



## The Cost of Dementia in the United States:

### Commentary on the April 2013 New England of Journal of Medicine Report

#### ABSTRACT

The prevalence of dementia appears to be increasing in most western countries. That when coupled with the increased average age of the older population has leads to an expectation that projections of financial costs to individuals, families and to society will grow over the next few decades. The current study, out of the United States, based on a number of robust data bases coupled with in-depth interviews has resulted in projections of the current true costs of caring for elderly people living with dementia. It also allowed for the projection of future costs over the next three decades. The results are quite mind-boggling: “We found that dementia leads to total annual societal costs of \$41,000 to \$56,000 per case, with a total cost of \$159 billion to \$215 billion nationwide in 2010. Our calculations suggest that the aging of the U.S. population will result in an increase of nearly 80% in total societal costs per adult by 2040.”

**KEYWORDS:** dementia, financial cost, elderly, society.



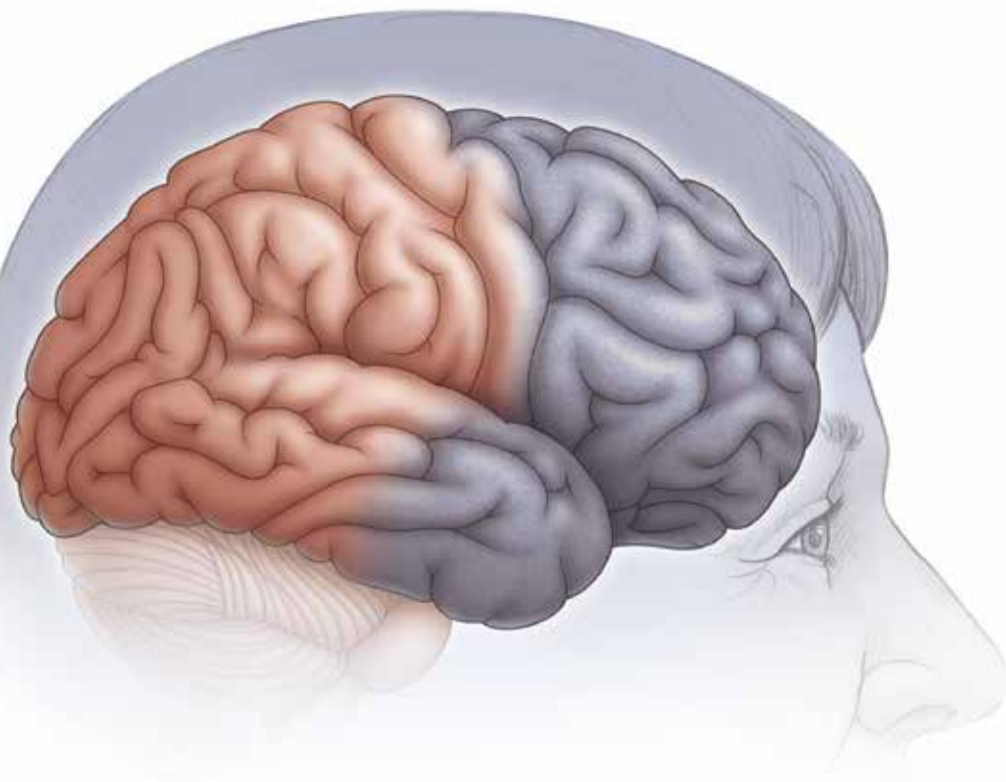
#### Introduction

Virtually all health practitioners other than those focusing exclusively on paediatrics and obstetrics will have a practice that includes older individuals. If that is the case unless it is a unique cross-section of the older population, a substantial proportion of that population will be living with some level of cognitive impairment or dementia, whatever other illness that may have brought them



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to an anatomical or physiological system-based physician or other health care professional. Although most practitioners recognize that there is a high prevalence of disorders related to cognition and behavioural aspects of Alzheimer's Disease and other dementias, they may not realize the extent to which their own small focused lens of practice is part of a much larger issue that will impact all western societies with a special impact on the health care system within its broadest meaning.

