The case of Joey Fiori was, of course, important for the relatively small circle of individuals who knew him, who cared for him, and who were involved in litigating his case. But Fiori’s situation was not unique. At any given time, between 15,000 and 35,000 U.S. citizens are being sustained in a persistent vegetative state (Council 1990: 426). Consequently, the number of people involved in and concerned about the issues raised by the Fiori case extends well beyond those directly involved in his situation.

The circle of affected parties extends even further because we all have a stake in the treatment of patients in a PVS, connected as we are to these individuals through shared understandings of social values and ethical standards. In addition, we all help to underwrite the health care expenses incurred by these individuals, estimated to be between $1 and $7 billion annually.¹

Potentially, we are all affected by the issues raised in the Fiori case in a more direct way as well. Most patients become incompetent to make medical decisions at the end of life, just as Fiori did. Most do not have an advance directive, just as Fiori did not. And most Americans will die, like Fiori, only after a decision to forgo life-sustaining treatment is made by someone else. Given this reality, it follows that most deaths in the United States will raise, to one degree or another, the same questions that were raised in Fiori and addressed by consensus groups both before and after the case was decided: Who should make end-of-life treatment decisions—courts or families and caregivers? When should these decisions be made—only when the patient is terminal, or also when he or she is seriously and irreversibly ill? And on what basis should decisions be rendered—on the basis of clear and convincing evidence, substituted judgment, the best interests standard, or something else?

Most of us will die having lost the ability to make decisions for ourselves, and many of us will also pass through a protracted vegetative state. Joey Fiori’s situation was sui generis, then, in only a very narrow sense.² It is
true that patients rarely linger in a persistent vegetative state for twenty years as Fiori did. But clinicians have come to realize that the persistent vegetative state is not an isolated syndrome. Rather, the PVS is a point on a continuum of brain functionality that begins with a healthy brain and runs through the stages of mild, moderate, and severe dementia before passing through the PVS and ending with brain death at the other extreme.

Many Americans continue living, with the assistance of tube feeding and other life-supporting technologies, in a severely demented, quasi-vegetative state that is similar to the PVS in many important respects (see Multi-Society Task Force on PVS 1994a, 1994b). This large and growing class of patients deserves our attention, for life-sustaining treatment decisions will have to be made for them at some point, just as they were for Joey Fiori. Even a decision not to make a decision has costs and consequences for all parties involved.

Pathogenesis of Severe Dementia

Alzheimer’s disease, often referred to as senile dementia of the Alzheimer’s type (DAT), is by far the most common cause of chronic dementia in the United States, accounting for approximately two-thirds of all cases. Dementia in the remaining cases is caused by related illnesses, such as Pick’s, Huntington’s, and Parkinson’s diseases. Dementia is also common in the end stages of acquired immunodeficiency syndrome (AIDS). Regardless of their origin, most chronic neurological disorders lead to death—on average, seven to eight years after the onset of the disorder and four to five years after diagnosis (most progressive neurological disorders are not diagnosed until several years after onset).

At the turn of the twentieth century, when the average life span was only forty-eight years or so, approximately 600,000 of the 78 million U.S. citizens alive at the time (or 1 in every 130 people) suffered from disorders like Alzheimer’s. Since then, as the population of the country has grown by about 350 percent, the number of citizens with progressive neurological disorders has increased 1,000 percent.

Today, Alzheimer’s disease or one of its related pathologies afflicts one in every forty-five Americans overall, one in every eight Americans over the age of sixty-five, and nearly half (47 percent) of the population over eighty-five (U.S. Senate 1991: XXII). Demographers predict that the population of patients suffering from Alzheimer’s or Alzheimer’s-like disorders will mushroom from 6 million to 30 million by the middle of the next century (OTA 1987b: 3). It is no wonder, then, that Patricia Hanrahan and Daniel Luchins (1995: 56) refer to dementia as an “epidemiological time bomb.”

Alzheimer’s disease was first brought to the attention of the medical community in 1907 by German neuropathologist Alois Alzheimer. The pathol-
ogy involves the progressive degeneration and loss of nerve cells associated with memory, learning, and judgment in the brain's cortex. Early symptoms of the disorder may be limited to impaired short-term memory, but as the disorder progresses to the moderate stage, those suffering from DAT may exhibit mood swings and personality changes that can be confounding and even frightening to the patient and to the patient's family and friends. Behavioral symptoms also become more pronounced and may include angry outbursts, violence, depression, paranoia, hallucinations, delusions, and wandering. Thought, judgment, perception, language, and functional abilities continue their slow but steady deterioration as the disease progresses.

The moderate phase of DAT may be the most difficult to manage. Family members often experience shame, embarrassment, denial, frustration, anger, depression, and guilt as they care for an Alzheimer's patient who may not recognize them, who may physically or verbally abuse them and others, and who inevitably becomes totally dependent on others for care and sustenance.

Dementia progresses to the severe state in one in every seven Americans over sixty-five and one in every four Americans past eighty-five. Over time, the condition inexorably degenerates and inevitably begins to mimic the PVS. The current population of 2 million severe dementia sufferers is projected to double to 4 million by the mid-2020s as members of the baby boom generation advance into old age (OTA 1987b: 15; see Table 4.1).

There are no standard or commonly accepted criteria that reliably establish the existence of severe dementia. Instead, clinicians look for the presence of one or more of the following conditions as a signal that the dementia has reached the "severe" stage: (1) incontinence, (2) the inability (or lack of desire) to speak (language in the severely demented often consists of only one or two words or cries), (3) significant decreases in mobility, and (4) loss of the ability to swallow (OTA 1987b: 67). These problems force many families of severely demented patients to turn to nursing homes where around-the-clock care can be provided, care that may often include the use of chemical and physical restraints. A large study of nursing home procedures in New York led researchers to estimate that between 53 and 60 percent of nursing home residents were receiving psychotropic medication and that anywhere from 25 to 85 percent were being physically restrained for their own safety and the safety of other residents (NYSTFLL 1992: 13–14).

