



Scaling-up an evidence-based intervention for family carers of people with dementia: Current and future costs and outcomes

Martin Knapp¹  | Klara Lorenz-Dant^{1,2} | Magdalena Walbaum¹ |
Adelina Comas-Herrera¹ | Eva Cyhlarova¹ | Gill Livingston³ | Raphael Wittenberg¹ 

¹Care Policy and Evaluation Centre, London School of Economics and Political Science, London, UK

²General Practice, Faculty of Medicine, University of Augsburg, Augsburg, Germany

³Division of Psychiatry, UCL, London, UK

Correspondence

Martin Knapp, Care Policy and Evaluation Centre, London School of Economics and Political Science, Houghton Street, London WC2A 2AE, UK.

Email: m.knapp@lse.ac.uk

Funding information

North Thames NIHR Applied Research Collaboration; University College London Hospitals Biomedical Research Centre; National Institute for Health and Care Research; Economic and Social Research Council, Grant/Award Number: ES/K006975/1

Abstract

Objectives: The STRategies for RelaTives (START) intervention is effective and cost-effective in supporting family carers of people with dementia. It is currently not available to all eligible carers in England. What would be the impacts on service costs and carer health-related quality of life if START was provided to all eligible carers in England, currently and in future?

Methods: Effectiveness and cost-effectiveness data from a previously conducted randomised controlled trial were combined with current and future projections of numbers of people with newly diagnosed dementia to estimate overall and component costs and health-related quality of life outcomes between 2015 (base year for projections) and 2040.

Results: Scaling-up START requires investments increasing annually but would lead to significant savings in health and social care costs. Family carers of people with dementia would experience improvements in mental health and quality of life, with clinical effects lasting at least 6 years. Scaling up the START intervention to eligible carers was estimated to cost £9.4 million in 2020, but these costs would lead to annual savings of £68 million, and total annual quality-adjusted life year (QALY) gains of 1247. Although the costs of START would increase to £19.8 million in 2040, savings would rise to £142.7 million and Quality adjusted life years gained to 1883.

Conclusions: Scaling-up START for family carers of people with dementia in England would improve the lives of family carers and reduce public sector costs. Family carers play a vital part in dementia care; evidence-based interventions that help them to maintain this role, such as START, should be available across the country.

KEYWORDS

carers, coping therapy, cost, dementia, economic evaluation, scaling-up

Key points

- Family carers are the mainstay of dementia support across the world.

This is an open access article under the terms of the [Creative Commons Attribution](https://creativecommons.org/licenses/by/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

© 2024 The Authors. International Journal of Geriatric Psychiatry published by John Wiley & Sons Ltd.

- The STRategies for Relatives (START) intervention has previously been shown to be clinically and cost-effective.
- Making START available to all eligible family carers in England, both currently and projected to 2040, would lead to significant savings in health and social care service costs, amounting to £143 million in 2040.
- Improvements in the mental health and quality of life of carers would also be substantial.

1 | INTRODUCTION

Care systems around the world rely on family carers as frontline care providers of support. Family members provide most of the care needed by people with dementia,¹ and most carers are women.² Unless very effective disease-modifying treatments become widely available soon, the number of people with dementia will increase considerably over the coming decades across all countries.³ In the absence of major changes in the funding and organisation of health and social care, the costs of supporting people with dementia will increase considerably. In England, for example, the number of people with dementia was 650,000 in 2015 and projected to grow to 1,350,000 by 2040,⁴ with 479,000 of those people in 2040 expected to be relying on unpaid care from family members or friends.⁵

While caring can be satisfying, carers often find it stressful and, compared to non-carers, are more likely to be physically unwell, absent from work, experiencing low quality of life, depression or anxiety.^{6–8} Family carers play crucial roles in determining positive outcomes for people with dementia: meeting needs and preferences, enhancing quality of life, improving health.⁹

Not surprisingly, supporting carers is a central plank of most national dementia plans. In England, the importance of supporting carers is emphasised in the Care Act 2014,¹⁰ the Prime Minister's Challenge on Dementia 2020¹¹ and in National Institute for Health and Care Excellence (NICE) guidelines.^{12,13}

A variety of practical arrangements and interventions have been found to be effective in reducing the negative health and quality of life outcomes on unpaid carers.^{14,15} Some of these interventions are also cost-effective.¹⁶ One approach found to be effective and cost-effective is an individual coping intervention for family carers: the STRategies for Relatives intervention (START).^{17–20} We undertook a study to estimate the costs and outcomes of making START available to all eligible family carers in England, currently and projected to 2040.