To illuminate with a very bright light the extent of the societal as well as health care system challenges of dementia in all its varieties, Michael D. Hurd, Ph.D., Paco Martorell, Ph.D., Adeline Delavande, Ph.D., *et al.* shared their very important work in the April 4, 2013 edition of the *New England Journal of Medicine* (NEJM) in their article *Monetary*

*Costs of Dementia in the United States.*<sup>1</sup> The fact that they chose to focus on the finances behind dementia fulfills a number of key objectives: nothing attracts the attention of policy-makers as much as money. Discussions about emotional challenges and family struggles and tragic loss of personality, all of which are part of the wide spectrum of recognized symptoms, don't grab attention as much as money. Even media focus on such public luminaries as the late President Ronald Reagan did not greatly change public policy. As noted in one of the internet blogs on June 12, 2004, "I'll just add that in this week's Reagan tribute in Time magazine, they mentioned that Ron spent many hours raking the leaves out of his swimming pool...unaware that his Secret Service detail would replace them after he was done." The recognition and provision of what might be construed as a sensitive and low cost intervention certainly did not generate new government policies to provide activities for elders living with dementia. That Reagan had the financial means to assure himself of proper 24/7 care did not generate a catastrophic response by the public if for some reason he had become poor and could not get the basic care that he needed despite his previous service to the nation.

The British film *The Iron Lady* tactfully reflects on the progres-

sive dementia of former Prime Minister Margaret Thatcher, one of the modern world's most renowned political leaders. The

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short vignette in the film where she “wanders” out of her home to buy some milk and comments on the increase in price since she last bought milk (implying in the film that it is something she has not done for a long while and also that perhaps she is not able to actually remember the price of milk more recently in her life rather than very remotely—often a manifestation of the memory changes in dementia). But as in the United States, the appearance of the film did not in its own right spur the British government to allocate huge sums of money for research and care for those with dementia.

### **Mini-Case Study**

When I was relatively new in medical practice I did a great deal of peri-operative care. As a general internist with an interest in geriatrics I was often asked to “clear” patients for impending surgery

or see them post-operatively if there were problems, the main one often being an acute delirium if the patient were elderly. This period of my life started prior to my receiving the first sub-specialty certificate after the recently introduced examination in Geriatrics in 1981. At the time most of my internal medicine colleagues were sub-specializing in organ-based specialties and few really understood “why anyone would focus on the elderly”. However the surgeons whose practice began to focus more and more on the elderly especially the very elderly as techniques and procedures for this population rapidly grew became exquisitely aware that if proper pre-operative planning was not implemented and post-operative care not tailored to vulnerable elders, their bed occupancy would not permit them to have the “flow-through” of patients. Therefore rather early on in my practice I received many pre-operative requests from orthopaedic, urologic, ophthalmologic and general surgeons, whose patients in general tended to be older and for some often came from the long-term care environment.

I recall vividly one example of how easy it was to overlook hints that pointed to vulnerability in the older patient in such a way that their post-operative course was prolonged which might have been a nuisance for the surgeon and the

surgical unit but it could also portend a level of complications from the surgery beyond the risk of the procedure itself. One such case was the of a community dwelling 82 year old man who was booked by his urologist for a transurethral resection of his prostate for typical prostatic symptoms of urinary urgency, hesitancy, nocturia with evidence of incomplete emptying of his bladder. One has to remember that his was prior to simple methods of determining retention through ultrasound and combinations of medications that improve bladder emptying, strength of urinary stream and other symptoms of benign prostatic hypertrophy (BPH).

Also in those days (late 1970's and early 1980's) it was almost standard practice to admit patients to hospital for such procedures often a day or two prior to the surgery itself. I was not asked to see him pre-operatively as the "clearance" had been provided by a cardiologist, known to the surgeon to whom this patient had gone in the past and whose consultation note focused on his heart and the conclusions was, "cardiologically stable for proposed surgery and anaesthetic. I was summoned the day after surgery that according to the operative note "went well" because the patient had become very confused and combative and was speaking "gibberish". When I arrived on the unit the charge

nurse said to me, "he must have had a stroke, at his age, what does one expect? The surgery seemed to go well."