Whether restrained or not, severely demented patients typically end up bedfast, and they require assistance for most if not all the daily living tasks they had typically completed on their own since childhood, including bathing, feeding, dressing, and toileting (Enck 1994: 69). According to the U.S. Office of Technology Assessment (OTA), two out of three patients with severe dementia need assistance with eating, 87 percent have to be dressed by others (many wear bed gowns most of the time), and 99 percent
Beyond the PVS: Severe Dementia

TABLE 4.1 Actual and Projected Growth of the Elderly and Demented Populations in the United States

<table>
<thead>
<tr>
<th>Year</th>
<th>Americans 65 Years Old and Older (million)</th>
<th>Americans 85 Years Old and Older (million)</th>
<th>Cases of Severe Dementia (million)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900</td>
<td>3.1 (4.0%)</td>
<td>0.1 (0.2%)</td>
<td>a</td>
</tr>
<tr>
<td>1910</td>
<td>4.0 (4.3%)</td>
<td>0.2 (0.2%)</td>
<td>a</td>
</tr>
<tr>
<td>1920</td>
<td>4.9 (4.7%)</td>
<td>0.2 (0.2%)</td>
<td>a</td>
</tr>
<tr>
<td>1930</td>
<td>6.6 (5.4%)</td>
<td>0.3 (0.2%)</td>
<td>a</td>
</tr>
<tr>
<td>1940</td>
<td>9.0 (6.8%)</td>
<td>0.4 (0.3%)</td>
<td>a</td>
</tr>
<tr>
<td>1950</td>
<td>12.3 (8.1%)</td>
<td>0.6 (0.4%)</td>
<td>a</td>
</tr>
<tr>
<td>1960</td>
<td>16.6 (9.2%)</td>
<td>0.9 (0.5%)</td>
<td>a</td>
</tr>
<tr>
<td>1970</td>
<td>20.0 (9.8%)</td>
<td>1.4 (0.7%)</td>
<td>a</td>
</tr>
<tr>
<td>1980</td>
<td>25.6 (11.3%)</td>
<td>2.2 (1.0%)</td>
<td>1.3</td>
</tr>
<tr>
<td>1990</td>
<td>31.6 (12.6%)</td>
<td>3.3 (1.3%)</td>
<td>1.9</td>
</tr>
<tr>
<td>2000</td>
<td>34.9 (13.0%)</td>
<td>4.6 (1.7%)</td>
<td>2.4</td>
</tr>
<tr>
<td>2010</td>
<td>39.4 (13.9%)</td>
<td>6.1 (2.2%)</td>
<td>2.8</td>
</tr>
<tr>
<td>2020</td>
<td>52.1 (17.7%)</td>
<td>6.6 (2.3%)</td>
<td>3.3</td>
</tr>
<tr>
<td>2030</td>
<td>65.4 (21.8%)</td>
<td>8.2 (2.7%)</td>
<td>4.0</td>
</tr>
<tr>
<td>2040</td>
<td>68.1 (22.6%)</td>
<td>12.3 (4.1%)</td>
<td>5.1</td>
</tr>
<tr>
<td>2050</td>
<td>68.5 (22.9%)</td>
<td>15.3 (5.1%)</td>
<td>a</td>
</tr>
</tbody>
</table>

*aNo data available.

SOURCE: Aging data are derived from OTA 1987a: 7. Dementia data are extrapolated from OTA 1988: 3.

need total assistance in bathing and personal hygiene. Over half of severely demented patients are diapered, and 98 percent are totally dependent on others for toileting (OTA 1987b: 501, 502).

Mercifully, psychological problems become less pronounced in the later stages of dementia as patients become less purposeful and communicative. At the same time, the manifestations of severe dementia put patients at greater risk for physiological problems that exacerbate their condition. The lack of mobility means patients with severe dementia are more likely to contract pneumonia and develop bedsores. The use of tube feeding increases the chances that patients will contract aspiration pneumonia. And incontinence increases the chances of contracting urinary tract infections. To treat these infections effectively, caregivers must do the necessary diag-
nostic tests (e.g., blood draws and sputum suctioning), which may cause discomfort and may also serve to confuse and upset the patient.

**Similarities Between PVS and Severe Dementia**

It is not radical to suggest that severely demented and PVS patients be considered part of the same class of patients in terms of end-of-life decision making, for medical researchers have been comparing the two groups and blurring the lines of distinction between them for years. Dr. Ronald Cranford, probably the most prolific writer on the subject and the most widely cited clinician in the subspecialty that deals with neurological disease, states that “from a strictly medical standpoint—in terms of consciousness and the capacity for experiencing suffering—there is not a major difference between no consciousness at all (the persistent vegetative state) and only minimal consciousness (profound dementia) (Cranford 1991a: 20). Both the PVS and profound dementia “are of recent vintage,” notes Cranford, and both are “creatures of modern medical technology. . . . Not only can modern medicine rescue these individuals, it can perpetuate their life for extended periods of time, even though those characteristics that make them uniquely human—thinking, feeling, talking, interacting with others—are permanently lost” (Cranford 1991a: 17; see also Tresch et al. 1991: 930).

Similarly, Judith Ahronheim and M. R. Gasner (1990: 278) note that “patients with end-stage dementia are not far from the PVS state.” Thomas Walshe and Cheri Leonard (1985: 1045, 1047) are equally direct: “The PVS is a feature of the terminal phase of several progressive neurological disorders. . . . The clinical features of PVS in the chronic diseases, although they arrive slowly, are much like those described in patients who develop the syndrome after acute injury.”

The New York State Task Force on Life and the Law, criticized by some as too cautious and conservative on certain right-to-die issues, has also found it appropriate to draw parallels between PVS and advanced dementia: “Permanently unconscious patients include those in a persistent vegetative state [and] patients who are in the end stage of degenerative neurological conditions such as Alzheimer’s disease” (NYSTFLL 1992: 160). Even the authors of the President’s Commission report (1983: 180), a document formulated well before consensus had begun to take shape on this and related issues, adopted this position: “Another group that might be classified as permanently unconscious are end-stage victims of degenerative neurological conditions such as Alzheimer’s.”