2 | MATERIALS AND METHODS

We drew on data from trial-based evidence of the effectiveness and cost-effectiveness of START, and epidemiological projections of the numbers of people newly diagnosed with dementia in England to estimate costs and health-related quality of life outcomes from scaling up this intervention to eligible carers between 2015 and 2040. We started from 2015 because our baseline calculations of

dementia costs and future projections relate to that year. Estimates of recent numbers and projections of future numbers of older people with newly diagnosed dementia were based on the Cognitive Function and Ageing Study (CFASII) data on dementia incidence²¹ and Office for National Statistics population projections.²² Proportions of people with dementia receiving unpaid care, health or social care were estimated from data from CFASII and NHS Digital. Analyses were conducted as part of the MODEM (Modelling outcome and cost impacts of interventions for dementia) study.²³

We also had discussions with our project advisors, including researchers and managers of local START services in England in 2022, to better understand operational details, including how many carers decline the offer of START, to feed into our sensitivity analyses.

2.1 | Intervention

The START intervention is a psychological training programme delivered to carers of people with dementia recommended by NICE for supporting adult carers.¹² Individuals participate in 8 sessions delivered by trained and supervised psychology graduates over 8–14 weeks. A randomised controlled trial (RCT) conducted from 2009 onwards looked at the impacts on carers, people with dementia and service utilisation for as long as 6 years. Effectiveness and cost-effectiveness of implementing START were evaluated by comparison with usual care, based around the individual, with each setting seeking to follow NICE clinical guidelines for good dementia care at that time.²⁴ This included 'assessment, diagnosis and information, drug treatment, cognitive stimulation therapy, practical support, treatment of neuropsychiatric and cognitive symptoms, and carer support'.¹⁷

One clinical psychologist trained and supervised 10 psychology graduates who delivered the START intervention to 173 participants (between 11 and 32 participants each over 2 years).¹⁹ A manual and relaxation CDs were provided so that carers could practice the skills and techniques at home. The programme was adapted from an American group-based, 16-session version, 'Coping with Caregiving'.²⁵ Sessions included information on:

- what dementia is and how it affects people;
- carer stress, how to recognise it and techniques for managing it;
- how to manage difficult behaviour;
- how to access local support for people with dementia and family carers;
- planning for the future;

- maintaining skills learnt and making an individual plan about which skills to use.

The RCT found START to be clinically effective and cost-effective in improving symptoms of depression and anxiety in family carers, both in the short and longer term.¹⁷⁻¹⁹ Carers had significantly reduced anxiety and depression and better quality of life compared with usual support after 8 and 24 months. START was cost-effective after 8 and 24 months by reference to thresholds used by NICE. Carers receiving START were still experiencing significant benefits after 6 years compared to controls, who were five times more likely to have clinically significant depression at that point.²⁰ Costs per patient in the START group were around a third of those for the control group by the 6-year point, but the reduced sample size at that final follow-up meant that the test for difference was underpowered. However, the findings suggest START might be cost-saving in the longer term. There was no significant difference between intervention and control groups in time until care home admission 2 years after the intervention,¹⁹ but a trend towards relatively reduced risk of admission in the START group after 6 years.²⁰

A qualitative study analysed participants' experiences of receiving START.²⁶ Carers who participated in the START programme completed a questionnaire 2 years after the study started. Carers reported that the intervention was helpful, providing a range of coping strategies. Two-thirds of respondents reported that they continued to use the relaxation techniques and, quoting from that qualitative study:

'The CDs are very relaxing... still very much being used today.'

A better understanding of dementia made it easier for carers to cope with some challenges they faced:

'Some of the problems that I eventually had to face had been discussed, making me aware of them and able to care better.'

