

Helping family carers of people with dementia to cope is cost-effective

by *Martin Knapp, Derek King, Gill Livingston, Renee Romeo*

Much policy attention is now being focused on dementia, and this includes attention to the many thousands of unpaid family carers who support people with this most devastating of illnesses. Those carers are often very stressed by their caring responsibilities. A new coping strategy delivered to individual carers could help. We describe the strategy and show how a careful evaluation demonstrated that it was both effective and cost-effective.

The 2013 Dementia Summit

In December, Health Ministers from the G8 countries met in London for an unprecedented event: a **Dementia Summit**. At the end of a day of presentations and discussions – and doubtless numerous side-meetings too – those Ministers issued both a *Declaration* and a *Communique*. These statements spelt out clearly the challenges so often experienced by family and other carers of people with dementia, and the need for action. This is paragraph 23 from the *Communique*:

“Carers themselves are often older adults, mainly women, who may be dealing with their own health problems. We call for greater social responsibility and innovation to improve the quality of life for carers and improve care while reducing costs and financial burden including:

- Training for carers, including how to deal with dementia related behaviours
- Improve the reconciliation of care and career for carers
- Support carers in acute situations and crises
- Local and affordable options for care and everyday support
- Promote civic engagement and the development of social networks
- Attract and train community representatives to support people with dementia in social environments
- Creating better and robust evaluation evidence
- Using existing evidence and knowledge.”

These concerns are not new. In England, for example, both the **National Dementia Strategy (NDS)** issued by the Labour Government, and the Prime Minister David Cameron’s **Challenge on Dementia** give great emphasis to the roles played by unpaid carers. The NDS emphasised how ‘Family carers are the most important resource available for people with dementia’ (p.12), and urged full implementation of the 1999 **Carers’ Strategy**. The Prime Minister’s **Challenge** recognised that ‘Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers’ (p.10).

Affordability

One very clear part of the quoted paragraph from the G8 *Communique* is the aim of improving carer quality of life while ‘reducing costs and financial burden’. There is little prospect that state-funded dementia services will, over the coming decades, expand enough to reduce reliance on unpaid family and other carers. Demographic trends will mean substantial growth in the number of people with dementia over the next 30 or more years. Even if we keep today’s care and support patterns unchanged, **this growth will lead to very rapidly escalating costs for health and social care systems**, and so the prospects for replacing unpaid carers with health and social care professional staff look very slim indeed.

Impacts of caring on carers



Most family carers want to provide care and support for their relatives. But a great many will suffer as a result. There could be economic consequences, for example if they have to give up work or reduce their hours, or perhaps if they have to pay for some of the support needed by their husband or wife or mother or sibling. There could be restrictions on their social life, with less freedom to go out or to mix with other people outside the family home. And there could be consequences for the carer's own health.

The updated national *Carers' Strategy* for England, published in 2010 is just one of many official documents to recognise this: 'Caring can be very rewarding and fulfilling but it can also be emotionally and physically draining without recognition and practical and emotional support' (p.26). Among the health consequences for carers, **two of the most common are anxiety and depression**. What can be done to address these potentially very distressing health needs?

New research evidence

As part of a team from LSE, University College London, the Institute of Psychiatry, and a number of clinical settings, we studied a new support arrangement for family carers of people with dementia. The new approach was based on the **Coping with Caring programme developed in the USA**, and was designed to teach carers better coping strategies. The intervention was delivered by psychology graduates without clinical qualifications, although with supervision from a clinical psychologist. They delivered it in eight sessions with each individual carer, over a period of 8-14 weeks. Carers were given information on where to get emotional support. They were also given techniques to improve their understanding of the behaviours of the person they cared for, manage behaviour, change unhelpful thoughts, promote acceptance, improve communication, plan for the future, relax and engage in meaningful enjoyable activities.

Our research looked at whether the intervention – called START (STrAtegies for RelaTives) – was effective in improving carers' mental health and health-related quality of life, and also cost-effective. The START study is still underway, but we have already looked at what effect the intervention had over a period of 8 months. Full details of the findings so far are in two papers published in the *British Medical Journal* in November last year.

We used a randomised controlled design for the study, and involved 260 family carers of people with dementia. We were interested in the usual kind of support available to carers in three localities in North London and Essex, and then what would happen when the manual-based coping therapy delivered by psychology graduates was added. In the **effectiveness study**, led by Gill Livingston, it was found that carers who only got the usual kind of support were four times more likely to have clinically significant depression than carers who got the additional coping intervention.

In the **economic evaluation**, led by Martin Knapp, we found that the additional cost of the coping intervention was *partly* counter-balanced by a reduction in service-related costs for those carers who got it. Overall, costs were slightly but not significantly higher for the group of carers getting the coping intervention compared to those who did not.

When we looked at the kinds of trade-off that might be made between the slightly higher costs and the improvements in outcomes, it was very clear that the coping intervention would be seen as an attractive ('cost-effective') use of NHS resources. We can draw that conclusion with some confidence because the incremental cost-effectiveness ratio – which is the means by which health economists pull together into one indicator both the outcome and cost results from trials such as this – is lower than the threshold that is usually seen as the maximum that the NHS should be paying for new treatments in England. This threshold is associated most closely with NICE (the National Institute for Health and Care Excellence), which prepares clinical guidelines to help the healthcare system get best value for money from its limited resources.

Next steps



Our results so far only relate to the first 8 months after the new coping approach was offered to those carers randomised to the intervention arm of the trial. We are therefore continuing our study to look at longer-term costs and effects – over as long as 24 months.

We also want to examine whether kinds of improvements to the health and quality of life of carers already observed can have knock-on benefits for the health and well-being of the people they support. Linked to that, we will assess cost-effectiveness in terms of the services used by people with dementia – rather than in terms of services used by carers, which has been our focus so far. In particular, we want to see whether this new intervention helps carers to cope with the challenges of unpaid care for longer, thus delaying admission into a care home or hospital for their relative with dementia.

The results obtained so far are very promising. The [2006 NICE/SCIE dementia guidelines](#) – built on a thorough appraisal of available evidence – had lamented the absence of cost-effective carer interventions. Our own [more recent review](#) had similarly found very little economic evidence on what is or is not a cost-effective strategy for supporting carers.

Our new results suggest that a coping strategy of the kind evaluated in START should be given serious consideration as an addition to local care and support arrangements across the country. The findings from START begin to address some of the concerns voiced at the G8 Summit and, more importantly, by the many thousands of dementia carers across the country.

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