?

Dr. Ezekiel J. Emanuel is one of the leading debunkers in the field, as he has been masterful in pointing out the methodological flaws in studies which attribute often giant cost savings to the use of advance directives and hospice in the final stages of life. His main arguments (which we will get to in a second) are persuasive. Still, it’s fascinating that he has claimed that the debate is composed of “more rhetoric than reality,” insofar as “what savings there may be from hospice and advance directives are comparatively small.”

Yes, savings may well prove “comparatively” small. But is it fair to describe that conclusion as *absolutely* so, at least as denominated by true-blue green dollars? One of the assumptions of this paper is that even if end-of-life costs can be reduced by a paltry *one percent* – not much more than a proverbial rounding error – that would still represent a savings of \$2 billion. (Two billion dollars is one percent of \$200 billion, which Americans shortly will be paying annually for end-of-life care, if we aren’t already.)

Breaking down these impossible-to-fathom numbers further, Minnesota, with about 5 million people, represents just slightly less than 2 percent of the American population. Two percent of \$2 billion is \$40 million. I take it as gospel that it would be a good and consequential thing – no penny-ante matter at all – if Minnesotans could be involved with saving \$40 million annually. (Or to err on the side of financial modesty, and recognizing the lack of sophistication in these calculations, it would be a good and consequential thing if Minnesotans could contribute to *slowing down* spurts in health spending by \$40 million a year.)<sup>33</sup>

More encouraging and promising, another assumption of this paper is that if Americans in general and Minnesotans in particular took substantially more conscientious advantage of advanced directives and hospice services than we currently do, health care savings at the end of life could add up to considerably more than that measly one percent. At that point, paraphrasing an old line commonly attributed to the late-Senator Everett Dirksen, we could be talking about *real* money.<sup>34</sup>

Let's return to Emanuel's analysis.

Writing in 1996, and as previewed above, he noted that, "Many people claim that increased use of hospice and advance directives and lower use of high-technology interventions for terminally ill patients will produce significant cost savings." However, he cautioned, studies that suggested larger savings than what he thought feasible consistently suffered from one or more of the following five methodological flaws: (1) selection bias in the very patients who use advance directives and hospice in the first place; (2) the use of different time frames in assessing costs; (3) limited types of medical costs evaluated; (4) variability in the reporting of savings; and (5) the lack of generalizability to other patient populations. He looked forward to someone conducting a more scientifically rigorous study, but until then, and based on then-existing data, he concluded this way:

[H]ospice and advance directives can save between 25% and 40% of health care costs during the last month of life, with savings decreasing to 10% to 17% over the last 6 months of life and decreasing further to 0% to 10% over the last 12 months of life. These savings are less than most people anticipate. Nevertheless, they do indicate that hospice and advance directives should be encouraged because they certainly do not cost more and provide a means for patients to exercise their autonomy over end-of-life decisions.<sup>35</sup>

The obvious question at this point is how Emanuel could simultaneously write (as he did, for instance, two years earlier) that prospects for saving a great deal of money at the end of life are an "illusion,"<sup>36</sup> and yet still talk about savings as high as 40 percent in the critical last month of life? Much of the answer has to do with the number of people who are inclined ("determined" is really the better word here) to "sign up" for advance directives. And who then, no less importantly, maintain the fortitude (Emanuel's word) to hold fast, to the very end, to their directives' medically non-heroic provisions.

He writes, in a concluding section on policy implications: "[T]he vast majority of Americans who die do not use hospice or advance directives, and even the majority who endorse advance directives in polls find it difficult to actually complete such documents." In light, various studies can generate "maximal" estimates of savings in an "idealized world we can dream about," but they are "not accurate predictions about actual savings to shape policymaking."<sup>37</sup>

Put aside any dizziness from trying to follow the dancing financial ball. Suffice it to say we *may* be talking about saving a lot of money, potentially. Instead, please focus on the next big questions: What it would take for many more people, not just to complete and sign advance directives, but also not waver from their restraints? Similarly, what would it take for people to take greater advantage of hospice? And what public policies, cultural values, and complexities of dying themselves stand in the way of reverent cost-savings? We'll get to those questions in a moment, but we first need to consider several in-the-news caveats.

One of the products of the Schiavo case has been magazine and other pieces citing research that is acutely skeptical of advance directives and living wills. The eminent political scientist James Q. Wilson, for instance, noted how, “Studies by University of Michigan Professor Carl Schneider and others have shown that living wills rarely make any difference.”<sup>38</sup> Eric Cohen, more specifically, in describing Schneider’s research (conducted in collaboration with Angela Fagerlin, also of the University of Michigan), wrote: “For decades, we have deluded ourselves into believing that living wills would solve our caregiving problems.”<sup>39</sup> Cohen based his conclusion on harsh appraisals by Fagerlin and Schneider, in their essay, “Enough: The Failure of the Living Will,” which I’ll get to in a moment. But first, a refresher on definitions.

