The Rising Cost of Dementia:
a look at the direct and indirect costs of medical care and social care

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Costs of Dementia

When examining the total cost of dementia care, several types of costs need to be calculated. The easiest to measure are the direct costs of medical care, which are the costs of treating dementia and other conditions in primary and secondary care. Included in this category are hospital care, medications, and visits to clinics.

The second cost to consider are the direct costs of social care provided by community care professionals and residential home professionals. This includes home care, food supply, transport, and residential and nursing home care.

The hardest category to measure is that of indirect care, or the informal, unpaid care provided by family members and loved ones. To calculate the total cost of indirect care, the time spent by caregivers must be weighed against the lost wages they would otherwise be earning. Similarly, this category includes the loss of wages and productivity of the patient.

Dementia costs in the US/year

The past two decades have seen an increase in the cost of care for patients with dementia that poses a formidable threat for the future of the healthcare system (Figure 1). In 1992, per capita Medicare expenditures for patients with DAT were 1.9 times that of controls, averaging to a cost of $6,208 (Weiner, 1998). In just two years, this jumped to $15,700 spent by medicare, per person, for those with diagnosed AD. This is 2 times that of controls (Sloan, 2002).
The numbers rose slightly in between 1994 and 1998 to $16,054 per person year for a patient with mild-moderate AD (Hux, 1998). This cost is lower if the patient has mild AD ($9,451), but much higher if the patient has moderate or severe AD ($25,724, $36,794) (Figure 2).
A 1999 study investigating the cost of ADRD in managed care organizations (MCOs) found that mean total costs were 1.5 times higher for patients with dementia relative to controls ($13,487 vs $9,276) (Gutterman, 1999). In 2001, it was estimated that costs for formal care average $27,672 per patient with AD annually, the most costly component being long-term care (Rice, 2001).

Combining the cost of formal and informal care, researchers estimated cost between $31,017 and $52,362 yearly per person, for an average of $41,689. Of this cost, the most important attributable cost was for nursing home care (49%, $13,900), followed by out-of-pocket expenses (22%, $6,200), formal home care (20%, $5,700), and Medicare (9%, $2,700) (Figure 3).

Figure 3: Distribution of care costs for patients with dementia. Created using data from Monetary Costs of Dementia in the United States. Hurd, M., Martorell, P., Delavande, A., Mullen, K., & Langa, K. (2013). New England Journal of Medicine, 368, 1326-1334.

Several studies have shown that as the severity of dementia increases, so do the costs to society and Medicare. For example, using a measure of activities of daily living (ADLs), it has been estimated that for each additional ADL impairment there is a $1,958 increase in healthcare costs for that patient (Hill, 2006).

Similarly, patients who scored highly on the NPI (neuropsychiatric inventory, measures the severity of behavioral symptoms) had formal costs between $3,162 and $5,919 higher than those in the low NPI group, with each 1 point increase in NPI resulting in an annual increase
Examining the effects of patient dependence (measured by the dependence scale, DS) and function (measured by blessed dementia rating scale, BDRS) on medical care cost, non medical care cost, and informal caregiving time found a similar relationship between impairment and costs (Zhu, 2008). Something as minor as a 1 point increase in either the DS score or the BDRS score could have as high as a 10% increase in cost (Figure 4).


Dementia Costs in the World/year

The worldwide cost of dementia has increased by 34% between 2005 and 2009 (Wimo, 2010). In 2009, the estimated worldwide cost of dementia was $422 billion US dollars, and in 2010 it was estimated to be $604 billion US dollars (Pouryamout, 2012). About 70% of the global costs occurred in just two regions: North America and Western Europe (Wimo, 2010). If Dementia care were a company, it would be the largest in the world with annual revenue higher than Wal-Mart and Exxon (Figure 5).
Similarly to the American studies, two Swedish studies discovered that the costs of care increase with the severity of the disease. Jonsson, et al found that a decrease of 1 point in the MMSE was associated with an increase of $US 2,000 for the cost of care (Jonnson, 1999). Another found that an increase in the clinical dementia rating score of just 0.5 points (from MCI to mild AD) corresponded to an additional $5,700 in excess costs (Lin, 2013).