Certainly, a number of clinical characteristics lead one to conclude that the two syndromes are similar in several important ways (see Table 4.2). As Cranford has pointed out, both syndromes are relatively new, made possible by medical technology that enables us to rescue and then sustain pa-
Beyond the PVS: Severe Dementia

### TABLE 4.2 Similarities Between PVS and Severe Dementia

<table>
<thead>
<tr>
<th>Contemporary phenomena</th>
<th>Both syndromes have emerged only recently, largely due to the advances of modern technology, including CPR, defibrillators, ventilators, ICUs and trauma centers, artificial feeding, and dialysis.</th>
</tr>
</thead>
<tbody>
<tr>
<td>The vegetative functions persist</td>
<td>Breathing, heartbeat, and respiration remain essentially intact, while the cognitive functions (e.g., feeling, thinking, and interacting) are either severely degraded or entirely absent.</td>
</tr>
<tr>
<td>Circadian rhythm persists</td>
<td>Both PVS and severely demented patients exhibit sleep-and-wake cycles. During waking hours, these patients have eyes open and may blink, cry, grunt, or move the limbs sporadically.</td>
</tr>
<tr>
<td>Other clinical characteristics</td>
<td>Incontinence; inability to swallow; sometimes there is bloating and facial swelling (from tube feeding), causing patients to lose their distinctive facial features; some exhibit severe contractions of the extremities and may tend to curl up into a fetal position.</td>
</tr>
<tr>
<td>Not technically terminally ill</td>
<td>Though very seriously ill, these patients would not be considered terminally ill in the conventional sense of the term as long as aggressive medical treatments are employed. If medical interventions continue, life can be prolonged for years or even decades.</td>
</tr>
</tbody>
</table>

**SOURCE:** Information for this table is drawn primarily from Cranford 1991a: 14–16.
ford (1991a), and others to make a dramatic proposal: Since PVS and severe dementia are essentially equivalent, patients in both classes should be treated similarly, in accordance with the guidelines of the consensus position described in Chapters 2 and 3. This proposal stands up quite well even after considering the major differences that exist between the two syndromes. In fact, the proposal may even be strengthened by considering the differences.

**Differences Between PVS and Severe Dementia**

Although severe dementia is similar to the PVS in many important respects, there also are significant differences between the two syndromes (see Table 4.3). First, most of the 25,000 or so patients currently in a PVS developed the condition shortly after the brain suffered an insult—either an interruption in the supply of oxygen (e.g., from a heart attack, stroke, suffocation, or a near drowning) or from a blow to the head (usually in a traffic accident or a serious fall). As a result, these individuals moved quickly from a normal, healthy state of consciousness to the PVS (usually in a matter of seconds if there was head trauma or minutes if there was a loss of oxygen to the brain).

By contrast, severe dementia results from an incremental loss of brain function over the course of years. Severely demented individuals pass through the various stages of dementia after Alzheimer’s disease or some other progressive neurological disorder begins robbing them of their ability to think, feel, remember, and interact with others. Many of these “biologically tenacious” (Callahan 1989: 63) individuals survive long enough to become “severely demented”—the last stage before the PVS and a phase of brain impairment in which many if not all of the end-of-life decision-making issues raised by the PVS apply.

A second and more important difference between severe dementia and PVS exists at the level of diagnosis. Generally, the PVS can be reliably diagnosed after three months to one year of observation and diagnostic testing. There are, however, no particularly reliable diagnostic tests that can accurately determine the degree of dementia that may exist in a patient suffering from a chronic brain disorder. The term itself—*severe dementia*—is not clearly defined in the medical literature in a universally acceptable and clinically determinable way.

Although it is fairly easy to diagnose the existence of an organic brain disorder, it is harder to pin down the specific level of dementia that exists as time goes on, for the lines between mild, moderate, and severe dementia are not always easily discerned.

The prospect of recovery is a third important area of difference between PVS and severe dementia. Patients in a PVS have, on occasion, had recoveries of sorts, though there is no documented evidence of a “good” recovery
<table>
<thead>
<tr>
<th>Onset and course</th>
<th>Persistent Vegetative State (PVS)</th>
<th>Severe Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sudden, caused by an interruption in the supply of oxygen to the brain or resulting from a blow to the head</td>
<td>Gradual onset of progressive neurological deterioration over years or decades</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Relatively straightforward and reliable after one to three months</td>
<td>Ascertaining various stages of dementia can be difficult at times</td>
</tr>
<tr>
<td>Prospects of recovery</td>
<td>A good recovery has never been documented in an adult after one to three months; a few recoveries have been documented after the three-month point, but patients are left severely impaired</td>
<td>None</td>
</tr>
<tr>
<td>Gradations of consciousness</td>
<td>None; all PVS patients are completely insensate</td>
<td>Extremely low levels of consciousness, progressing toward the vegetative state over time</td>
</tr>
<tr>
<td>Self-awareness</td>
<td>None; all PVS patients are completely insensate</td>
<td>Patients are largely unaware of themselves as unique individuals after passing the point of moderate dementia</td>
</tr>
<tr>
<td>Sensation of pain</td>
<td>None; all PVS patients are completely insensate</td>
<td>Present but to a decreasing degree as the dementia becomes more advanced</td>
</tr>
<tr>
<td>Number of cases nationwide</td>
<td>15,000 to 35,000</td>
<td>Approximately six million Americans suffer from dementia; as many as two million suffer from severe dementia</td>
</tr>
<tr>
<td>Landmark court cases (state)</td>
<td>Quinlan and Joles (N.J.), Brophy (Mass.), Delio (New York), Cruzan and Busalacchi (Mo.), Fiori (Pa.)</td>
<td>Conroy (N.J.), O'Connor (N.Y.), Dinnerstein (Mass.), Rasmussen (Ariz.)</td>
</tr>
</tbody>
</table>

SOURCE: Information for this table is drawn primarily from Cranford 1991: 14–16.
after a patient has been in a PVS for more than a few months. Patients with severe dementia, however, never recover (Multi-Society Task Force on PVS 1994b: 1574).

A fourth important difference between the two syndromes has to do with levels of awareness. On the one hand, patients in a PVS are completely unaware of themselves and their surroundings. As such, they have no capacity to sense physical or emotional distress of any kind. On the other hand, patients who are severely demented but not entirely vegetative may retain some ability to sense physical pain, emotional strain, or both. Physically painful stimuli may cause severely demented patients to wince or cry out. These patients may also retain some vague awareness of their debilitated condition, an awareness that may prove to be a source of significant emotional distress (Meyers and Grodin 1991: 527).