As might be expected nowadays, the patient had a post-operative delirium. When I told the surgeon that he likely had an underlying dementia he said, "I guess we should have known as he kept coming to the office asking my secretary if it was the day he was to be admitted to hospital. She kept correcting him and telling him the day and writing it down, but he would come back the next day and the next, never having the paper on which she wrote the information for him." When I asked if he had any family the surgeon said, "not as far as I know" which proved to be erroneous as he had a daughter and a son who both lived out of town, but when contacted about discharge plans which were going to be a bit complicated they said they "did not know about the surgery" and had been concerned about his memory for the past couple of years but just attributed "to his age". The result of this single example of a case was that the patient was put at risk, probably did not recover completely from his post-operative delirium, probably required long-term care or some in-home supervisory care, the family had to be mobilized in an urgent manner rather than deliberately making appropriate plans and the

surgeon lost a bed for admission for a week until the patient could be discharged. This scenario was probably repeated as many as thousands of times per year in the past and perhaps fewer times now but frequently enough that it affects many aspects of health care delivery, the cost of care and the lives of families and individuals affected by dementia.

### **NEJM study: Methodology**

The startling statistics quote in the NEJM article might be shocking to many readers but are not hard to fathom. They used the Health and Retirement Study (HRS), “a nationally representative longitudinal survey of persons 51 years of age or older that began in 1992. Because the HRS lacks a direct measure of dementia status, a subset of 856 HRS respondents underwent a detailed in-home clinical assessment for dementia, 3 to 4 hours in duration, as part of the Aging, Demographics, and Memory Study (ADAMS), a nationally representative study of dementia in the United States.” To quote again from the NEJM study, “The HRS asks respondents about health care utilization and coverage, and whether they have incurred any out-of-pocket health care expenses for the following services or items: nursing home stays, hospital stays, medical visits, outpatient surgery, home

health care, special services (e.g., outpatient rehabilitation), prescription drugs, and dental services. Total annual out-of-pocket spending and spending according to type of care were computed for each year in the study period. All spending measures were converted to 2010 dollars with the use of the medical care Consumer Price Index.”

The authors did their best to capture the main categories of costs that could be attributed to the care of someone with dementia taking into account an average of people at all levels of the disease with various levels of function and need for caregiver or institutional support. They divided the costs into the following: Out of Pocket Spending, Spending by Medicare,(the equivalent to Canadian spending by the public health care system) Net Nursing Home Spending,( would also have to include retirement home funding although that is harder data to gather as such institutions do not provide statistics in the same way that long-term facilities must), Formal and Informal Home Care (this too is an estimate of time spent by community workers as well as friends and family whether paid or not.

A very important point made in the article that has an impact on attribution of costs is explained as follows: “Persons

with dementia have more coexisting conditions than those without dementia, conditions that by themselves lead to greater costs.

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To isolate the costs attributable to dementia, we estimated multivariate regression models that related a given cost component to the imputed probability of dementia, to coexisting conditions (stroke, diabetes, heart disease, hypertension, lung disease, cancer, psychiatric problems, and arthritis), and to demographic characteristics (age, household income, educational level, sex, and marital status).”

As for the costs actually due to the dementia itself, the authors explain their rationale as follows: “We estimated two measures of the cost attributable to dementia. The first includes costs for care purchased in the market and is equal to the sum of the estimated increases in cost associated with dementia for out-of-pocket spending, Medicare spending, nursing home spending, and spending on in-home care. These estimates

come from the multivariate models discussed above. The second measure adds in the monetary value of time spent by unpaid caregivers that is attributable to dementia, calculated as either the replacement cost or the cost of forgone wages.” This latter part of the equation is often overlooked when estimates of cost are made and is more likely in jurisdictions such as Canada where because of the publicly funded health care system, for the most part governments are mainly interested in “their costs” that is the costs to the system.