A health care directive is a “document in which you give instructions about your health care if, in the future, you cannot speak for yourself.” A traditional living will “states your wishes about life-sustaining medical treatments if you are *terminally* ill” (emphasis supplied). In a Health Care Power of Attorney, an individual appoints someone to “make medical treatment decisions for you if you cannot make them for yourself.”<sup>40</sup>

Living wills, in other words, generally connote end-of-life situations. Advance directives generally connote a fuller range of serious health problems, and are usually thought of as subsuming living wills and powers of attorney, though all these terms have been known to be used interchangeably.

This last point about interchangeability brings us back to the Fagerlin and Schneider essay. The two researchers ask an “obvious but unasked question” about “living wills” specifically:

What would it take for a regime of living wills to function as their advocates hope? First, people must have living wills. Second, they must decide what treatment they would want if incompetent. Third they must accurately and lucidly state that preference. Fourth, their living wills must be available to people making decisions for a patient. Fifth, those people must grasp and heed the living will’s instructions. These conditions are unmet and largely unmeetable.

As an illustration of why they’re convinced living wills cannot work consistently as intended, they ask: Why is it that so few men and women have them after there has been so much “propaganda” urging them to complete one? Do people *really* want living wills? Or are they just saying what they think researchers want to hear?

“The living will has failed,” they conclude, “and it is time to say so.”<sup>41</sup> Nevertheless – and the point to be made here is major – they simultaneously seem unexpectedly fond of durable powers of attorney, which they salute as “simple direct, modest, straightforward and thrifty”<sup>42</sup> But going back to our definition of key terms, don’t advance directives, in essence, *contain* durable powers of attorney? Yes they most certainly do. While Fagerlin and Schneider’s strictures are not without germs of merit, grains of salt are needed on the wounds they inflict.

More encouraging, and I also would like to think more compelling, is this response by Luisa Margolies, a medical anthropologist in Caracas, Venezuela.

In my view, some of the conditions [Fagerlin and Schneider] consider irremediable can actually be addressed by educating both the potential patient and the medical community. For example, a simple tutorial to prepare people in the “dos” and “don’ts” of medical technology would avoid a lot of grief down the road. People often pay more attention to picking out a new car than trying to understand the implications of terms like “heroic,” “extraordinary,” “terminal,” “lifesaving,” and so on. And the medical staff might be more inclined to act on a patient’s directives if they did not have the fear of a lawsuit hovering in the background, and if they were trained to insist that a living will or durable power of attorney [physically] accompany the patient throughout. . . . Can living wills serve their original purpose – to avoid prolonged suffering in a pending death? Yes, but it will take vigorous planning and effective communication.<sup>43</sup>

Likewise, I would ask again, is there any doubt the Terri Schiavo case would have played out differently if she had completed an advance directive when she was healthy? This holds whatever she would have stipulated: Either to be kept alive for as long as possible, at all costs – or to pursue a quite different course of treatment.

#### **(IV) Barriers**

It’s too glib by half, but Gail Wilensky, who once ran Medicare and Medicaid in the U.S. Department of Health and Human Services, made her point when she said, “We are one of those societies that regard death as an option.”

Her rib is included in the introduction of a very good 2003 report, “Financing End-of-Life Care: Challenges for an Aging Population,” published by AcademyHealth, a program of the Robert Wood Johnson Foundation, a huge New Jersey-based foundation that focuses exclusively on health care.<sup>44</sup> The report continues, less satirically, this way: “American medicine is focused on aggressive, continual treatment, even when such care may be futile. While aggressive treatment should be made available to those who may benefit from it, health care consumers need to understand that there comes a time when palliative measures may be more appropriate.”

Why focus time and attention on end-of-life issues, the report asks rhetorically, when there are so many other health care conundrums to grapple with? “Because,” an official of the foundations says, “it is important to honor the wishes of the dying.” And also because loved ones need to understand that “death can be peaceful and that the delivery of end-of-life care may, in fact, be a less costly alternative to futile, aggressive treatment.”

We’ve already noted the unremarkable fact that Americans can be uncomfortable when it comes to matters of dying and death. In this squeamishness, I trust, we’re not alone

around the globe. But are there more specific impediments – at times tied to specific public policies in this country – that inhibit more sensible, economic, and soothing care at the close of our days on earth? Here are three clusters.

### A. Timing

In talking about end-of-life care, it's easy to fall into the trap of assuming that physicians know more than they really do about the timing of death; about when any one person will die. It wasn't without reason, for example, that the 1997 federal Balanced Budget Act increased benefit periods for hospice services to two 90-day spans, followed by an *unlimited* number of 60-day periods if necessary.<sup>45</sup> Sen. Ron Wyden, in fact, in offering a 2004 bill aimed at permitting "Medicare patients to seek hospice care as they continue curative treatment," said, "I believe more people would use the hospice benefit if they did not have to give up hope of recovery."<sup>46</sup>

Obversely, it's easy to find fault when very sick older people die in expensive Intensive Care Units instead of in less-costly settings, including hospice and nursing homes. But at the same time, it's too easy, a University of Minnesota researcher has rightly noted, "to say ICU care for the elderly is [always] bad," insofar as doctors don't necessarily know, for sure, who they can save.<sup>47</sup> Or, as someone else has put it, "Long-term care necessarily comes into end-of-life care; there is no natural boundary."<sup>48</sup>

In a recent study in the Netherlands, researchers found that while health care expenditures rise "sharply towards the moment of death," the increase starts "starts too late (in around the last two or three months of life) to substantially influence costs over the last full year." This begs the question – in tandem with the just-noted problem of doctors not knowing who among their patients might be saved – of whether anyone earthly knows, with reasonable precision and confidence on a regular basis, when the last "two or three months of life" kick in? Of course not, is the answer.<sup>49</sup> Interestingly, this study from the Netherlands also estimated that "only" about 10 percent of Dutch health care costs are for people in the last year of their lives – virtually identical to the 10-12-percent estimate in the United States.<sup>50</sup>

A very personal and sage illustration of how difficult all this can be is captured in the following few paragraphs recently related by an old friend of mine.