Finally, with only 15,000 to 35,000 cases at any given time, the PVS can be considered a relatively rare phenomenon (1 case per 13,000 U.S. citizens), and no one predicts any dramatic increases in these statistics. But severe dementia is widespread and promises to become substantially more prevalent over the next several decades. The OTA’s estimate that there are some 2 million cases of severe dementia in United States today means that approximately 1 in every 135 Americans suffers from this affliction (OTA 1987b: 7), a proportion that will increase dramatically as the baby boomers begin entering their retirement years shortly after the turn of the twenty-first century. As Daniel Callahan puts it, we can expect to see “a substantially larger number of people in the future who are going to be in a vegetative, semi-vegetative, or otherwise terribly debilitated state but simply will not die” (Callahan 1989: 63).

In sum, there are four important differences between patients in a PVS and patients who are severely demented. One of those differences—the problem with diagnosing severe dementia with medical certainty—tends to weaken the proposition that the two classes of patients are similarly situated. How can we treat severely demented patients as if they were persistently vegetative when we cannot be sure if they are severely demented or not? The flaw in this critique has to do with the term *medical certainty*, which is something of an oxymoron. In fact, very few things of significance in medicine are certain.

More typically, physicians and medical researchers speak in terms of probabilities. And though the probability of making a mistake in diagnosing the PVS is lower than it is with severe dementia, errors in diagnosing either syndrome are uncommon. Dementia usually progresses slowly and relatively predictably over the course of years, giving clinicians plenty of time to observe and adjust their diagnoses along the way. In most cases, then, it is unlikely that the diagnosis of severe dementia, which typically would come years after the initial diagnosis of a dementing disorder, will be wildly
Beyond the PVS: Severe Dementia

off the mark (Walshe and Leonard 1985: 1045). Consequently, although problems with diagnosis continue to be a concern, they are not of a magnitude sufficient to exempt all those diagnosed with severe dementia from coverage under the consensus principles laid out earlier.

The other three differences between a PVS and severe dementia, by contrast, tend to strengthen the “death with dignity” claims some have made regarding the importance of including severely demented patients under the consensus position’s umbrella of principles and guidelines. First, even though some confusion persists over the incidence and degree of recovery that certain PVS patients have experienced, there is no ambiguity whatsoever about the chances of a patient recovering from a degenerative brain disorder such as Alzheimer’s. It may be difficult to tell exactly when a patient passes from the “moderately demented” to the “severely demented” category, but one thing can be reliably conveyed to the family regardless of the level of dementia: The patient will never recover.

Second, since some severely demented patients may retain marginal levels of consciousness, continued existence may be more burdensome for them than it is for the PVS patient, who is entirely unaware of his or her plight. Pain and discomfort may also be felt by the severely demented patient; the PVS patient suffers no such sensations.

Third, there are a hundred severely demented patients for every one PVS patient. Thus, severely demented patients as a group consume many more public resources, strain many more family budgets, cause much more emotional trauma within families, and suffer far more personally than PVS patients, as a group.

In the end, there may be considerable merit to providing families of severely demented patients with the same life-sustaining treatment options and protections that families of PVS patients enjoy under the consensus position laid out in Chapter 2 and bolstered in Chapter 3. Certainly, the public seems supportive of this notion, as Table 4.4 reveals.

This table summarizes the results of a study of 507 individuals (405 hospital outpatients and 102 members of the general public) in which seven specific therapies (antibiotics, IV fluids, ANH, kidney dialysis, mechanical respiration, CPR, and pain medication) were proposed under three different scenarios (dementia, PVS, and dementia with terminal illness). Consistently high percentages of respondents indicated that they would prefer to refuse the six proposed treatments that would tend to prolong life (antibiotics, IV fluids, ANH, dialysis, respiration, and CPR). The only treatment that respondents seemed interested in was pain management, a treatment that, as explained in the survey, also has the potential to hasten death.8

For each therapy proposed, the percentage of respondents saying they would refuse the treatment was lowest within the dementia scenario and highest within the dementia with terminal illness scenario; the PVS refusal
TABLE 4.4  Choices Regarding the Use of Life-Sustaining Treatments

<table>
<thead>
<tr>
<th>Treatment Decision</th>
<th>% Who Would Agree If Suffering from Dementia</th>
<th>% Who Would Agree If in a Persistent Vegetative State</th>
<th>% Who Would Agree If Suffering from Dementia and Terminal Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would refuse antibiotics</td>
<td>69</td>
<td>76</td>
<td>79</td>
</tr>
<tr>
<td>Would refuse intravenous (IV) fluids</td>
<td>73</td>
<td>77</td>
<td>82</td>
</tr>
<tr>
<td>Would refuse artificial nutrition</td>
<td>76</td>
<td>80</td>
<td>82</td>
</tr>
<tr>
<td>Would refuse kidney dialysis</td>
<td>75</td>
<td>80</td>
<td>83</td>
</tr>
<tr>
<td>Would refuse mechanical respiration</td>
<td>75</td>
<td>80</td>
<td>84</td>
</tr>
<tr>
<td>Would refuse CPR</td>
<td>72</td>
<td>83</td>
<td>84</td>
</tr>
<tr>
<td>Would accept pain medication, even if it would bring about an earlier death</td>
<td>77</td>
<td>b</td>
<td>79</td>
</tr>
</tbody>
</table>

aRespondents were 405 outpatients of 30 primary care physicians at Massachusetts General Hospital and a cohort group of 102 members of the general public from the Boston area.

bPatients in a persistent vegetative state are unable to sense pain, making pain medication irrelevant.

SOURCE: Data summarized and cited in Emanuel et al. 1991: 893.

rates fell somewhere in between. Even in the dementia scenario, however, the desire to forgo life-sustaining treatments was overwhelming, even though the level of dementia (e.g., mild, moderate, or severe) was not specified. More than two out of every three respondents said they would forgo relatively simple treatments—such as antibiotics (69 percent) and intravenous fluids (73 percent)—if they were demented. More than three-quarters of the respondents said they would refuse tube feeding, and four out of five said they would forgo mechanically assisted respiration.

Whatever subtle nuances exist in the desire for refusing various treatments in these three patient scenarios, it is clear that, as a rule, the vast majority of respondents would prefer to forgo everything except pain medication when their ability to enjoy conscious life has been compromised and the prospects for recovery are slim. A closer look at dementia-related costs
and case studies only strengthens the arguments of those who contend that severely demented patients and PVS patients are alike for purposes of making life-sustaining treatment decisions and should therefore be covered by the consensus position outlined in Chapter 2.