**Co-morbidity Costs**

When discussing the cost of care for patients with ADRD, it is important to consider the costs of co-morbid conditions. Compared with the normal population, ADRD individuals are more likely to have mental health conditions, cognitive disorders, neurologic conditions, cerebrovascular disease, diabetes, and injuries (see figure 6). AD patients have 5 times more risk of having major depressive, bipolar, and delusional disorders than the controls (Kuo, 2008).
Since a patient with ADRD has trouble complying with self-management, medication, and diet, treating co-morbid conditions becomes difficult and expensive when compared to non-impaired people (Hill, 2002). They require a higher utilization of inpatient and skilled nursing facilities, had greater numbers of hospital admissions (2.5 times that of control subjects), and had longer lengths of stay (2 days longer than controls).

## Diagnosis Costs

In 2005, over 3,000 patients were screened using a formal diagnosis assessment with an overall cost of $128 per patient screened and $3,983 per patient diagnosed with dementia (Boustani, 2005). Weimer confirmed that the cost per diagnosis of dementia was approximately $4000 based upon estimated charges and costs as well as negative results and refusals to proceed (almost 50% of those who screened positive refused further evaluation) (2009).

A discrete event simulation of ADRD progression and the effects of treatment interventions was developed by researchers in the UK in 2012. They followed simulated individuals for 10 years and found that to diagnose one patient with AD, 17 patients needed to be assessed, resulting in an average assessment cost of $6,000 (Getsios, 2012). Despite high up-front costs, they determined that early diagnosis reduced healthcare costs by $5,300 per patient and societal costs by $11,400.
their high costs. Compared with the standard diagnostic work-up, use of MR imaging cost $598,800 per quality-adjusted life year gained (McMahon, 2003).

**Pre-diagnosis costs**

Even before an official diagnosis, a patient may incur increased costs compared to patients who do not develop ADRD. Among elderly people over the age of 75 in the US, the prodromal period of AD was associated with an excess medicare-based primary care cost of roughly $128.5 to $194.7 million. This is an excess cost of $1,167 for men (85% higher) and $239 for women (26% higher) (Albert, 2002).

This higher cost is attributable to higher than average use of medical services prior to ADRD diagnosis compared to normal subjects. Eaker found that prior to diagnosis, AD cases used an average of 33 medical services per year, other dementia cases used 29, and controls used only 20 (Eaker, 2001).

**Caregiver costs**

Caring for a loved one with dementia is a physically, mentally, emotionally, and financially draining task. This type of caring falls under the informal care category, which also includes loss of wages and productivity in the patient. The Alzheimer’s Association reported that in 2011 there were 17.4 billion hours of unpaid care provided for ADRD patients, valued at more than $210 billion (Lin, 2013). Cost measures include: value of caregiving time, caregiver’s lost income, out-of-pocket expenses for patients, and caregiver’s excess health costs, usually caused by the stress of caring for someone with dementia (Moore, 2001). A more recent study used data from the 2011 and 2012 American time use survey and found that family members and friends spend 30 billion hours yearly caring for the elderly, with an annual cost of $522 billion (Chari, 2014). Langa, 2001 found that as the dementia diagnosis increased, so did the informal care hours spent each week on the patient (i.e., a severely demented patient required an additional 41 hours, compared to 8.5 hours for someone with mild dementia).

Caregivers of patients with dementia are also at risk for poor physical and mental health. An estimated 33% of caregivers exhibit more than 6 items on the geriatric depression scale, indicative of depression (Covinsky, 2003). An additional study found that 76.9% of caregivers reported stress, 72.4% reported having medical issues, and 67% were on medication (Bruce, 2005).
References