You asked about my mother's experience with end-of-life decisions. It's really a simple story but it demonstrated to me how end-of-life choices can be more complicated, in reality, than it seems they should be in concept.

Fifteen years ago my father, then in his eighties, had had several fairly serious health issues but had survived them and had been living a relatively active life. He and my mother had agreed there would be no extraordinary measures taken for either of them when the end of life seemed imminent. When his health failed again, he was given a series of treatments that might have pulled him through, but

instead he seemed to be failing. He would get a little better than take a bad turn, etc. He was given antibiotics, oxygen, and medications to keep his kidneys functioning, and was given fluids intravenously. He was conscious part of the time and semi-conscious at other times. He was put on a ventilator to help with breathing, but wasn't able to cough well enough to clear his lungs. All this took place over several days.

Finally, my mother was told they could keep him on the ventilator, but that intravenous fluids were not sufficient to sustain life. If he were to keep living, he would need a feeding tube installed, and that with a tube and ventilator he might live for a long while. Because of their pledge to refuse extraordinary end-of-life measures, it seemed right to refuse the feeding tube. She asked what would happen without the tube and was told, essentially, that he would starve to death over the course of a couple of weeks. She could not face watching him starve to death, so she asked for the tube.

As it turned out, my father developed pneumonia within a couple of days and he died of that. The experience showed me how the question of using extraordinary measures to extend life seem simple and clear-cut in the abstract, but can become quite complex when one is faced with a series of choices in dealing with a developing and changing health situation for a loved one.<sup>51</sup>

Perfectly put. My understanding – drawn most intimately from the time my own father was dying five years ago, as well as what I've learned from my chaplain wife – is that withholding food from patients *who have suffered organ failure and who are close to death or approaching it* does not cause them pain. In fact, they might well feel discomfort if they *are* fed in some makeshift way. Most precisely, the absence of food in circumstances like these is not the prime mover of demise. The villain is the underlying and unyielding disease or injury. Or more exactly, without the disease or injury, there would be no moral justification for removing feeding tubes and similar devices in the first place. During such emotionally overwhelming times, when final good-byes are imminent, I would suggest that the term “starving to death” can be a gross and diverting misnomer.

The contrast here with Terri Schivo's case should clear, as there is no reason to believe she would have been close to death if her feeding tube had not been removed, insofar as there were no reports that her heart, liver, kidneys, or other vital organs had not been shutting down beforehand. As for whether she was in any pain over the final two weeks of her life after her feeding tube was removed – presumably in stark contrast to my father, who died several days after we stopped his feeding – I'm in no position to say.

Another key point in my friend's story can be abbreviated, if not graciously under the circumstances, to the adage about being in for a penny, then in for a pound. When, precisely, does one start accepting and preparing for death instead of railing against it? There's hardly a manual for the job.

A judicious medical and policy response here is to move palliative care “upstream.” According to this view, palliative care need not be reserved for those who are close to end. Instead, it could be made available “soon after diagnosis so that patients can learn about and adjust to the illness early on from a team of professionals trained to administer to the social issues, psychological issues, pastoral issues, existential issues, and financial issues that are all part of whole-picture, personalized care.”<sup>52</sup>

## **B. Suspicions**

Another set of impediments to sensible and soothing care at the close of days has to do with personal values and preferences – and often deep suspicions.

On the one hand, some people live in fear of physicians pulling figurative plugs too quickly, either for themselves or their loved ones.

On the other hand, some people live in fear that physicians will disregard clearly expressed wishes to forego heroic measures, thereby, prolonging their own suffering or that of their loved ones.

For an example of the former belief and sensibility, consider this charge from Oregon Right to Life.<sup>53</sup>

Imagine visiting your 85-year-old mother in the hospital after she has a debilitating stroke. You find out that, in order to survive, she requires a feeding tube and antibiotics to fight an infection. She once told you that no matter what happened, she wants to live.

But the doctor refuses further life-sustaining treatment. When you ask why, you are told, in effect, “The time has come for your mother to die. All we will provide is comfort care”

Sound far-fetched? It’s not. It’s already happening.

“It isn’t the treatment that is deemed futile,” the Oregon writer claims, “but, in effect, the patient.”

Daniel Eisenberg, a physician drawing on Jewish theology and tradition, also has written about how “futility of treatment is often confused with ‘futility’ of life.”

