

# Pay Me Now or Pay Me Later

## Dementia and the Cost of Health Care

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By CLARKE E. COCHRAN, PhD

**O**nce a day, Janice, a rancher in rural West Texas, drives the 120-mile round trip from her home to Lubbock, where she spends time with her husband, Earl, a resident of a long-term care facility. Earl suffers from advanced Alzheimer's and seldom recognizes Janice. Their two young sons manage the ranch while Janice is gone. Their family's story was broadcast on a local TV station.<sup>1</sup>

Earl remains ambulatory. Relatively young, he has little comorbidity and takes a limited number of medications. Even so, the strain on Janice's face is evident.

Earl's blank stare and visible tremor suggest mental and physical changes that will require major decisions relatively soon. What current drugs might delay physical decline and what are their risks? Are there experimental pharmaceutical trials that promise to delay dementia's deepening? What about the looming need for more intense nursing home care, including the question of artificial nutrition and hydration? What about hospitalization and aggressive acute care for severe infections or organ system failure?

Lurking behind the complexity of these questions are concerns about the cost of Earl's care for Janice, their sons and their health insurance, and the cost to society of caring for millions of Earls now and in the next few decades. Already on an unsustainable cost path, the U.S. health care system must discover ways to address the financial challenge of dementia care for an aging population.

The drivers of elder medical costs are foundationally cultural — America's fascination with

medical technology; its reluctance to face decline and death; and aging in the context of a fractured family system. What this tells us is simple. You can pay now for aggressive technology and treatment, or you can pay later for care during longer periods of frailty and disability.

In dementia's worst-case scenario, it's both: We will pay for aggressive, costly care now, and for treatment of long, chronic, dementia-related decline later. Without cultural change, there is little hope of addressing the medical manifestations of dysfunction in dementia care, not to mention throughout medicine.

Understanding the economic challenges posed by dementia means understanding the complex interplay of direct and indirect costs as they interact with dementia's moral, spiritual and emotional toll. The direct costs of dementia care are relatively clear, and they fall into several categories, such as ordinary care that has minimal effect on the course of the disease — routine visits to the primary care physician or, occasionally, a specialist; common prescription medications; assistance from home health aides for activities of daily living, for example. Other categories include medical equipment, personal care products and



safety costs, all of which vary greatly depending on the dementia in question and the existence of comorbidities.

The indirect costs associated with dementia are much less clear. They include such very real, but difficult to quantify, expenses as lost productivity from workers with early onset dementia; lost productivity from family members (and sometimes friends) who leave the workforce or reduce their hours worked in order to care for loved ones with dementia; reduced efficiency from workers who come to work tired, strained and less effective from hours spent in caregiving or in relieving primary caregivers.

Added up, these costs are considerable at the individual level. Published in *The New England Journal of Medicine*, a very careful study of dementia costs in those over age 70 (excluding any costs of comorbidities) yielded \$28,501 per year per person in direct costs (in 2010 dollars). Notably, Medicare covers only about \$2,800.

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Indirect costs were substantial, according to the study, ranging from \$13,188 to \$27,789 per year per person, depending on the method used to calculate these costs. Annual totals are \$109 billion direct and \$50-\$106 billion indirect.<sup>2</sup> The financial burden often falls on those least able to bear it, with the incidence of dementia higher for women, nonwhites, single and older persons, and those with lower education and household incomes.<sup>3</sup>

The incidence and cost of dementia also exacerbate a serious fiscal crisis in care for an aging population. Expenditures on long-term care have risen dramatically in recent decades, along with the number of elderly, and the number of Americans needing long-term care will double by 2050. Home health costs rose to \$80 billion annually by 2012 and nursing facility expenditures to \$150 billion.<sup>4</sup> Those living past age 65 now average three years of disability at the end of life. Half of those living past age 85 will have serious cognitive

decline. Increasingly, those living to these ages have limited family support and limited personal savings upon which to draw.

Current treatment regimens are highly fragmented, with responsibility falling largely to the elderly themselves or their children, who often lack the ability to navigate complex insurance, medical and other organizations to build a coherent system of care.

