

DEMENTIA: ECONOMIC CONSIDERATIONS



Professor Martin Knapp
Personal Social Services Research
Unit, London School of Economics
and Political Science & NIHR School
for Social Care Research

Dementia is costly. The costs (to the public purse as well as to individuals) will get considerably greater as the population ages. This has focused the minds of many governments on ways to contain those costs, whilst ensuring that people with dementia and their carers can live well. What needs to be done to achieve that important goal?

COSTS

The annual cost of dementia in the UK today exceeds £26 billion (Prince et al 2014). Costs to the NHS are substantial, equivalent to almost 4% of total health spend in the country, but costs to the social care sector are 2.5 times higher. More than half the social care cost falls directly to the people who use services (as self-funders or through user charges). But the largest cost is the time spent providing care and support by unpaid family members and other carers.

Some of these costs are welcome, others not. The ‘good costs’ represent the appropriate, evidence-based treatment and care responses to assessed

needs. The ‘bad costs’ result from late or no diagnosis, unavailability of effective care, crisis admissions to hospital and unnecessarily long inpatient stays. It is hard to calculate the relative sizes of the ‘good’ and ‘bad’ costs, but as a society we surely want to shift the balance from the latter to the former, by developing, and making more widely available, good quality (evidence-based) treatment and care arrangements.

The need to shift the cost balance is obvious if we look at future projections of dementia prevalence. There are 816,000

people with dementia in the UK today, and that number will double in 25 years. Even though the age-specific prevalence rate might be slowing (Matthews et al 2013), the total number with dementia will still grow rapidly as the population ages. Consequently, unless we can do something to change those trajectories, there will need to be even greater reliance on unpaid carers and big increases in health and social care service costs.

RESPONDING TO THE CHALLENGE

The figures summarised above are just aggregates. They are not cost-effectiveness findings. They do not tell key decision-makers what they might do to improve

the situation for individuals affected by dementia, or how to make better use of resources.

There are several options for reducing future costs and improving lives. One is risk-reduction: reducing the number of people who develop dementia, or delaying the age at which the condition interferes significantly with their lives. Known risk factors for the development of Alzheimer’s disease and other dementias include diabetes, mid-life hypertension, mid-life obesity, physical inactivity, depression, smoking and low educational

attainment. Norton et al (2014) estimate that ‘around a third of Alzheimer’s Disease cases worldwide might be attributable to potentially modifiable risk factors’.

Another strategy would involve more timely identification of dementia and better screening (ie faster responses to early signs of dementia, and better screening tools to improve diagnostic accuracy). This would undoubtedly help individuals to plan their lives and should also enable them to get better health and social care support, although access remains variable across the country. Timely diagnosis might therefore also head off some crisis-related costs.

Post-diagnostic support is where most of the costs of dementia arise: this support encompasses all community and other health and social care services that people with the condition might use, plus unpaid support from carers. It also includes costs of care home residence and hospital inpatient admissions. Those latter costs can be huge, but the benefits for quality of life and health can also be substantial.

We now have a small body of robust evidence on what works in post-diagnostic support. Research has focused on areas such as carer support, staff skills, symptomatic medications, psychosocial treatments, better home-based care (including

growing interest in, but not much evidence on assistive and information technologies) and care co-ordination. We also now have a body of *economic* evidence, helping us to recognise what resource consequences might flow from those interventions (Knapp et al 2013).

SUPPORTING FAMILY CARERS

An example of new evidence that can provide guidance to

... more timely identification of dementia ...

commissioners and other decision-makers comes from a study of START: an intervention to help family carers of people with dementia to develop better coping strategies. It was delivered by psychology graduates, with each carer having eight one-to-one sessions. Carers were given information on where to get emotional support, and taught (personalised) techniques to improve their understanding and manage the behaviours of the person they cared for, change unhelpful thoughts, promote acceptance, improve communication, plan for the future, relax and engage in meaningful enjoyable activities.