The Torah teaches us that every moment of life is intrinsically valuable; life itself is never futile. . . . [W]e have no “yardstick” to measure value of life. Even for a deaf, demented elderly man, incapable of doing any mitzvot [observing any commandment], we must violate the Shabbat [Sabbath] to save his life. It is not within our moral justification to decide what quality of life is “not worth living”

and therefore unworthy of treatment. The only components that are open to halachic [Jewish law] debate are those involving futility of *treatment*.<sup>54</sup>

The political philosopher Robert George, in a March interview on the Shivo case, spoke similarly: “What we must avoid, always and everywhere, is yielding to the temptation to regard some human lives, or the lives of human beings in certain conditions, as *lebensunwerten Lebens*, lives unworthy of life. . . . Any society that supposes that there is such a category has deeply morally compromised itself.”<sup>55</sup>

As for physicians *prolonging* treatment contrary to a patient’s wishes, consider this summary statement from a superb study of American’s attitudes about dying: “It is easily seen beneath the surface that these Americans are skeptical about how modern medical technology is applied at the end of life. They feel such technology often prolongs death rather than preserves life. This conflicts with what they want for themselves and for their loved ones: death with dignity.”<sup>56</sup>

Beliefs like these are of a piece with what many patients and their families see as hyperactive readings by many doctors of their Hippocratic Oaths; their compulsion to “cure,” damn the wreckage of their therapeutic torpedoes. Such beliefs are likewise tied up with what many people see as bouts of acute nervousness suffered by many medical personnel who fear being sued if they don’t pursue every intrusive option, no matter how unlikely to work or soothe. Wide swaths of doctors surely wouldn’t disagree a milligram on this last point about litigation, as they would claim their overdone precautions are completely justified, given the legal lay of the land.

Other conclusions are worth culling at length from this very good 1997 report based on 36 focus groups, “The Quest to Die with Dignity.” They coincide with many themes and problems already discussed.

-- When we opened the conversation about health care at the end of life, Americans most often began by telling us what they don’t want. They talked about being “hooked up to machines,” suffering and having no control over what happens to them.

-- In talking about hospitals, doctors, insurance companies, and managed care plans, these Americans portrayed a system incapable of responding to their concepts of how they want to die. They described a system that is so focused on curing illness that it neglects the dying.

-- They often see money as the root of the problem. They believe the dying process is driven by which services insurance companies do or do not cover, and that this selection encourages hospitalization of the dying. While many would prefer to remain in their homes or go to a hospice facility during the last days of their lives, they fear their insurance companies will not cover adequate home care or hospice services. Yet, these same insurance companies, they note, will pay

tens of thousands of dollars to prolong their lives “hooked up to machines” in a hospital. They fail to see the logic in such a reimbursement system.

-- Some said the system *encourages* treatment and keeps people alive to make money. Others said the system *denies* treatment and cuts people off to make money.

-- Being as pain-free as possible is central to these Americans’ wishes for the end of their lives. . . . If the system has the ability to relieve the suffering of dying individuals, it has the moral obligation to do so, they asserted. They scoffed at concerns of medical professionals who worry about the legal consequences of providing adequate pain relief.

-- These Americans take comfort in the belief that that their loved ones will make the “right decisions” for them at the end of life. They have this security even though they may not have spoken to their spouses, children or parents about what they would want. The vaguest of references, they think, provides adequate guidance to those who may have to make the most difficult decisions.

-- Relieving family members of the responsibility and possible guilt of making decisions for them is the major motivation for individuals to complete advance directives.

-- [W]hen these Americans discussed their abhorrence to “being hooked up,” they did so in the sense of the long term. In listening to them, one soon learns that there is a period of time when being on life support systems is desirable. The dilemma comes in determining the right amount of time before one knows that further care would be futile.

-- [T]hese Americans view dying as a complex process. It is not, they feel, as simple as the choices presented in most advance directives.

-- Finally, the legality of advance directives presents many obstacles for them. They do not know or they misunderstand the laws that apply to end-of-life decisions. The documents themselves have names that are immediately associated with the legal system: living *wills* and *durable powers of attorney* for health care. Many of these Americans naturally assumed that they would need a lawyer to complete the documents and that it would be costly for them. . . . Once an executed document gets in the hands of the “system” – either health care of legal – they fear they will lose the ability to change their minds.

Two more complicating numbers of pertinence:

About 75 percent of patients don’t have “decision-making capacity when choices about life-sustaining interventions need to be made.” Compounding the problem is that approximately 30 percent of elders “do not have a family member or close friend to speak

for them regarding end-of-life care in the event . . . they are unable to communicate their preferences.”<sup>57</sup>

Finishing off this section about suspicions, there is evidence to suggest that hospice care is used disproportionately by upper-class and upper-middle-income men and women.<sup>58</sup> Where there is also evidence, encouragingly, that hospice-use disparities among various races is decreasing, many minorities nevertheless “retain a feeling of distrust about the health care system, including aspects of it that relate to end-of-life care.” The argument goes this way: Since minorities and lower-income people “often feel that they are excluded from the health care system in America,” they may not be receptive to the suggestion “they are better off forgoing curative care,” which, they believe, may have been denied them previously in their lives.<sup>59</sup>

### C. Policies

In discussing American shortcomings when it comes to end-of-life health care, a transnational qualification is in order: The United States is by no stretch the only prosperous and democratic nation which could serve its dying citizens better. Canada, for instance, has a road to go before its severely ill people and their kin sleep in better peace, never mind that some might imagine its single-payer, government-run health care system immune to such problems. Not so.