Carers also valued the personal contact with staff and the opportunity to share their concerns with a health professional:

'I think I found the 'talking through' with a knowledgeable person the most helpful.'

2.2 | Target population

We estimated the target population of diagnosed eligible new family carers of people with dementia in England from 2015 onwards. First, we estimated the number of people expected to develop dementia by applying incidence rates²¹ to population projections²² by age and sex. We then made three *sequential* subtractions, at a constant annual

rate: 10% of incident dementia would never be diagnosed; 39% of the remainder would be ineligible for START because of not having a family carer⁵ and 38% of the remainder would decline participation, based on the trial¹⁷ and expert opinion. Data sources are given in Table 1.

2.3 | Costs

To estimate the cost and outcome consequences of scaling up START we used findings from the trial up to the 24-month point.¹⁹ At the 6-year follow-up of trial participants, data were not collected on the same range of outcomes as at earlier time-points, and costs were in part extrapolated from the 24-month values.²⁰

We used costs estimated in the START trial, covering all services used and support received by carers and people with dementia,^{18,19} inflated to 2015 prices using the hospital and community health services index.²⁸ A real cost of care inflation index (modelling based on Office for Budget Responsibility data) was applied to estimates for subsequent years since wages usually run ahead of general inflation. Costs and outcomes in the second year were discounted at a rate of 3.5%. Assuming that psychology graduates stay in their role for 2.5 years on average, and that training would occur only once during this period, we estimated the START intervention cost at £203.78 per carer (at 2015 prices). Costs of health (NHS) and social care service use by carers and people with dementia were estimated over 24 months in the trial.¹⁸ Inflating to 2015 price levels, there was a cost difference in relation to carers' service use of £182.37 per carer between the two groups, with carers in the intervention group using fewer services. Savings from service use by people with dementia were £1467.54 after discounting the second-year figures and adjusting for inflation.

2.4 | Outcomes

Over a 2-year period, the previously conducted trial found that the START intervention improved carers' anxiety and depression, measured by the Hospital Anxiety and Depression Scale,²⁹ and health-related quality of life measured by the EQ-5D.³⁰ Carers in the control group were seven times more likely to have clinically significant depression after 2 years than those receiving the START intervention, and relative quality-adjusted life year (QALY) gains were 0.03 per carer.¹⁹

The trial found that START was cost-effective (with QALY as the outcome) for both carers and people with dementia by reference to NICE thresholds: there was a 67% probability of cost-effectiveness at the £20,000 per QALY willingness-to-pay threshold, and 70% at the £30,000 threshold.¹⁹ As noted above, given sample attrition and slimmer data collection beyond the 24-months follow-up point, we conservatively assumed that QALY gains only occur in the first 2 years post-intervention.

TABLE 1 Values and sources for model parameters.

