

Coping strategy therapy for family dementia carers works long-term

July 12 2019



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A programme of therapy and coping strategies for people who care for family members with dementia successfully improves the carers' mental health for at least a six-year follow-up, finds a UCL study.



Carers who took part in the programme were five times less likely to have clinically significant depression than carers who were not offered the therapy, according to the findings published in the *British Journal of Psychiatry*.

The intervention has also been shown to be cost-effective in a prior study.

"Taking care of a family member with dementia can be immensely difficult, particularly as their condition deteriorates and they may not appreciate their carer, so close to four in 10 family carers experience depression of anxiety," said Professor Gill Livingston (UCL Psychiatry), the trial's principal investigator.

"We now can offer an evidence-based approach to support their <u>mental</u> <u>health</u> in the short- and long-term, which benefits both the carer and the person they're caring for."

The START (STrAtegies for RelaTives) programme is delivered by psychology graduates, trained and supervised by the research team, instead of qualified clinicians, making it easy to implement in many settings.

Those delivering the therapy work with carers to develop coping strategies, supporting them to manage their own wellbeing in the long run without needing further therapy sessions. Carers received eight sessions during which there is an emphasis on planning for the future and accessing further support if needed.

260 family carers took part in the trial, most of whom were caring for a family member who had only recently been diagnosed with dementia.

173 of the participants were enrolled in the START programme for a two-year period and the other 87 were randomly assigned to a control



group that did not receive the intervention.

Six years after receiving the therapy, the carers who were in the START programme had significantly fewer symptoms of depression and anxiety, and the researchers say the therapy programme appeared to be both preventative and improve existing mental ill-health.

Patient-related costs were close to three times lower among the families in the START programme (averaging £5759 for those in START versus £16 964 in the control group in year six), which the researchers say is likely due to the carers being more able to cope and provide care for their loved one.

The difference of patient-related costs did not reach statistical significance, but the researchers say this is due to the fact medical costs can be very large and variable. However, their results do strongly suggest the programme is not only <u>cost-effective</u>, but could save money for healthcare services.

"We've designed our programme to keep costs low, and our results suggest it could actually result in cost savings in the longer term as dementia patients will have fewer costly medical problems if their <u>family</u> carer is healthy and supported," said Professor Livingston.

The START team have developed manuals to make it easier for any healthcare provider to deliver the intervention, and plan to provide accredited training at UCL in the near future. Alzheimer's Society are supporting the team to explore different options for getting the intervention further implemented into practice, and provided funding to make cultural adaptations to widen access to minority ethnic groups. The training manuals are also available in Japanese and Spanish, and are currently being translated into Urdu.



James Pickett, Head of Research at Alzheimer's Society, said: "Being a carer can be a gruelling job; physically and emotionally demanding, 24 hours a day and often done purely out of love. Unfortunately, depression and anxiety can be an inevitable side effect—with 90% of carers telling us they experience stress and anxiety several times a week. Yet, for the 700,000 carers across the UK, many receive little or no support, despite NICE guidelines recommending that they do.

"This is a major breakthrough. We are absolutely thrilled to see this monumental evidence that START is clinically effective at reducing depression and anxiety in carers, and that the effects can still be seen six years later. This could turn the tide for carers and we would love for it to be available to all people who care for someone with dementia. Alzheimer's Society is delighted to be supporting the further development and implementation of the START programme so as many people can benefit as possible."

Shirley Nurock, a former carer who worked on the project as a liaison with the families, commented: "After my husband developed Alzheimer's disease in his 50s, I spent 15 years caring for him. I was stressed and anxious throughout, feeling powerless as I watched him deteriorate, torn between prioritizing care for him, seeing my children through their teenage years and keeping an eye on my ageing parents.

"I can see now that an intervention like START would have allayed some of my earlier anxieties by giving me appropriate practical information, advice about services, support, coping strategies, and helping me learn how to relax. Learning that it can have such long-term effects is extremely encouraging."

More information: Gill Livingston et al, Clinical effectiveness of the START (STrAtegies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with



dementia: 6-year follow-up of a randomised controlled trial, *The British Journal of Psychiatry* (2019). DOI: 10.1192/bjp.2019.160

Provided by University College London

Citation: Coping strategy therapy for family dementia carers works long-term (2019, July 12) retrieved 23 April 2024 from

https://medicalxpress.com/news/2019-07-coping-strategy-therapy-family-dementia.html

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