A 2000 report, for instance, by a Canadian parliamentary committee, reported that “insignificant or nonexistent” progress had been made in the previous five years on improving health care for the dying. This had been caused by “funding cutbacks” and, more generally, because “[c]alls for a more compassionate and comprehensive approach to end-of-life seem to be assigned a low priority in the existing health care system.”<sup>60</sup>

With chauvinistic caveats and ideological indulgences out of the way (warranted though they may be), what health care policies need to change this side of the border? I turn again to an aforementioned report on the financing of end-of-life care, published by AcademyHealth. Bonnie J. Austin and Lisa K. Fleisher are the authors.<sup>61</sup>

Core themes of the study and its recommendations are identical to the main messages of countless other reports concerning publicly funded and/or privately funded social programs: Services ought to be better coordinated; financial incentives ought to be made more sense; and the “whole person” ought to be the object of providers’ attention, not disparate bits and pieces of their various conditions and needs. Such an appraisal is not meant to be dismissive, as the report is sound and savvy. Nevertheless, it’s hard to imagine, for instance, massive bureaucracies ever being sufficiently equipped and receptive (as called for by the report) to integrate numerous “payment silos” into a “single system.”<sup>62</sup> Not that some progress toward that streamlining goal, among others, is out of the question.

In more detail, the report has things like this to say.<sup>63</sup>

The current payment system is siloed and, as such, does not promote a continuum of care at the end of life. Integrating the major end-of-life care funding sources may offer at least one solution to the challenge of providing comprehensive, cost-efficient, high-quality care. The challenge for policy makers is to develop an innovative financing model that captures the Medicare and Medicaid reimbursements for dual-eligibles and to supplement that financing model with private funding. Such financing could come from commercial payers or individual out-of-pocket reimbursements to create a single pool of dollars for a broad based-end-of-life care program.

And,

While the private insurance market may not be the dominant source of financing for end-of-life care, private purchasers are powerful agenda-setters that often serve as a guide for public payers. . . . [L]arge national purchasers often set the standard for what is included in benefit packages. . . . Large purchasers have the leverage to challenge health plans to evaluate the quality of their end-of-life benefits and to provide adequate compensation for care.

Austin and Fleisher go on to note that a significant amount of care for those who are dying is “paid out of people’s pockets,” and that financial devastation is sometimes the result when informal caregivers are forced to leave their jobs to provide for terminally ill family members. The report proposes that affording tax incentives to such caregivers would provide a measure of help. In addition, the study suggests that family caregivers with no employer-sponsored insurance could be subsidized in buying into Medicare or private health insurance plans at reduced rates. And that publicly or privately underwritten training programs and respite support for informal caregivers might also prove helpful. (No fiscal details are offered for any of their package of recommendations.)

Finishing up a synopsis of the report, Austin and Fleisher also recommend that financial incentives for physicians and hospitals be moved away from reimbursing providers for “aggressive, inpatient medicine,” toward rewarding them for “providing palliative care and consultative services outside of the acute-care setting.”

Dr. Joan Teno, one of the nation’s leading academic authorities on nursing homes, makes points similar to the last. Current economic incentives in nursing homes, she writes, reward “a focus on improving and maintaining function” and not on providing “quality end of life care.” Often, nursing homes are reluctant to refer patients to hospice programs because it means losing more highly reimbursed, skilled nursing home days. Simply put, she argues, the incentives are aligned “to do more” rather than honoring a patient’s possible preference for less aggressive treatment. Not incidentally, such incentives also are aligned to cost more money than is necessary.<sup>64</sup>

Elsewhere Teno is quoted as saying: “There’s a paradox in the system. Technology is readily available. I can easily order an MRI (magnetic resonance imaging scan), but I can’t ensure that [nursing home] staff is available to turn my patients to prevent bedsores.”<sup>65</sup>

According to Teno, and as mentioned in the Numbers section at the top, one in four people in the United States now dies in a nursing home, with that ratio expected to climb to nearly one in two people by 2020, just 15 years away. Given this trend, neither public policy nor public opinion seems to be properly configured for the fuller use of these not-always-appreciated institutions.

As you might have noticed, it’s miles beyond my ken and the scope of this paper to actually propose *solutions* to complicated program design and funding problems like those right above. The more limited aim is to spotlight what are invariably terribly complex and arcane inadequacies that need fixing and hope that others who are much better trained for the job – led by elected officials – jump in.

Here’s one last example of a policy problem – access to hospice services in rural communities – for which my contribution doesn’t rise much above acknowledging it.