Parameter	Value	Sources and details
Annual incidence of dementia 2015	124,700	Cognitive function and ageing study (CFASII) incidence rate for 2015. ²⁰ Incidence for subsequent years estimated by applying ONS population projections for England, by age and sex. ¹⁹
Proportion never diagnosed	0.10	NHS data analysis show that 70% of prevalent cases of dementia have been diagnosed (i.e., at a point of time): It therefore includes people who will never be diagnosed and people who have not yet been diagnosed. Consequently, the proportion experiencing onset of dementia who will never be diagnosed in their lifetime is less than 30%, possibly much less.
Proportion not having an unpaid carer	0.39	Proportion of people with dementia (with unpaid carer and social care need) based on people with dementia living in the community (61.35%) derived from the MODEM aggregate model ²⁷ ; assuming one carer per person with dementia.
Annual number eligible for START	68,853	Based on estimate of annual overall incidence of dementia, proportion of people assumed to never receive a diagnosis, and proportion of people with dementia living in the community without an unpaid carer.
Proportion not using memory clinics	0.1	Number of carers to whom START can be offered taking into consideration only carers visiting a memory clinic. Assumes that for every person with dementia with an unpaid carer, one carer would be offered the intervention.
Proportion declining START	0.38	Based on share of potential participants that declined their participation in the study and local services for sensitivity analyses.
Annual number receiving START	38,484	Derived from number of people eligible for the intervention, the proportion not declining and annual incidence.
Cost of START per person	£203.78	Calculated in two stages. First, hourly costs for clinical psychologist and graduate mental health workers adjusted from 2009 to 10 prices (as in the trial) to 2015 prices using the hospital and community health services index. ²⁸ Second, psychology graduates assumed on average to stay 2.5 years in their role, based on the approximate work experience required before graduates enter training to become clinical psychologists. Initial training assumed to be provided once. Time spent by graduate mental health workers and clinical psychologists on training (100 h) calculated separately from time mental health workers spent on delivering the intervention. Time added for weekly supervision of psychology graduates by clinical psychologists. All costs include employer costs (national insurance and superannuation contributions) and appropriate overheads (capital, administration, and managerial, including recruitment costs).
Difference in costs of NHS and social care service use by carers between intervention and control groups (per carer)	£182.37	Based on costs over 24 months reported in the trial, ¹⁹ adjusted for baseline characteristics, with second year discounted at 3.5% and adjusted for real cost inflation (Office for Budget Responsibility convention). All costs include employer costs (national insurance and superannuation contributions) and appropriate overheads (capital, administration, and managerial, including recruitment costs).
Difference in costs of NHS and social care service use by people with dementia between intervention and control groups	£1467.54	Based on costs over 24 months reported in the trial, ¹⁹ adjusted for baseline characteristics, with second year discounted at 3.5% and adjusted for real cost inflation (Office for Budget Responsibility convention). All costs include employer costs (national insurance and superannuation contributions) and appropriate overheads (capital, administration, and managerial, including recruitment costs).
Quality adjusted life years (QALYs) gained (per person, 24 months)	0.03	Regression methods used to estimate group differences after 12 and 24 months for QALYs calculated from EQ-5D. Random-effects models accounted for therapist clustering in START group, adjusted for baseline total score and centre (by which randomisation was stratified). ¹⁹
Number of psychology graduates needed	2219	In the trial, 10 psychology graduates without further clinical training were trained to deliver the intervention. Each graduate worked with between 11 and 32 participants (mean 17.3). ^{17,19}

Values, sources and assumptions for all parameters are given in Table 1.

2.5 | Sensitivity analysis

Probabilistic sensitivity analyses tested for robustness of results to changes in key parameters such as decline rate, QALYs and costs. Decline rates reported by local services delivering START were variable: some memory services reported up to 43% of carers decline to take up the service, increasing with length of time on waiting list (unpublished data). Given the potential to reduce the decline rate among eligible carers, we explored the impact of changing the rate by $\pm 20\%$, ranging between 30% and 45%, assuming a normal distribution. For costs, we assumed baseline cost $\pm 20\%$ variation in the mean value using a gamma distribution, and for QALYs we used the mean value derived from the trial of 0.03 with a 95% confidence interval (CI) of 0.0–0.06, assuming a normal distribution.

Analyses were carried out using Excel (Microsoft Excel Office 365 V2212), with 10,000 Monte Carlo simulations using the Visual Basic for Applications (VBA) macro fully parameterised to conduct the Probabilistic sensitivity analyses.

3 | RESULTS

3.1 | Incidence and target population

The number of older people with incident dementia is projected to increase from 124,700 in 2015 to 203,200 in 2040 (Table 2).

Accounting for people with dementia never diagnosed and carers declining or ineligible for START, the estimated number of carers receiving START would rise from 38,500 in 2015 (95% CI: 33,700 to 43,200) to 62,600 in 2040 (95% CI: 54,900 to 70,200). To deliver the intervention to eligible carers, 2219 psychology graduates would be needed in 2020 and 3616 in 2040.

3.2 | Costs and outcomes

Provision of START to eligible people is estimated to cost £11.5 million in 2025 (95% CI: £8.9 million to £14.1 million) (Table 3), but these costs would lead to total annual savings estimated at £61.3 million (95% CI: £43.7 million to £78.9 million), as well as total QALY gains of 1397 (95% CI: –65 to 2859). By 2040, the annual costs of START would increase to £19.8 million (95% CI: £15.1 million to £24.5 million), total annual savings to £105.2 million (95% CI: £73.4 million to £137.0 million) and total annual QALY gains to 1883 (95% CI: 47 to 3715).