It is easy and very convenient to overlook the costs of those providing care. Although the income tax returns allows for some minor deductions for dependent care, that of the family caregiver is not really part of the cost equation and can be quite substantial.

### **Estimated Costs according to the NEJM article:**

Within the defined limits of available information and taking into account some degree of variation, the authors found the following: “The yearly Cost per Person Attributed to Dementia, in 2010 Dollars was \$33,329 for care purchased in the market (95% confidence interval [CI], \$24,223 to \$42,434). That is, someone with a probability of dementia of 1.0 would be expected to incur \$33,329 more in health care costs than someone whose probability of dementia was

zero, when costs were aggregated over all payers. Adjustment for coexisting conditions (i.e. cardiac, respiratory, arthritis) and demographic characteristics reduced the cost estimate to \$28,501 (95% CI, \$20,881 to \$36,122), a reduction of approximately 14%. The adjustments reduced attributable out-of-pocket spending and costs for formal home care and nursing home care by 3 to 18%, but the adjustments reduced attributable Medicare costs by 47%. On the basis of adjusted values, the most important attributable cost was for nursing home care (approximately \$13,900), followed by out-of-pocket spending (approximately \$6,200), formal home care (approximately \$5,700), and Medicare (approximately \$2,700)."

Although it is always hard to translate costs from one jurisdiction to another, especially in the face of profound differences in health care systems, the fact that the vast majority of dementia patients are elderly and are therefore Medicare eligible means that their medical and hospital costs might be closer to Canadian Medicare costs although actual dollar values for various services and costs are often very different in the different jurisdictions. Long-term care is a different story as in Canada, depending on the province, long-term may be somewhat or highly subsidized whereas in the

United States, if you do not qualify for Medicaid payment for Long-term care (which varies from State to State as it does from Province to Province in Canada) the actual costs is personal and often result from pooled sources from supporting family members if the person does not have their own funds. But however it is paid for the actual costs of long-term care can be determined based on average per diem rates for units that care for people with dementia.

The authors point out something very important: "The monetary value of informal home care attributable to dementia did not vary substantially when controlled for coexisting conditions and demographic characteristics. However, it varied by a factor of more than 2 when calculated on the basis of the replacement cost as compared with the cost of forgone wages. After adjustment for coexisting conditions and demographic characteristics, the attributable yearly cost per person, including both the cost of care purchased in the marketplace and the cost of informal care, was \$41,689 (95% CI, \$31,017 to \$52,362) when the valuation of forgone wages was used and \$56,290 (95% CI, \$42,746 to \$69,834) when the valuation of replacement cost was used. Calculating the value of informal home care in terms of forgone wages yielded an estimate of the

cost of unpaid caregiving that was 31% of the total cost; calculating the value of informal home care

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in terms of the replacement cost yielded an estimate of 49%.

### **Estimated Total Costs**

Estimates of the total cost of dementia to the U.S. economy now and in the future are a bit mind-boggling. “The projected total a Per-Person Annual Monetary Costs of Dementia in the United States, in 2010 Dollars based on the statistical estimate of dementia prevalence of 14.7% in the population older than 70 years of age and an annual population cost of \$109 billion for care purchased in the market, with an estimated total cost of \$159 billion to \$215 billion when the estimated monetary value of informal care was included. By 2040, assuming that prevalence rates and cost per person with dementia remain the same, our estimates suggest that these costs will more than double because of the aging of the population.

Although the ability to pay these costs will be ameliorated somewhat by a growing population, they are still expected to increase by 79% when calculated per adult (with adults defined as persons 18 years of age or older).

### **Discussion and Conclusion**

According to the authors in their conclusion, “We found that dementia leads to total annual societal costs of \$41,000 to \$56,000 per case, with a total cost of \$159 billion to \$215 billion nationwide in 2010. Our calculations suggest that the aging of the U.S. population will result in an increase of nearly 80% in total societal costs per adult by 2040. The main component of the costs attributable to dementia is the cost for institutional and home-based long-term care rather than the costs of medical services—the sum of the costs for nursing home care and formal and informal home care represent 75 to 84% of attributable costs.