... head off some crisis-related costs ...

START was evaluated over 24 months in a randomised controlled trial in North London and Essex. Results were very positive. Carers who received START had significantly better health-related quality of life and better mental health by the 24-month follow-up point than carers who got usual support. There were no effects (negative

or positive) on people with dementia (illness severity, neuropsychiatric symptoms or quality of life). And START was clearly cost-effective. Although service costs went up over time for people in both the intervention and control groups - which is not surprising given how dementia usually progresses - overall, the START intervention was no more costly than standard support arrangements.

NEW SCENARIOS

My colleagues and I recently examined the economic consequences of different scenarios for future dementia care (Knapp et al 2014). Some scenarios looked at the wider availability and use of evidence-based interventions, while others looked at the consequences of introducing a disease-modifying treatment (as yet undiscovered) with the potential either to slow disease progression or to delay its onset.

When we looked at the wider availability of interventions such as anticholinesterase inhibitors, cognitive stimulation therapy, case management and carer support, we found that the

overall impact nationally was actually rather modest in cost terms, although with important improvements in health and quality of life. In other words, more widely implementing what we know today to be effective and cost-effective would definitely improve the situation for people with dementia and/or their carers, but it would not

bring down the total cost 'bill' of dementia by any noticeable amount.

On the other hand, a disease-modifying treatment - or, indeed, a risk-reduction strategy - that delayed onset by a year or longer would bring down costs substantially. Slowing the progression of the disease would also potentially reduce costs, because it would delay the need for people to go into care homes or hospital. There would also be gains in health and quality of life for the individuals at risk of developing dementia and their families.

However, disease-modifying treatments do not yet exist, and it is difficult to conjecture when they might become available. It is also difficult to know what they might cost per patient. A high price for a new disease-modifying medication, for example, would considerably reduce (indeed perhaps

... understand the aetiology of the various dementias ...

completely wipe out) the savings on care costs that would be suggested by slowed progression or delayed onset.

MODEM

With colleagues at LSE and other universities, I have recently started a study which will be projecting numbers of people with dementia from now to 2040, the costs of supporting them and the quality of life outcomes under present care, support and treatment arrangements. We will then explore what would happen in cost and outcome terms if better interventions were more widely available. We will run through the scenario exercise described, but now projecting

over a 25-year period, exploring a wider range of potential interventions (including risk-reduction), and carrying out more exacting analyses.

This is the MODEM study. It is funded by the Economic and Social Research Council and the National Institute for Health Research. It will start to generate findings in the next couple of years, and provide a platform of evidence to inform decisions about how the country can develop affordable, effective and cost-effective systems of care and support.

POLICY RESPONSES

In England we have been fortunate over recent years to have had two well-structured policy frameworks: the National Dementia Strategy (Department of Health 2009) and the Prime Minister's Challenge on Dementia (Department of Health 2012). A new dementia

policy ('Vision') is currently being discussed for England, offering suggestions for how society can best respond to dementia over the coming years.

In parallel, on the international stage, the G8 countries - along with the OECD and WHO - have committed to collaborative action to address the dementia challenge. This includes setting up the World Dementia Council. The Council (of which I am a member) is looking for ways to improve finance for investments in new treatments, better care, research collaboration (across governments, academics and industry), harmonised regulatory pathways to accelerate drug development, sharing data,

identification and dissemination of best practice, and awareness-raising with respect to the economic and social challenges of dementia.

A THREE-PRONGED FUTURE

I have mostly concentrated on economic issues, although set in their wider context. We know that dementia is a major, world-

... START intervention was no more costly ...

wide challenge for health and care systems, and for societies more generally. Unless someone suddenly discovers an affordable cure, those challenges will get considerably bigger over the next 40 years. The costs of dementia will also increase considerably. That will

necessarily include the (often hidden) burden falling on unpaid family and other carers.