Beth A. Virnig and Ira S. Moscovice of the University of Minnesota report that 1.76 million Medicare recipients across the country, age 65 and older, died in 1999, with hospice services used by 365,700 of them. The two scholars, along with two other coauthors, found that lowest rate of hospice use (15.2 percent of deaths) was in rural areas not adjacent to urban areas. The middle rate (17 percent of deaths) was in rural areas near urban areas. And the highest rate (22.2 percent) was in urban areas themselves. They also found, unsurprisingly, that hospices based in rural communities had a smaller number of elderly patients than hospices in urban communities, and were more likely to have very low volumes: an average daily census of three patients or less. Virnig and Muscovice conclude: “The consistently lower use of Medicare hospice services before death and small sizes of rural hospices suggest that the combination of Medicare hospice payment policies and hospice volumes are problematic for rural hospices.” They suggest (in typical academic understatement) that “adjusting Medicare payment policies might be a critical step” in assuring hospice services for terminally ill Americans regardless of where they might live.<sup>66</sup>

## (V) Conclusion

I opened by declaring two goals.

The first was to examine whether there are feasible and ethical ways of saving significant amounts of money in providing end-of-life health care. I made it clear that questions surrounding euthanasia were not on the table.

The second goal was to examine how public policies, cultural attitudes, and personal behaviors must change if we are to die better (for lack of a better and more faceted word).

What have we learned?

In regards to money, I cited enough methodological and accounting complexities to fill the Mayo Clinic from basement to roof, but I nevertheless contended that a very substantial amount of money was, in fact, available for saving. I calculated several by-the-seat sums, but the overarching point I made is that since the amount of money spent on American health care in general, and end-of-life care in particular, is so utterly immense, that cutting costs by only a fraction could result in huge savings of actual dollars. As conceded, savings of this sort would not be giant-sized as measured proportionately. But they surely could be substantial as measured by absolute, concrete dollars. I argued that such economies could be realized if significantly more citizens completed and bravely followed through on health care directives. And then if, in their final days – and only if appropriate and humane – they took greater advantage of hospice services instead of more expensive, acute-care hospital services.

In regards to public policies, cultural attitudes and the like, the list of vagaries was again long, including very practical dilemmas such as not knowing *at the time it's happening* when the last stages of a loved one's life has begun. Other barriers included popular suspicions that some physicians are apt to pull plugs too fast – while other doctors are inclined to pull them too slowly. A further obstacle was a wholly unsurprising reluctance on the part of millions of people to talk about, much less prepare procedurally for, their inevitable deaths. The central conclusions to be reached here are two.

First, public policies, starting with Medicare and Medicaid funding formulas, need to be in better concert with the requirements of less aggressive, more comforting, hospice care. This is a job of policy leaders and technical experts well beyond my pay grade.

And second, advance directives need to work better. This goes beyond saying more people need to use them. It also means that the many prosaic yet still serious problems with them need to be ameliorated. Doctors, for example, need to comply with them better. Advance directives need to be filled out clearly enough so doctors can understand them better in the first place. Which is to say that such documents need to be transparent enough so medical personnel can grasp them readily and accurately during pressure-saturated moments. And most practically of all, advance directives must be kept physically proximate to patients at almost all times they're seriously ill, not missing in action at home under a mattress.

How many more men and women would have to complete and faithfully observe advance directives in order to save *real* money? I don't know, as it would not be mathematically or otherwise wise for me to go beyond the seat-of-the-pants calculations I've already offered. No more than 20 percent of Americans, if that many, currently have advance directives. I would like to think that raising that proportion by a modest but noteworthy amount – say, to 25 or 30 percent – is not beyond any realm of possibility. Yes, some

claim that advance directives have been pushed hard for a long time and that their use has hit a ceiling. But my sense is they have not been promoted *that* hard or imaginatively, and that I would like to believe there remains headroom for improvement.

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<sup>1</sup> Newsletter of Hospice of Baltimore, a program of the Greater Baltimore Medical Center, <http://www.gbmc.org/hospice/hospnews.cfm>.

<sup>2</sup> Joost W. van Act and Tom Stoker, "Decisions at the End of Life," *Applied Health Economics and Health Policy* 2002: 1 (1), p. 11.

<sup>3</sup> Ezekiel J. Emanuel, M.D., "Cost Savings at the End of Life: What Do the Data Show?" *JAMA*, June 26, 1996, p. 1907, p. 1913.

<sup>4</sup> Dr. James Duffy, Chairman of the Steering Committee of the Connecticut Coalition to Improve End-of-Life Care, as cited in a press release of New Britain General Hospital, February 6, 2003.

<sup>5</sup> National Hospice and Palliative Care Organization, <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3657>.

<sup>6</sup> Center to Advance Palliative Care, [http://www.capc.org/site\\_root/Documents/document\\_154161538.html?nav=Defining%20Palliative%20Care](http://www.capc.org/site_root/Documents/document_154161538.html?nav=Defining%20Palliative%20Care).

<sup>7</sup> Hospice Minnesota, <http://www.mnhospice.org/displaycommon.dfm?an=2>.

<sup>8</sup> Center to Advance Palliative Care, <http://64.85.16.230/educate/content/rationale/saunders.html>.

<sup>9</sup> Hospice Minnesota, <http://www.mnhospice.org/displaycommon.cfm?an=4>. Also see "The Minnesota Health Care Directive," University of Minnesota Extension Service, 2003.

<sup>10</sup> Minnesota Board on Aging, <http://www.mnaging.org/seniors/assistance/directive.html>.