These considerations have led some to label dementia as the next “plague”<sup>5</sup> and assign it a much higher economic impact than described in the *New England Journal of Medicine* study. But panic metaphors are not particularly helpful. We all can agree that dementia care is expensive (\$109 billion annually, similar to cost of care for heart disease). Although costs are estimated to hit \$129 billion annually by 2020,<sup>6</sup> in context they are not overwhelming. The \$109 billion figure for direct dementia care for persons over 70 in 2010 was about one-tenth of the combined Medicare

and Medicaid spending that year (most of which goes for elderly and disabled persons). And it was a small fraction of the \$2.6 trillion in total health care spending that year. Even when indirect costs are added, dementia care remains a relatively small portion of health spending in the U.S.

This is not in any way meant to diminish dementia’s challenge. Alzheimer’s disease (the source of most dementias) is the only major killer for which there has been no significant progress on prevention, treatment or for turning it into a manageable chronic disease (which even HIV has become).<sup>7</sup> Moreover, the emotional, spiritual and physical toll on caregivers often is, indeed, overwhelming. Dementia should be a priority on medical, moral and spiritual terms, not strictly economic ones, but it is important to look ahead and inquire into whether dementia care will be a significant contributor to the rising cost of health care.

A case can be made that many dementia-related expenditures in the United States are driven by high prices, fragmented care and overspecialization — all of which are not unique to dementia care, but typical of the U.S. health system. However, three variable factors could be related to dementia; therefore, their contribution to the rising cost of health care should come under special scrutiny. These are population aging, the growing burden of chronic disease and rates of mental and behavioral illness.

## POPULATION AGING

Older Americans are the most rapidly growing demographic group, especially the number over 85, who are the most susceptible to dementia. Today the average 65-year-old male will live to age 83, and the average 65-year-old female will live to age 85. Presently, there are about 19 million Americans over age 75, that is, about 6 percent of the population. In 30 years, there will be close to 30 million, or about 11 percent. Over the same period, the proportion of the population over age 85 will grow from 2 percent to 3.5 percent.<sup>8</sup>

The aged have more severe health care problems than working adults or children. They also have more instances of disability and of inability to perform the ordinary activities of daily living. The elderly require substantially more acute care, more chronic care and more assisted living care than persons of other ages.

Since approximately 15 percent of persons over 70 have mild to moderate dementia, the burden of dementia will exacerbate the other illnesses and infirmities of aging. We should not, however, exaggerate the effects of aging on health spending. Although the elderly account for the largest share of spending, care for working-age adults is currently the most rapidly growing share. Medicare spending, for example, is growing less rapidly than originally projected, as a result of provisions of the Affordable Care Act and various changes in the health care delivery system. The major cost driver in health care is not the increasing incidence of diseases like dementia, but more aggressive treatment of existing diseases.<sup>9</sup>

There is no way for the health care system directly to attack aging. The age distribution of

instead of part of human life. The sick and aged increasingly turn to medical specialists, hospitals and long-term care.

## CHRONIC DISEASES

Chronic conditions, including dementia, related to obesity, sedentary living, smoking and other behavior and cultural changes drive health care spending. Especially important are chronic and acute care related to these changes: diabetes, hypertension, chronic obstructive pulmonary diseases and congestive heart failure are conditions found disproportionately among older persons.

The increasing incidence of these conditions, combined with more aggressive treatment, is a major factor in the rising cost of health care. Yet, reducing their incidence or severity would not, in and of itself, dramatically affect the rate of dementia and its related costs in the short run.

There is some evidence that rates of behavioral conditions, including dementia, have increased independently of factors discussed above. To the extent that is true, then this would be a factor in the rising cost of health care. However, successful prevention or treatment could either slow or exacerbate the rate of growth depending upon the cost profile of the measures employed.

## TECHNOLOGY

Health economists almost universally agree that technological innovation and its rapid diffusion nearly always increase health care spending.<sup>10</sup> Technology is a broad category, encompassing new diagnostics, testing, devices, procedures and pharmaceuticals. Innovation increases spending for a variety of reasons, including salaries of specialist technicians and physicians who use the technology.

Technology contributes to “service intensity” (meaning the addition of new technologies to existing technologies, rather than replacement). Thus, the average patient today receives more services than the average patient yesterday. New technologies often allow more aggressive treatment of conditions that formerly would not have been treated or would have been treated for a shorter time and/or less expensively. Counter-intuitively, the often less invasive nature of the new technology (for example, laparoscopic rather than open procedures) means lower unit cost, but higher aggregate spending as the number of

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the population is affected by birth rates, death rates and immigration demographics. Beyond aging itself, the public's exaggerated expectations of medical science, coupled with its fear of illness, old age and death, contribute to cost increases. Americans treat these conditions as abnormal



procedures rises dramatically. Finally, expensive technologies often are duplicated in medical arms races between physician practices and between hospitals.