4 | DISCUSSION

4.1 | Scaling-up START

A previously conducted trial found that implementing START—an individual coping intervention for family carers of people with dementia—would improve carers' mental health and quality of life, while reducing health and social care costs.¹⁹ The current NICE guideline on supporting adult carers¹² recommends implementing training programmes based on the components of START. The

TABLE 2 Estimated incident and target population, England, 2015–2040.

Variables	Source	Base	Projections				
		2015	2020	2025	2030	2035	2040
Annual overall incidence of dementia	PSSRU model using CFASII data	124,700	138,200	157,700	180,000	196,900	203,200
Proportion never diagnosed	Assumption	0.1	0.1	0.1	0.1	0.1	0.1
Proportion of people with dementia not having unpaid carer	MODEM aggregate model	0.39	0.39	0.39	0.39	0.39	0.39
Annual number eligible for START	Calculated	68,797	76,245	87,003	99,306	108,630	112,105
Proportion not using memory clinic	Assumption	0.1	0.1	0.1	0.1	0.1	0.1
Annual number offered START	Calculated	61,917	68,620	78,303	89,375	97,767	100,895
Proportion declining START (mean and 95% CI)	RCT evidence	0.38 (0.3–0.45)	0.38 (0.3–0.45)	0.38 (0.3–0.45)	0.38 (0.3–0.45)	0.38 (0.3–0.45)	0.38 (0.3–0.45)
Annual number receiving START (mean and 95% CI)	Calculated	38,484 (33,736–43,232)	42,517 (37,448–47,587)	48,684 (42,877–54,492)	55,333 (48,529–62,138)	60,721 (53,285–68,157)	62,572 (54,894–70,249)

TABLE 3 Baseline and projected future costs and outcomes (England, 2015 prices).

Variables	Base	Projections				
	2015	2020	2025	2030	2035	2040
Real cost of care inflation index	1.000	1.093	1.166	1.275	1.408	1.554
Cost of START per person ^a	204 (161–247)	222 (177–267)	236 (190–283)	260 (209–311)	288 (230–346)	316 (253–380)
Annual total cost of START	7,853,466 (5,968,423 to 9,738,510)	9,446,287 (7,193,772 to 11,698,802)	11,509,304 (8,910,075 to 14,108,532)	14,356,951 (11,105,795 to 17,608,107)	17,489,679 (13,456,519 to 21,522,838)	19,792,885 (15,129,516 to 24,456,254)
NHS & social care costs from START (per person)	182 (146–218)	200 (159–241)	213 (171–255)	232 (186–278)	257 (203–311)	283 (227–339)
Annual NHS & social care costs	7,005,728 (5,410,879 to 8,600,576)	8,495,622 (6,543,613 to 10,447,631)	10,361,586 (7,993,083 to 12,730,089)	12,828,043 (9,837,778 to 15,818,308)	15,584,846 (11,830,410 to 19,339,283)	17,724,964 (13,601,036 to 21,848,892)
Saving service use people with dementia (per person)	1455 (1160 to 1751)	1596 (1267 to 1925)	1709 (1375 to 2043)	1869 (1484 to 2253)	2064 (1647 to 2480)	2281 (1827 to 2735)
Annual savings	56,019,551 (42,484,346 to 69,554,758)	67,907,498 (51,129,918 to 84,685,079)	83,168,617 (64,486,237 to 101,850,996)	103,402,092 (78,462,751 to 128,341,432)	125,336,794 (95,439,280 to 155,234,308)	142,746,816 (109,304,548 to 176,189,084)
Total net annual costs	−41,160,358 (−54,072,029 to −28,248,687)	−49,965,589 (−34,069,953 to −65,861,225)	−61,297,727 (−43,662,709 to −78,932,744)	−76,217,098 (−52,542,705 to −99,891,491)	−92,262,269 (−63,712,534 to −120,812,003)	−105,228,967 (−73,435,949 to −137,021,984)
QALY gain per person (24 months)	0.03 (0.0–0.06)	0.03 (0.0–0.06)	0.03 (0.0–0.06)	0.03 (0.0–0.06)	0.03 (0.0–0.06)	0.03 (0.0–0.06)
Total annual QALY gain	1157 (−10 to 2324)	1247 (−44 to 2537)	1397 (−64 to 2859)	1621 (35 to 3206)	1839 (15 to 3663)	1883 (50 to 3715)
Total number psychology graduates needed	2219	2459	2806	3203	3504	3616
Clinical psychologists	222	246	281	320	350	362