<sup>11</sup> These distinctions are explained clearly in "Shape Your Health Care Future with Health Care Advance Directives," a helpful booklet produced and funded by the American Association of Retired Persons, the American Bar Association Commission on Legal Problems of the Elderly, and the American Medical Association in 1995. "A health care advance directive is a document in which you give instructions about your health care if, in the future, you cannot speak for yourself. You can give somebody your name (your 'agent' or 'proxy') the power to make health care decisions for you. You also can give instructions about the kind of health care you do or do not want. In a traditional Living Will, you state your wishes about life-sustaining medical treatments if you are terminally ill. In a Health Care Power of Attorney, you appoint someone else to make medical treatment decisions for you if you cannot make them for yourself. The Health Care Advance Directive in this booklet combines and expands the traditional Living Will and Health Care Power of Attorney into a single, comprehensive document. Unlike most Living Wills, a Health Care Advance Directive is not limited to cases of terminal illness. If you cannot make or communicate decisions because of a temporary or permanent illness or injury, a Health Care Advance Directive helps you keep control over health care decisions that are important to you. In your Health Care Advance Directive, you state your wishes about any aspect of your health care, including decisions about life-sustaining treatment, and choose a person to make and communicate these decisions for you."

<sup>12</sup> William H. Frist, M.D., "Health Care in the 21<sup>st</sup> Century," *New England Journal of Medicine*, January 20, 2005, p. 268. Dr. Frist, a Republican from Tennessee, is also *Senator* Frist, the Majority Leader of the U.S. Senate. Given the immensity of the subject, different sources consistently cite different numbers when describing American health care. No claim is made to the metaphysical or epistemological exactitude of any statistic; each should be read as an informed and illustrative estimate.

<sup>13</sup> *Cato Handbook on Policy* (Washington, DC: Cato Institute, 2005), pp. 85-86.

<sup>14</sup> Prof. Bryan Dowd, University of Minnesota, email correspondence, May 6, 2005.

<sup>15</sup> *The New York Times Almanac: 2004*, edited by John W. Wright (New York: Penguin Reference), p. 276.

<sup>16</sup> *Ibid.*

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- <sup>17</sup> Bonnie J. Austin and Lisa K. Fleisher, "Financing End-of-Life Care: Challenges for An Aging Population," AcademyHealth, an initiative of the Robert Wood Johnson Foundation, February 2003, p. 1.
- <sup>18</sup> Emanuel, p. 1907. There is reason to believe that Emanuel was referring to the last year of life specifically.
- <sup>19</sup> Austin and Fleisher, "Financing End-of-Life Care," Foreword and p. 2.
- <sup>20</sup> *Cato Handbook*, p. 86.
- <sup>21</sup> Associated Press, "Medical Care for Elderly Varies Across U.S.," *The Virginian-Pilot*, October 15, 1997, p. A3.
- <sup>22</sup> Austin and Fleisher, p. 10.
- <sup>23</sup> Frist.
- <sup>24</sup> *Ibid.*
- <sup>25</sup> *Ibid.*
- <sup>26</sup> Joan M. Teno, M.D., "Now is the Time to Embrace Nursing Homes as a Place of Care for Dying Persons," *Journal of Palliative Medicine*, Vol. 6, No. 2, 2003, p. 293.
- <sup>27</sup> Minnesota Department of Health. *Minnesota Health Care Spending Trends, 1993-2000*, April 2003. Cited by Bryan Dowd in John Brandl, Bryan Dowd, et al., *What Works: Stronger Policies for Public Service in Minnesota*, Hubert H. Humphrey Institute of Public Affairs, University of Minnesota, January 2005, p. 37.
- <sup>28</sup> L. L. Emanuel, "Advance Directives for Medical Care; Reply," *NEJM* 325 (1991); 1256. As cited in Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report*, March-April 2004, p. 32. Please note that this estimate is almost 15 years old.
- <sup>29</sup> M. Mezey, M. M Bottrell, & G. Ramsey, "Advance Directives Protocol: Nurses Helping to Protect Patients' Rights," *Geriatric Nursing* 17, (5), pp. 204-10. As cited by Julianne Johnson, R. N. , "Final Choices: Keeping Your Dignity in Death: A Comprehensive Program to Educate Patients About Advance Directives," Arizona State University, 1998.
- <sup>30</sup> "Mythbusters," Canadian Health Services Research Foundation, Ottawa, 2003.
- <sup>31</sup> *The New York Times 2004 Almanac*, p. 477.
- <sup>32</sup> According to an Illinois think tank, the figure was \$1.7 trillion in 2003. "A Health Care Reform Agenda for Illinois: Promoting the Patient Power Paradigm," Illinois Policy Institute, February 2005.
- <sup>33</sup> I use the awkward construction "Minnesotans could be involved with saving \$40 million annually" as I suspect the large programs and bureaucracies that Minnesotans pay for – Medicare, Medicaid, HMOs, insurance companies, etc – would be the most immediate and direct beneficiaries of any such savings, not individuals.
- <sup>34</sup> Here's another shattered myth I came across in writing this paper. According to Dirksen's biographer, Edward Schapsmeier, there is no documented evidence that the Illinois Republican, who died in 1969, ever said, "A billion here, a billion there, and pretty soon you're talking about real money." E. L. Schapsmeier, *Dirksen of Illinois: Senatorial Statesman* (Urbana: University of Illinois Press, 1985). Next, somebody will claim he wore a wig.
- <sup>35</sup> Emanuel, p. 1907.
- <sup>36</sup> E. J. Emanuel and L. L. Emanuel, "The Economics of Dying: The Illusion of Cost Savings at the End of Life," *New England Journal of Medicine*, 1994; 330, pp. 540-544.
- <sup>37</sup> Emanuel, p. 1913.
- <sup>38</sup> James Q. Wilson, "Killing Terri," *Wall Street Journal*, March 21, 2005.
- <sup>39</sup> Eric Cohen, "What Living Wills Won't Do: The Limits of Autonomy," *The Weekly Standard*, April 18, 2005, p. 18.
- <sup>40</sup> "Shape Your Health Care Future with Health Care Advance Directives."
- <sup>41</sup> Angela Fagerlin and Carl E. Schneider, "Enough: The Failure of the Living Will," *Hastings Center Report*, March-April 2004, pp. 30; 32-33.
- <sup>42</sup> *Ibid.*, p. 39.
- <sup>43</sup> Luisa Margolies, "The Living Will Merry-Go-Round: Frustrating Progress and Frightening Moments," <http://www.thehastingscenter.org/news/features/lwmerrygoround.asp>.
- <sup>44</sup> Austin and Fleisher, p. 1.
- <sup>45</sup> Hospice of Baltimore.