A very startling conclusion when one thinks about the public’s perception of the “war on diseases” paradigm within which Dementia is generally not thought of in such a category that is great for media outlets and fund-raising campaigns. The authors state, “Our estimate places dementia among the diseases that are the most costly to society. The cost for dementia care pur-



chased in the marketplace (\$109 billion) was similar to estimates of the direct health care expenditures for heart disease (\$96 billion in 2008, or \$102 billion in 2010 dollars) and significantly higher than the direct health care expenditures for cancer (\$72 billion in 2008, or \$77 billion in 2010 dollars). These costs do not include the costs of informal care, which are likely to be larger for dementia than for heart disease or cancer.

It is of interest to compare the US experience with that of other countries in the western world. One such report from 2009 by Alzheimer Europe did that. Despite a range of costs depending on the country and the methodology used to aggregate the costs, the conclusion of the authors was, “Nevertheless, the societal costs of dementia in Europe are enormous and has a great impact of the social and health care systems in all countries. Given the demographic forecasts with an increasing number of elderly people and as a consequence, an increasing number of people with dementia, it is obvious that there is a great need for a EU policy regarding dementia.”<sup>2</sup> Of course the same conclusion can be made from this recent American study.

With this in mind, one can imagine changes in the way and when dementia is identified and perhaps treated so as to change the trajectory of its progress. New

approaches to care that might alter the mix of institutional to home-based care with a decrease in the need of personal professional or family-based support. The use of technologies to enhance care and safety with less in the way of human resource need and the ability to postpone the trajectory of decline so that individuals with the “diagnosis” can function as independently for as long as possible might be able to change the financial equation presented in this paper. If one remembers that at the height of the polio epidemic in the early 1950’s whole institutions were filled with iron lung machines. The Salk vaccine was developed in 1952 and required a few years of clinical trials before it was finally licensed for mass inoculation in the United States in 1955. Children’s vaccination campaigns were launched. In the U.S, following a mass immunization campaign promoted by the March of Dimes, the annual number of polio cases fell from 35,000 in 1953 to 5,600 by 1957.[http://en.wikipedia.org/wiki/Polio\\_vaccine](http://en.wikipedia.org/wiki/Polio_vaccine) - cite\_note-Sass-30 By 1961 only 161 cases were recorded in the United States.

### **The Future?**

Could a dramatic and disease trajectory altering breakthrough occur with dementia? Of course the parallel with Polio or other previously rampant infectious diseases is far

from comparable. Unlike dementia, Polio is a disease caused by one identifiable virus (with a number of disparate strains) and therefore it is a specific disease which unlike Dementia is probably a number of diseases that co-exist including some with a neuro-degenerative component, some with a primarily vascular component and many with a mixture of both in addition to others which we may know something about (such as recurrent head injury) or know little about such as those with strong genetic links. But a combination of medical interventions, life-style modifications to reduce the vascular risk factors and perhaps undertakings that stimulate neuronal growth and the complexity of the neural networks may offer some degree of promise. Even

small changes in the current equation of the dementia picture, could have monumental benefits in terms of quality of life of those likely to experience dementia as well as the substantial emotional and financial costs to the public and the nation. The same issues that exist in the United States exist in Canada and despite difference in health care systems, the ultimate challenges and possible outcomes remain very similar if not the same.

## References

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## SUMMARY

According to the authors in their conclusion, “We found that dementia leads to total annual societal costs of \$41,000 to \$56,000 per case, with a total cost of \$159 billion to \$215 billion nationwide in 2010. Our calculations suggest that the aging of the U.S. population will result in an increase of nearly 80% in total societal costs per adult by 2040. The main component of the costs attributable to dementia is the cost for institutional and home-based long-term care rather than the costs of medical services—the sum of the costs for nursing home care and formal and informal home care represent 75 to 84% of attributable costs.

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