Efforts to understand the aetiology of the various dementias need as much support as we can muster, as do efforts to find biomarkers and treatments. We urgently need to understand what risk-reduction strategies might be effective,

and how best to implement them. We also need to know what care and support arrangements work best. Then we need to assess whether they represent cost-effective uses of society's always scarce resources.

The policy imperatives are clear, if slightly daunting. If the overarching objectives are to achieve better health and quality of life for people with dementia – indeed for everyone – and to make the best use of resources, then we need a three-pronged strategy to reduce risk, improve care and find a cure.

References

Department of Health (2009) *Living Well With Dementia: a national dementia strategy*. Department of Health: London.

Department of Health (2012) *Prime Minister's challenge on dementia - Delivering major improvements in dementia care and research by 2015*. Department of Health: London.

Knapp M, Lemmi V, Romeo R (2013) *Dementia care costs and outcomes: a systematic review*. *International Journal of Geriatric Psychiatry*, 28(6), 555-561.

Knapp M, Comas-Herrera A, Wittenberg R et al (2014) *Scenarios of Dementia Care: What are the impacts on costs and quality of life?* PSSRU, LSE: London,

Livingston G, Barber J, Rapaport P, Knapp M et al (2014) Long-term clinical and cost-effectiveness of START (STrategies for RelaTives) psychological intervention for family carers and the effects on cost of care for people with dementia: a randomised controlled trial. *Lancet Psychiatry*, 1(7), 539-548

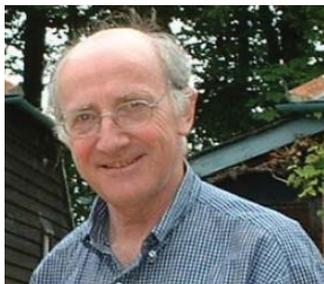
Matthews F, Arthur A, Barnes L et al (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function & Ageing Study I and II. *Lancet*, 382, 1405-12.

Norton S, Matthews F, Barnes D, Yaffe K, Brayne C (2014) Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. *Lancet Neurology*, 13(8), 788-794.

Prince M, Knapp M, Guerchet M, et al (2014) *Dementia UK: second edition*. Alzheimer's Society: London.



HOUSE OF LORDS SCIENCE AND TECHNOLOGY SELECT COMMITTEE



The members of the Committee (appointed 12 June 2014) are Lord Dixon-Smith, Baroness Hilton of Eggardon, Lord Hennessy of Nympsfield, Lord O'Neill of Clackmannan, Baroness Manningham-Buller, Lord Patel, Lord Peston, Lord Rees of Ludlow, Viscount Ridley, the Earl of Selborne (Chairman), Baroness Sharp of Guildford, Lord Wade of Chilton, Lord Willis of Knaresborough and Lord Winston.

Resilience of Electricity Infrastructure

In July 2014, the Committee launched an inquiry into the resilience of electricity infrastructure. The inquiry is focusing on the resilience of the UK's electricity infrastructure to peaks in demand and sudden shocks. It is interested both in the short term (to 2020) and in the medium term (to 2030) as electricity generation is decarbonised. Oral evidence was taken until late January 2015 and the Committee will report by the end of the Session.

2025: Priorities for Scientific Research

In July 2014, the Committee conducted a short inquiry looking at the key challenges that the Government's forthcoming *Science and Innovation Strategy* should tackle and the UK's

main priorities for scientific research. No report was produced but evidence was taken in public and transcripts were published and brought to the Government's attention.

Behaviour Change

In May and June 2014, the Committee took oral evidence from a small number of witnesses to follow up on its 2011 report into behaviour change and assess what progress has been made in this area. This focused on the two behaviour change case studies that the Committee had investigated in its original inquiry: modal shift in transport and obesity. The Committee wrote to the Minister for Government Policy, Rt Hon Oliver Letwin MP, in July, making a number of observations and posing a series of questions, and received a reply.