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<sup>46</sup> “Wyden Fights for Better End-of-Life Health Care: Senator introduces two bills that aim to improve terminal illness care and hospice care.” News release, November 16, 2004. Senator Wyden is a Democrat from Oregon.

<sup>47</sup> Beth Virnig, as quoted in the *Virginian-Pilot*, October 15, 1997.

<sup>48</sup> Joanne Lynn, director of the Washington Home Center for Palliative Care Studies, quoted in Austin and Fleisher, p. 1.

<sup>49</sup> Here’s a remarkable statistic: [O]n the day before death, the median prognosis for patients with heart failure is still a 50% chance to live 6 more months because patients with heart failure typically die quickly from an unpredictable complication like arrhythmia or infection.” J. Lynn, “Learning to Care for People with Chronic Illness Facing the End of Life,” *JAMA* 284 (2000): 2508-09.

<sup>50</sup> van Act and Stoker, p. 10

<sup>51</sup> Personal email correspondence, February 28, 2005.

<sup>52</sup> Austin and Fleisher, p. 6.

<sup>53</sup> Wesley J. Smith, “License to Kill: Hospitals Reserve the Right to Pull Your Plug,” *Life in Oregon*, Vol. 11, No. 3, June-July 2003.

<sup>54</sup> Daniel Eisenberg, M.D., “Should Terri Schiavo Live or Die?”

[http://www.aish.com/societyWork/sciencenature/Should\\_Terri\\_Schiavo\\_Live\\_or\\_Die\\$.asp](http://www.aish.com/societyWork/sciencenature/Should_Terri_Schiavo_Live_or_Die$.asp). For a helpful discussion about medical futility and recommendations for dealing with hard cases, see “Medical Futility in End-of-Life Care: A Report of the Council on Ethical and Judicial Affairs of the American Medical Association,” *JAMA*, Vol. 281, No. 10, 1999.

<sup>55</sup> “Always to Care, Never to Kill: Terri Schiavo and the Right to Life,” *National Review Online*, March 21, 2005. <http://www.nationalreview.com/interrogatory/george200503211140.asp>.

<sup>56</sup> “The Quest to Die with Dignity: An Analysis of Americans’ Values, Opinions, and Attitudes Concerning End-of-Life Care,” A Report by American Health Decisions, 1997. Data for this study were gathered through 36 focus groups, involving 385 demographically diverse men and women.

<sup>57</sup> Julianne Johnson, “Final Choices.”

<sup>58</sup> Linda Emanuel. Meeting discussion, “Financing End of Life Care,” February 6, 2002.

<sup>59</sup> Meeting discussion, “Financing End-of-Life Care,” February 6, 2002; Report to the Congress, “Medicare Beneficiaries’ Access to Hospice,” Medicare Payment Advisory Commission, May 2002.

<sup>60</sup> “Quality End-of-Life Care: The Right of Every Canadian,” Standing Senate Committee on Social Affairs, Science and Technology. The Honourable Sharon Carstairs, chair. June 2000.

<sup>61</sup> Austin and Fleisher.

<sup>62</sup> *Ibid.*, p. 7.

<sup>63</sup> *Ibid.*, p. 5; Foreword.

<sup>64</sup> Joan M. Teno, M.D., p. 294.

<sup>65</sup> “End-of-Life Care in U.S. Found Lacking,” news release of the National Women’s Health Information Center, January 6, 2004, <http://www.4woman.gov/News/English/516828.htm>.

<sup>66</sup> Beth A. Virnig, Ira S. Muscovice, Sara B. Durham, and Michelle M. Casey, “Do Rural Elders Have Limited Access to Medicare Hospice Services?” *Journal of the American Geriatrics Society*,” Vol. 52, Issue 5, May 2004, p. 731.