As if this were not enough, exaggerated public expectations often result in the widespread reimbursement for new technologies before comparative effectiveness research is undertaken. And even very effective technologies can bring their own host of unintended and costly consequences — among them, drug-resistant microbes and aggressive treatment of late-stage cancers with diminishing returns in length and quality of life.

As important as technology is in cost increases, it has not heretofore been a major factor in dementia care. New surgical procedures are not important in dementia care. Advanced diagnostics may have increased the counting of dementia, but they have not increased treatment costs majorly.

Pharmaceutical treatments for dementia have been disappointing, but it is certainly possible that future medications may halt or slow dementia's progression. Such drugs are likely to be expensive, and, indeed, spending for highly specialized drugs of all kinds is expected to quadruple in the next decade. Yet, the rate of growth of all drugs is expected to be modest over the next decade and to constitute only about 9 percent of total health spending.

There is great debate over other causes of rising health spending. Included in the list of suspects are: social and environmental conditions (poverty and economic inequality, pollution); drug abuse; medical malpractice and defensive medicine; over-regulation; and fraud and abuse. Each of these deserves examination as a possible contributor to the rising cost of health care, but none seems likely to impact dementia more than other conditions of aging. This being said, dementia costs raise a few special concerns.

#### CARE COORDINATION INITIATIVES

Care for frail elderly persons is notoriously difficult to coordinate. Gaps in care exacerbate patient conditions and caregiver stress. Duplications of care can be dangerous and, at the very least, wasteful of expensive resources. Coordination is especially difficult for patients with dementia, particularly in its advanced stages, when they have little or no ability to assist in pulling together

the scattered fragments of the medical system. Thus, better care coordination has the potential to save dollars and improve care.

The Affordable Care Act has reinforced the medical delivery system's search for better ways to coordinate care across the medical spectrum. What do these efforts promise in dementia care?

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The experiments are just beginning, but some early results are demonstrating improved outcomes, caregiver satisfaction and cost savings.<sup>11</sup> Because some early results are promising, and because dementia care coordination aligns well with other care coordination experiments, this is clearly an area for continued experimentation, implementation and evaluation of results. However, implementation faces important barriers: health system fragmentation, patients with multiple comorbidities, the difficulty of redesigning medical practice settings, information system limitations and workforce limitations.

Moreover, many dementia patients do not incur high costs in the early stages of the disease, so initial experiments should focus on potentially high-cost patients, and they must include both patients and caregivers as the focus of attention.<sup>12</sup>

Coordinated care will be particularly successful if it helps patients to avoid or delay entry into those parts of the health system dominated by institutions (hospitals and nursing homes) and specialized physicians. Various parts of the ACA will help in this respect. Quality incentives (rewards and punishments), preventable readmissions and avoiding emergency department visits are examples.<sup>13</sup> Bundled payment and accountable care organization experiments align inpatient and outpatient treatments across episodes of illness. Applying these methods to patients with dementia, if successful, should reduce the cost of their care. But this cannot be a unique dementia strategy; it must be applied across the board to all chronic conditions.

A major uncertainty is whether growth in geriatric specialists or the emergence of dementia

specialization will lower or increase spending on dementia care. Dementia care is ripe for application of evidence-based medicine and cost-effectiveness analysis.

### DEMENTIA PREVENTION

Intuitively, it seems that the most promising way to save money and to improve quality of life would be to prevent dementia onset in as many persons as possible. The “holy grail” of aging research is simultaneously to extend life and to compress morbidity, that is, to reduce the amount of time before death that persons experience limitations on activities of daily living from disease or frailty. Preventing persons from experiencing dementia, especially Alzheimer’s, would be a contribution to this goal.

Full discussion of the evidence for and against current compression of morbidity is well beyond this article. However, the allure of prevention as the model for approaching many conditions (obesity, smoking, mental illness, cancer, heart disease) is powerful enough that we must consider it in relation to dementia.

The most likely candidates for prevention are modification of risk factors for dementia. Although it is not entirely clear what these are, most attention focuses on the usual suspects of behavior that are preventive for many diseases — controlling weight, maintaining physical fitness, avoiding smoking and excessive alcohol

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consumption, controlling blood pressure, keeping active mentally, and so forth. There is some evidence that these can lower the risk and/or delay the onset of dementia, as well as slow its progression.<sup>14</sup>

The other primary preventive strategy is early diagnosis of disease in the brain and the development of drugs to halt or even reverse brain effects.