Resources

In addition to the issues associated with the physical and emotion distress and deterioration suffered by demented patients, issues of resource allocation might reasonably be raised. Anecdotal and quantitative evidence abounds that, generally speaking, perhaps too much in the way of medical procedures are provided to demented patients who are at or near the end of their lives.

Ezekiel and Linda Emanuel (1994: 543) estimate that 3.3 percent of all health care spending (close to $33 billion in 1998 dollars) might be saved if each of the approximately 2 million Americans who die every year were to choose hospice care, use advance directives, and refuse aggressive, in-hospital interventions toward the end of life (cited in Scitovsky 1994: 585–586). P. A. Singer and F. H. Lowery estimate that the cost of caring for dying patients could be cut in half, saving approximately $55 billion annually, if the decision to forgo life-sustaining medical treatment was made more regularly, through the use of advance directives, for example (cited in Maksoud, Jahnigeeen, and Skibinski 1993: 1250; see Box 4.1). It is possible that a fair proportion of these savings could be realized if the severely demented were not treated so aggressively.

Aggressive Care and Spending Patterns

Perhaps the extravagance of current medical practices regarding treatment at the end of life is best represented by the use—some would argue overuse—of the intensive care unit for treating elderly patients. According to Dr. David Finley, director of a hospital’s critical care services, the fact that many U.S. hospitals have ICUs filled with the frail elderly is deplorable. “End-stage care is not what [the ICU] is intended for,” argues Finley. “It was originally supposed to be for people with treatable illnesses and a reasonable chance of recovery” (cited in Clark 1992).

In a similar vein, Dr. Steven Schrroder, an internist, noted the differences between ICU patients in the United States and Europe after touring a number of European facilities. ICUs in European countries, he reported, were smaller, accounting for between 1 and 5 percent of all hospital beds. In the United States, ICUs typically account for 15 to 20 percent of all beds (Stout 1993). Schroder also noted that “the patients there were different. They were healthier and they were younger. The common patient in an ICU in a
Increased use of advance directives may be one way to begin realizing savings in caring for patients at the end of life. A recent study of 476 Medicare patients who died in private, university-based hospitals over a three-year period revealed that the 132 patients who had advanced directives incurred average total inpatient charges of $30,478. The 342 patients in the study who did not have advance directives had average total inpatient charges of $95,305 (Chambers 1994: 541)—more than three times as much. In two of the three years of the study, there were no appreciable differences in the severity of illness between the two groups of patients, those with advance directives and those without. And the difference in spending levels was maintained even after controlling for demographic characteristics (e.g., age, race, and gender), use of the ICU, and the number of procedures employed, suggesting that it was not only the sickest of the patients who had advanced directives (Chambers 1994: 545).

A second study, conducted in 1993 by Alfred Maksoud, Dennis Jahnigeen, and Christine Skibinski (1993: 1250), found much the same thing. The 12.5 percent of patients who were admitted to the hospital with DNR orders in place and subsequently died had average final inpatient charges of $10,631; the remaining 87.5 percent of the patients who entered the hospital without DNR orders and subsequently died had average total bills of approximately $68,000 (Maksoud, Jahnigeen, and Skibinski 1993: 1249). One significant finding of this study was that when advance directives were executed after admission, they often came too late to save much if any money. In fact, Maksoud, Jahnigeen, and Skibinski (1993: 1249) found that DNR orders executed in the hospital were written, on average, only two days before a patient's death, and the average charge for these patients was actually higher (approximately $73,000) than it was for patients who died in the hospital without ever having executed DNR orders (approximately $57,000).
annual cost of caring for the demented elderly has been estimated at between $24 and $48 billion when costs of supervision and assistance—often provided by family members and counted as lost wages—are added to the medical costs (OTA 1987b: 447; Nuland 1994: 103).

Treatment—or perhaps overtreatment—of elderly demented patients probably helps to explain the skewed patterns in health care spending data for the elderly. According to the Health Care Finance Administration (HCFA), although only 5 percent of Medicare beneficiaries die in any given year, 28 percent of the Medicare budget (about $20 billion) is spent in attempting to address the health care needs of this group. About half of this amount ($10 billion, or 1 out of every 7 Medicare dollars) is spent on patients in the last two months of life, and about a third of this amount ($7 billion, or 1 of every 14 Medicare dollars) is spent in the patient’s last thirty days. Overall, 6 Medicare dollars are spent on those who die in the hospital for every dollar spent on elderly patients who survive hospitalization (Sicotovsky 1994: 562, 578). Will Rogers once said that in the world of politics, it costs a fortune just to get beat. Perhaps it could also be said that in today’s world of medicine, it costs a fortune just to die.

Comparing utilization patterns across age groups raises even more questions. Although the elderly in the United States make up only about 13 percent of the general population, they account for 34 percent of all health care expenditures (63 percent of those dollars come from the public sector). The 13 percent of the population over the age of sixty-five also occupy 40 percent of the nation’s hospital beds and consume 67 percent of all medications prescribed (U.S. Senate 1991: 133). The uninsured rate among the elderly—anther measure of resource distribution in society—is essentially zero, thanks to Medicare and Medicaid, but the uninsured rate hovers around 15 percent for the rest of the population and approaches 15 percent among U.S. children.

Medicaid, the program designed to address the health care needs of poor Americans, spends seven dollars per capita, mostly on long-term care for “apparently poor” elderly, blind, and disabled individuals (some really are poor, but others have sheltered their resources to appear poor), for every dollar spent on health care for “actually poor” children (U.S. GAO 1995: 1–2). This disparity in spending between the young and the old has become more pronounced in recent years. According to Victor Fuchs, overall spending on health care for the elderly has outpaced spending for those under sixty-five by an average of 4 percent per year (1984: 149). Fuchs explains that only about half of the difference in spending can be explained away by the increase in the size of the elderly population relative to those under sixty-five. The rest of the increase represents a real net shift in spending on the elderly relative to younger Americans (Fuchs 1984: 149–150).