There are very good ethical and medical arguments for pursuing these strategies and for preventing or substantially delaying the onset of dementia. Cost savings, however, will be unlikely.

There are three main reasons.

- Prevention efforts that focus on behavior changes are very difficult to implement and to produce results. Behavior is extraordinarily difficult to modify. And it’s costly. Because early identification of persons who actually will develop a disease is quite difficult, many persons who will never develop the disease must be educated and motivated to modify their behavior, adding to the cost of prevention. Moreover, the “payoff” often arrives many decades after the added spending.

- Early diagnosis of many diseases (including dementia) doesn’t achieve anything unless there is a treatment to be offered. Thus, even if screening becomes available for dementia, there are expenditures associated with screening large pools of persons (many of whom will never develop the diseases), with risk of false negatives and false positives. Early treatment of risk factors generates considerable spending over many years.

- The “pay me now or later” factor. Prevention of dementia may simply be a matter of delaying onset of dementia or of some other disease. Once it does occur, spending will follow. So far in history, the human mortality rate stands at 100 percent. We all die of something. In an aggressive medical culture, that something will be treated — often at very high cost — before it kills us. Successful prevention only drops the cost curve on a one-time basis; then growth resumes at the same rate as before.<sup>15</sup>

This is not an argument against research into dementia prevention. There are compelling moral and human reasons for prevention. It is, rather, an argument not to rely on prevention as a silver bullet, especially as a means to cost control.

### TECHNOLOGY AND TREATMENT

To date, all drug trials to slow the progression of Alzheimer’s disease have proven disappointing. To the degree that care succumbs to the allure of the technological model of disease treatment, instead of the care coordination model, dementia will contribute significantly to cost increases in the future. For example, a new test to differentiate Alzheimer’s from other forms of dementia carries a cost between \$3,000 and \$10,000. How widely and rapidly should it be disseminated?<sup>16</sup>

Treatment that slows the progression of dementia (as desirable as that is from a human



perspective) is likely to mean less compression of morbidity, thus more time that patients (and their caregivers) cope with limitations on activities of daily living. More time spent living with dementia translates to higher costs for treatments and drugs related to the dementia, as well as more spending on testing, treatment and pharmaceuticals for other illnesses of old age.

Instead of costly, aggressive treatment of end-stage dementia, suppose medicine and families adopted Dennis McCullough's proposal of "slow medicine," meaning excellent chronic care by families and friends in partnership with physicians, nurses, home health aides and other health care professionals?<sup>17</sup> Such care would avoid potentially high costs and stark ethical dilemmas, as well as being more humane.

#### INDIRECT COSTS

The most difficult questions of dementia and health care costs involve whether health policy should adopt proposals to pay for some or all of the care now donated by family and friends. As a consequence of demographic changes such as smaller family sizes, family fragmentation from divorce or geographic separation, and greater female entry into the full-time workforce, traditional practices of caring for frail elders have come under strain and criticism — fewer hands to do the caring, and criticism because traditional practices most often involve female relatives foregoing opportunities for their own well-being in order to remain at home to care for frail family members.

One way to allow persons with dementia to remain at home for a longer part of their illness, and to facilitate "slow medicine," would be to have government or private insurance pay more generously for professional caregivers — home aides, therapists, social workers, nurses — to give care now provided for free. This would provide both respite and the opportunity for family members to remain employed.

Or, government and private insurers could devise a method directly to compensate informal caregivers for their time and for gone wages. This solution to the intersection of contemporary demography and rising rates of dementia is very appealing from three perspectives: avoiding some of the costs of institutionalization and aggressive treatment; being fair to family members who accept the brunt of difficult caregiving; and pro-

moting the moral and cultural value of reciprocal family obligations to bear one another's burdens.

As attractive as such proposals might be, they would add substantially to the future costs of health care. This is so, even recognizing that allowing caregivers to remain longer in the workforce would add to economic productivity, offsetting some of the proposals' costs.

Indirect costs of care are difficult to estimate, but seem to range from \$13,000 to \$28,000 annually. Monetizing them would add spending between \$60 billion and \$126 billion annually by 2020 (in 2010 dollars).<sup>18</sup> Moreover, any scheme for monetizing all or some indirect dementia care costs, in fairness, would have to be applied also to informal caregiving related to all kinds of illnesses and disabilities, generating additional hundreds of billions in spending.