This shift in spending across age groups is taking place at a precarious time, demographically speaking, for the ratio of working-age Americans to
elderly Americans has been decreasing dramatically ever since the turn of the twentieth century. In 1900, there were more than fourteen working-age adults available to support every person over sixty-five. Today, there are only about four working-age adults for every elderly American. Between now and the middle of the next century, demographers predict that the ratio will drop even further, leaving only two-and-a-half workers to support every one elderly American (see Figure 4.1).

Utilization and Spending Patterns in Perspective

This overview of spending trends is not presented to suggest that the demented elderly are taking advantage of the rest of society by overusing health care resources (although some would be happy to draw this conclusion). Indeed, the elderly pay for about 30 percent of their general health care costs and approximately half of all long-term care out of their own pockets (OTA 1987b: 172–173). In addition, older members of our society should be expected to consume more in the way of health care resources, given the multitude of medical problems that commonly attend the aging process. The data provided here are meant only to stimulate discussion, not end it.

Nonetheless, long-term care for the elderly, especially the severely demented elderly, is an important and often overlooked economic and ethical concern. As Anne Scitovsky notes (1994: 588–589):
In the many studies of medical care at the end of life, the emphasis has been almost exclusively on high-cost, high technology care. Largely ignored has been the problem of patients dying in nursing homes. . . . As the population ages, this group of decedents will become increasingly important and may well pose greater economic problems than the high-cost decedents on whom most of the research has focused. . . . They also present ethical problems different from, and possibly more difficult than, those posed by critically ill patients. Chronically ill patients present us with the dilemma not so much of when to forego "heroics," but rather or when to halt ordinary care (such as treatment with antibiotics in case of infection) and sustenance.

The authors of the President's Commission report (1983: 96–97) sound a similar chord when they suggest that one must be cautious when factoring the costs of care into the balance, for strict rationing along these lines may lead to ethically tenuous consequences. Individuals place different values on sustained life, and there is a danger in creating hard-and-fast rules about what costs can be incurred under what circumstances; to do so could lead to discrimination and devaluation of the lives of society's most vulnerable members. Yet according to the President's Commission report (1983: 96–97), allowing decisions about life-sustaining care to be made with total disregard for the costs they impose on others has equally serious implications. Enormous expenditures may be made for very limited benefits, such as sustaining a painful and burdened life of someone who has little or no capacity to enjoy it. . . . The fact that a therapy is life-sustaining does not automatically create an obligation to provide it.

In the end, cutting health care costs is not the primary motivation for laying out the end-of-life decision quandary addressed in this volume. Other, more important issues are at stake, including the enhancement of patient autonomy, the decrease in suffering for patients at the end of life, and a much needed increase in the degree to which compassion and dignity attend the modern dying process (Emanuel and Emanuel 1994). As such, the cost and resource allocation issues raised here are just one part—potentially important but not preeminent—of the debate about end-of-life decision making. We certainly should not bank on the increased use of advance directives, proliferation of hospice care, and rejection of aggressive life-sustaining therapies at the end of life to solve the more general health care finance problems that face the United States today.

At the same time, the data suggest that some money, perhaps a substantial amount of money, could be saved if patients and their surrogates agreed not to extend life interminably after severe dementia develops. Adopting a less medically aggressive, more natural approach to dying in the United States would be, according to a number of ethicists and clinicians, just as defensible for severely demented patients as it is for PVS patients, for both
could easily be covered under the consensus position’s umbrella. A review of some notable cases involving life-sustaining treatment decisions for patients suffering from severe dementia helps to illustrate the point.

State Court Cases Involving Severe Dementia and the Right to Die

There have been approximately eighty appellate-level court cases in the states involving the right to die since 1977, when the parents of Karen Ann Quinlan became the first to stake an explicit, right-to-die claim in the state courts. Eighty percent of those cases have involved patients who were incompetent to make decisions for themselves (Ahronheim and Mulvihill 1991: 1124). And fully one-quarter of all cases heard at the appellate level have involved patients over the age of sixty-five. In all but three of these cases, the patient was determined to be too demented to be involved in making medical treatment decisions. A review of the medical conditions and judicial decisions in some of the more important of these cases will shed further light on the parallels between the PVS and senile dementia, at least in the eyes of the courts.

Shirley Dinnerstein

One of the earliest cases to deal with dementia involved Shirley Dinnerstein, a sixty-seven-year-old Massachusetts woman with advanced Alzheimer’s disease. Her adult son and daughter brought this case to the courts in 1978, just two years after the Quinlan decision was handed down in New Jersey.

Dinnerstein’s children petitioned the court for permission to execute a “do not resuscitate” order on behalf of their mother. The court ruled that the family could decide to put DNR orders in place without court involvement in “hopeless” cases such as the one at hand. Perhaps more important, the court also backed away from an earlier Massachusetts ruling that involved a terminally ill, mentally retarded adult by the name of Joseph Saikewicz. In Saikewicz, the court ruled that the judiciary should be involved in any decision to forgo treatment. In Dinnerstein, the court indicated that judicial approval would be required only if the treatment in question would offer the incompetent patient hope of cure or remission (Choice in Dying 1994b, In re Dinnerstein: 2).

Claire Conroy

The 1985 case of Claire Conroy in New Jersey is among the most important and most cited cases to date in which surrogate decisionmakers at-
tended to implement a palliative care treatment plan on behalf of an elderly, demented family member. Miss Conroy was described as having led a simple, even cloistered life that involved only her sisters (with whom she lived) and a few friends. Conroy was admitted to a nursing home at age seventy-nine after her sisters had died and her own physical and mental condition began to decline. She had never been to the doctor and had “scorned medicine” her entire life (Stryker 1989: 228).

After five years in the nursing home, Conroy had deteriorated to the point where she was entirely bedridden and in a semifetal position. She suffered from hypertension, diabetes, and arteriosclerotic heart disease. Conroy had extensive bedsores, and her left leg was gangrenous to the knee. She was entirely incontinent and was fed through a nasogastric tube. Assessments of her mental state varied, depending on the physician, from unaware and confused to severely demented. “Though unable to speak, she occasionally scratched herself, [and] pulled at her bandages, [nasogastric] tube, and [urinary] catheter” (Choice in Dying 1994b, Conroy: 1).

The surrogate decisionmaker in this case was Conroy’s only surviving blood relative, Thomas Whittemore, a nephew. Whittemore had known Conroy for over fifty years and visited her weekly during the four years prior to her admittance to the nursing home. Eventually, Whittemore asked that his aunt’s nasogastric tube be removed so that she could be allowed to die. He was supported in his request by a Roman Catholic priest who testified at a subsequent trial that Catholic moral theology, as laid out in the Vatican Declaration on Euthanasia, would consider withdrawal of Conroy’s feeding tube a morally acceptable course of action (Stryker 1989: 231–232).

The New Jersey Supreme Court ruled that artificial nutrition and hydration was just another form of invasive medical treatment that might be withheld or withdrawn as long as one of three tests was met. Under the court’s “subjective test,” surrogates would be allowed to direct that life-sustaining treatment be withdrawn from a patient if the surrogate could demonstrate—through written or oral statements, through reactions the patient had to the treatments of others, or through consistent patterns of conduct—that the patient would reject such treatment if he or she were competent to make the decision. (This standard is roughly equivalent to the substituted judgment standard.)

If the subjective test could not be satisfied, one could move on to the “pure-objective test,” which would permit termination of treatment if, on balance, the pain and suffering of the patient’s prolonged life were considered to outweigh the benefits the patient was thought to derive from continued life. (This standard is roughly equivalent to the best interests standard.)

The third standard of decision making, the “limited-objective test,” is really a mix of the first two, to be used when there is insufficient evidence un-
der either of the first two standards. It allows the withdrawal of treatment if some trustworthy evidence of the patient's desire to have treatment withdrawn (substituted judgment) could be combined with some evidence that continued treatment would only serve to prolong suffering without providing significant benefits beyond continued biological existence (best interests).\(^\text{14}\)

Fairly rigorous review standards were also proposed by the court. First, the decision was applied only to elderly nursing home residents who were expected to die within a year. Second, the court indicated its desire to become involved in determining incompetency. The court also wanted to play a role in the designation of a guardian, if one were required. The court ruled that this guardian had to inform the state Office of the Ombudsman, which then had to notify other state agencies and initiate an adversarial investigation of any request to forgo treatment. Finally, the court ruled that life-sustaining medical treatment could be withdrawn only if the guardian, the attending physician, two unaffiliated physicians, the state ombudsman, and (in the case of the pure- or limited-objective tests) the patient's next of kin all concurred on the proposed course of action.

The Conroy decision was an important landmark for several reasons. It endorsed a new, hybrid decision rule—the mix of best interests and substituted judgment—for situations in which there was not enough information to support either the best interests standard or the substituted judgment rule alone. Conroy also explicitly rejected the use of language that, it was argued, only tended to muddy the waters regarding end-of-life decision making. Drawing heavily on the President's Commission report, the court set aside as unhelpful the ordinary-extraordinary distinction, the distinction between withholding and withdrawing treatment, and the application of the term *euthanasia* in cases involving the forgoing of life-sustaining medical treatment. In essence, it began wiping the slate clean and led courts across the country to start over with a new set of language and concepts that allowed decisionmakers to deal more with "proportionality" and the "benefits and burdens" of life-sustaining medical treatment.\(^\text{15}\) These principles have endured and now serve as a central part of the general consensus on end-of-life decision making, as discussed earlier in this volume.

The rigid rules associated with the appointment of a guardian and the determination of incompetency were not adopted by other courts or embraced by the consensus groups, however. In fact, these rules did not even work very well in New Jersey. For example, Joseph Sullivan (1986) reported that families and health care professionals in the state appeared to be avoiding the Conroy court's prescribed procedures for withholding and withdrawing life support as too cumbersome. Despite data suggesting that scores of these decisions were being made on a weekly basis in hospitals across the state, the Office of the Ombudsman reported that only a couple of telephone inquiries were made regarding the new procedures in the first
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year. In all but one case, callers failed to follow up by initiating official pro­ceedings to establish incompetency and assign a surrogate.

Common sense suggests that business is still going on as usual in New Jersey, with caregivers and family members quietly collaborating to make end-of-life decisions for incompetent patients, all without the assistance of the courts. Not surprisingly, no other appellate courts have adopted New Jersey’s review standards, and even the New Jersey court has since backed away from its rigid stance (see In re Peter 529 A. 2d 404 [1987]).

Mildred Rasmussen

Mildred Rasmussen left behind no evidence of her medical treatment preferences and had no close relatives to help make those decisions for her when, after a series of three strokes, she became severely demented at age sixty-eight. She lay in a fetal position, unable to move, speak, or participate in her own care, and all physicians involved in her case agreed that her lack of awareness was irreversible. An out-of-state relative deferred to the judgment of the primary care physician, who proposed writing two treatment orders—one directing caregivers not to resuscitate the patient should her heart stop (a DNR order) and a second directing that the patient should not be tube fed if she were no longer able to swallow.

The patient died of pneumonia in 1987 before an Arizona court could decide whether the physician’s proposed orders could have been authorized under the best interests standard that had been adopted by other states. But the court nonetheless pressed ahead with the case because it believed an important question was at stake, and it wanted to establish a case law precedent to guide decision making in the future (the supreme court in Pennsylvania pressed ahead with the Fiori case after Joey Fiori had died for the same reasons).

Ultimately, the Arizona court determined that none of the state’s interests in preserving life outweighed Rasmussen’s right to privacy and autonomy. The court cited the AMA’s Council on Ethical and Judicial Affairs regarding the propriety of withdrawing life-prolonging medical treatment for those who appear to be irreversibly vegetative: “Even if death is not imminent but a patient’s coma is beyond doubt irreversible . . . it is not unethical to discontinue all means of life-prolonging treatment (Choice in Dying 1994b, Rasmussen v. Fleming: 2). The court also cited the President’s Commission report (1983) in formulating the meaning of “best interests” as “the course that will promote the patient’s well-being as it would probably be conceived by a reasonable person in the patient’s circumstances” (see President’s Commission 1983: 136). Finally, the court ruled that, in the future, its role should be limited to dispute resolution. Where no dispute existed, the court would not need to be involved, it said.
Mary O’Connor

The New York case of seventy-seven-year-old Mary O’Connor cut sharply across the grain of decisions handed down by appellate courts almost everywhere else, including the three cited earlier in this chapter. O’Connor had suffered a series of strokes, which led to severe dementia. She was conscious but bedridden, unresponsive, and unable to stand or feed herself when members of her family decided that further life-sustaining treatment was not desirable.