We may envision a future in which Janice will not have to make the daily two-hour trip to visit Earl because dementia will have been defeated or its effects minimized. Perhaps we could even make that vision a reality. What we *cannot* do is pretend that such a reality will reduce the cost of health care. America's cultural commitment to denial of death and to aggressive medical technology guarantee that massive technology or prevention strategies will be paid for now or later in much higher spending. Instead, better care coordination and better "slow medicine" possess better potential to make dementia care more humane and less expensive.

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#### NOTES

1. The names and details of this story are adapted from a case reported in spring 2014 on KCBD-TV in Lubbock, Texas. Names have been changed for privacy purposes.
2. Michael D. Hurd et al., "Monetary Costs of Dementia in the United States," *New England Journal of Medicine*, 368 (April 4, 2013): 1326-34.
3. Hurd et al., "Monetary Costs" and Peggys Dilworth-Anderson et al., "Social Justice, Disparities, and Culture in the Care of the Elderly," *Journal of Law, Medicine, and Ethics*, 40 (Spring 2012): 26-32.

4. Clarke E. Cochran et al., *American Public Policy: An Introduction*, 11th edition (Boston: Wadsworth, 2015): 278-9, from which this paragraph draws.
5. [www.healthbeatblog.com/2014/04/the-next-plague-alzheimers/](http://www.healthbeatblog.com/2014/04/the-next-plague-alzheimers/); accessed August 26, 2014. See [www.alz.org](http://www.alz.org); accessed September 2, 2014.
6. Hurd et al., "Monetary Costs" and Gigi A. Cuckler et al., "National Health Expenditure Projections, 2012-2022: Slow Growth until Coverage Expands and Economy Improves," *Health Affairs* 32 (October 2013): 1820-31.
7. Jonathan S. Bor, "The Search for Effective Alzheimer's Therapies: A Work in Progress," *Health Affairs* 33 (April 2014): 527-33.
8. For aging projections, see [www.aoa.gov/Aging\\_Statistics/future\\_growth/DOCS/p25-1138.pdf](http://www.aoa.gov/Aging_Statistics/future_growth/DOCS/p25-1138.pdf); accessed September 20, 2014.
9. See for example, Charles S. Roehrig and David M. Rousseau, "The Growth in Cost per Case Explains Far More of U.S. Health Spending Increases than Rising Disease Prevalence," *Health Affairs*, 30 (September 2011): 1657-63.
10. See, for example, Kaiser Family Foundation, *Health Care Costs: A Primer* (May 2012); [kff.org/health-costs/issue-brief/health-care-costs-a-primer/](http://kff.org/health-costs/issue-brief/health-care-costs-a-primer/).
11. Kristen Hall Long et al., "Estimating the Potential Cost Savings from the New York University Caregiver Intervention in Minnesota"; Marilyn G. Klug et al., "North Dakota Assistance Program for Dementia Caregivers Lowered Utilization, Produced Savings, and Increased Empowerment"; and Dustin D. French et al., "Healthy Aging Brain Center Improved Care Coordination and Produced Net Savings," all in *Health Affairs*, 33 (April 2014): 596-618.
12. Christopher M. Callahan et al., "Redesigning Systems of Care for Older Adults with Alzheimer's Disease," *Health Affairs* 33 (April 2014): 626-32.
13. On potentially avoidable hospitalizations and emergency department use, see Zhanlian Feng et al., "Hospital and ED Use among Medicare Beneficiaries with Dementia Varies by Setting and Proximity to Death," *Health Affairs* 33 (April 2014): 683-90.
14. Pei-Jung Lin et al., "Unintended Benefits: The Potential Economic Impact of Addressing Risk Factors to Prevent Alzheimer's Disease," *Health Affairs*, 33 (April 2014): 547-54.
15. This phenomenon can be observed even in literature strongly supporting massive efforts to delay the onset of dementia; see the graphs in "Defeat Dementia," at [www.alzheimersresearchuk.org](http://www.alzheimersresearchuk.org); accessed August 29, 2014.
16. See "Test Limits Meet Resistance," *Modern Healthcare*, (July 8, 2013): 4.
17. Dennis McCullough, MD, quoted in David A. Gruenewald, "Can Health Care Rationing Ever Be Rational?" *Journal of Law, Medicine, and Ethics*, 40 (Spring 2012): 18.
18. Hurd et al., "Monetary Costs."

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