In court proceedings to determine if tube feeding could be withdrawn, O’Connor’s two daughters (both practical nurses) testified that their mother had clearly stated she would not want to be a burden to anyone or be maintained by artificial means if unable to care for herself. These statements were made after O’Connor had tended her husband and brothers during long final illnesses and after she had worked as a hospital employee for twenty years. A longtime friend and coworker also testified that O’Connor had said it was “monstrous to keep someone alive by using ‘machinery,’ things like that when they were not going to get better” (Choice in Dying 1994b, In re Westchester County Medical Center: 1). Meanwhile, in court, doctors disagreed over whether the dehydration that would follow the course proposed by the daughters would be painful.16

In a 5-to-2 decision, New York’s highest court found that Mrs. O’Connor’s statements regarding medical treatment were insufficient evidence of her desires under the clear and convincing evidence test adopted previously by that court (see In re Eichner and In re Storar).17 The court went on to reject the substituted judgment approach that had been adopted by other courts and a wide variety of professional organizations, stating that it was inconsistent with “the fundamental commitment to the notion that no person or court should substitute its judgment as to what would be an acceptable quality of life for another” (Choice in Dying 1994b, In re Westchester County Medical Center: 2). Furthermore, according to the court’s decision, “every person has a right to life, and no one should be denied essential medical care unless the evidence clearly and convincingly shows that the patient intended to decline the treatment under particular circumstances” (Choice in Dying 1994b, In re Westchester County Medical Center: 2).

The court’s opinion also echoed that of the doctors in the case who testified that the death that would ensue if nasogastric feeding was withheld might be painful (Lo, Rouse, and Dornbrand 1990: 1228). They came to this conclusion even though the medical literature on the subject suggests that people in a state of severe dementia have very little sense of pain and that dehydration is not painful and may even be a relatively comfortable way to die (see Chapter 5). In the end, the court ordered that a nasogastric tube be inserted, over the objections of O’Connor’s daughters. O’Connor died one year after the decision was rendered, with her nasogastric tube in place.
Life After O’Connor

Nearly all hospitals in New York State interpreted the O’Connor ruling to mean that, in the absence of any written statements, families must prove—by presenting clear and convincing evidence—that an incompetent patient would not want to be kept alive by machines before life-sustaining treatment could be withheld or withdrawn. The case of Rosemarie Doherty provides a good illustration of the effect of New York’s decision.

Doherty’s husband, with the concurrence of their son, attempted to have life support—feeding and endotracheal tubes—removed after Mrs. Doherty lapsed into a persistent coma. But acting in accordance with the O’Connor decision, a Brooklyn nursing home declined to honor these requests. “They said I would need five people to swear Rosie had specifically said she never wanted this tube, that tube, this antibiotic, that transfusion... We never talked like that. Who talks like that?” said Mr. Doherty. “But I know she would not want to live like this. No one would. Would you?” Continuing, Mr. Doherty said his wife should have signed a health care proxy. “She should have—she didn’t.... She didn’t sign and she can’t sign now,” he said. “Does that mean she has to be sentenced to this?” (Belkin 1992).

Subsequently, the New York State Task Force on Life and the Law (1992:74) argued that the standard for decision making charted by the O’Connor court and applied in the case of Rosemarie Doherty has proven untenable: “In practice, the clear and convincing evidence standard is often unworkable and inhumane. It is a legal standard that translates poorly at the bedside where families and health care professionals must confront the hard choices that incurable illness and medical advances present.”

Summary

Although the decisions rendered in the Dinnerstein (Massachusetts), Conroy (New Jersey), and Rasmussen (Arizona) cases differed from the O’Connor ruling in New York, these cases do have something in common. None involved a patient diagnosed to be in a PVS, and in none of the cases was the clinical diagnosis a determining factor. Rather, it was the permanence of the incompetence that was important; the technical cause of incompetence was irrelevant.

An extensive review of case law on end-of-life decision making reveals that severe dementia and PVS are equivalent in the eyes of many courts, for most decisions have turned on the degree of evidence required to make end-of-life decisions, not on the conditions of the patients themselves. Almost nowhere has the prognosis of dementia given the courts pause. Regardless of the final decision (and the vast majority of such cases have been resolved in favor of the families, in accordance with the consensus position), demen-
dementia, like the PVS, has been accepted as just one of any number of diagnoses involving incompetence in which surrogate decisionmakers might be empowered to make end-of-life decisions for patients.

As noted earlier, there are really only four important differences between PVS and advanced dementia. First, it has become relatively easy to identify the PVS through clinical testing and observation, whereas severe dementia can be difficult to accurately diagnose. Second, a few PVS patients have experienced “miraculous” (if far from complete) recoveries, but severely demented patients never recover. Third, PVS patients cannot feel pain, anguish, or agitation at all, whereas severely demented patients may retain some ability to experience these sensations. And fourth, the PVS patient population numbers in the tens of thousands and is remaining relatively stable, while the severely demented population, currently around 2 million, is expected to grow to 4 million in the not too distant future.

The first of these differences suggests that we should use some caution before treating severely demented patients as if they were persistently vegetative. But the other three differences might suggest that patients with advanced dementia have an even greater interest than PVS patients in being treated only with palliative care.

There is a sticking point here, however—a complication tied to the concept of palliative care that has caused a great deal of anxiety, confusion, and dissent in recent years. This complication involves the issue of artificial nutrition and hydration. One of the hallmarks of severe dementia is the gradual loss of the ability to swallow; consequently, whenever the question of moving away from aggressive treatment and toward palliative care arises, the issue of artificial nutrition and hydration inevitably comes up as well.

The consensus position, public opinion polls, religious writings, and court decisions all suggest that ANH is just another medical treatment that can be appropriately withheld or withdrawn from irreversibly incompetent patients, using either a substituted judgment test or a best interests analysis. Nonetheless, it is clear that some physicians and a significant segment of the lay public continue to struggle with this issue. Food and drink have strong symbolic significance in our culture, even when they are provided by artificial means. Can Americans come to terms with the idea of declining ANH for members of their families as death draws near? The answer to this question may well turn on the degree to which decisionmakers are fully informed about the costs and benefits associated with the decision to either accept or refuse tube feeding at the end of life.