^aAll costs at 2015 prices.

guideline additionally suggests that, given the cost-effectiveness evidence for START, it was reasonable to expand the approach to all eligible unpaid carers. Although the trial did not find that START had a direct impact on the quality of life of people with dementia, there was a decrease in their total service use and, by the 6-year follow-up, a possible benefit of delayed admission to residential care.²⁰ Moreover, carers reported that receiving START had been a positive experience, providing them with helpful and long-lasting tools to help them cope with the challenges of caring for family members with dementia.²⁶ However, based on our discussions with managers of local START services, the intervention has not been widely delivered in England.

Our new analyses explored what would happen if START was available to all eligible family carers of people with dementia across England. Scaling-up START in this way would cost around £11.6 million in 2025, for example, with total annual health and social care

service savings of £60.8 million, making it not only effective and cost-effective, but also cost-saving. (This contrasts with a similar analysis for cognitive stimulation therapy that we conducted recently which found significant outcome gains but no cost savings.³¹) Savings would be generated in both the health and social care systems, including reductions in GP appointments, inpatient hospital stays, social worker and community worker contacts, and day care attendances.¹⁹

Providing START across England would require investments that increased annually given the expected rise in the number of people with dementia. The annual cost of implementing START would increase from around £11.6 million in 2025 to £19.8 million in 2040. In return, these investments would lead to significant savings, with total savings of £104.4 million, alongside significant improvements in carer mental health and quality of life (with total annual QALY gains of 1909 in 2040) over the 2-year period after initiating START, although we know that these gains appear to continue up to the 6-year point.²⁰

Since the START trial, some other approaches have been explored for supporting carers of people with dementia. The Caring for Me and You study compared online cognitive behaviour therapy (CBT) with or without telephone support with a psychoeducational standard care treatment for carers with mild to moderate depression or anxiety caring for people with dementia in an exploratory RCT.³² Although the team were unable to follow up most participants, CBT with telephone support or online psychoeducation appeared to be effective (in terms of carer mental health) and cost-effective (from a health and social care services perspective) compared to online CBT without telephone support.³³ More recently, the New psychosocial intervention to support Independence in Dementia (NIDUS-family) programme aims to help unpaid carers to support people with dementia to stay living independently for longer. The intervention achieved higher goal achievement but had no effect on carers' anxiety or depression.³⁴

4.2 | Strengths and limitations

We used well-regarded cohort data and government projections of future demographic trends to estimate future numbers of people with dementia. These numbers would need to be updated as new evidence is published to calibrate and validate our projections. (Recently, it has been suggested that incidence in England and Wales may be increasing again.³⁵) Evidence on outcomes and costs was obtained from a well-conducted randomised trial conducted in the UK with a diverse range of people. We used trial results up to the 2-year follow-up point to give us the most robust and comprehensive basis for scaling up, but we know from the trial that depression and anxiety outcomes for carers in the intervention arm were better than for carers in the control arm up to at least the 6-year follow-up point, suggesting that we are underestimating the true impact. We used data on costs and QALYs from the trial to estimate the impacts of scaling up the intervention. One possible limitation, however, is that EQ-5D as a tool to estimate QALYs for carers might not be sensitive enough to pick up the full set of impacts of being a dementia carer, particularly overlooking some mental health impacts.²⁷ Given the findings of the original trial that START was particularly effective in addressing carers' mental health needs, it may be that EQ-5D underestimated the true impact of START on carers.

Our calculations included costs of translators (as in the original trial), but further adaptation of the intervention may be needed for carers from some population groups. Work has already been completed to tailor START for South Asian and Black communities³⁶ and make it available in some other languages, as well as showing the feasibility of delivering it in the third sector.³⁷ This is important when considering implementation of START across all communities: our projections do not cover these adaptations. The estimated number of carers to whom START could be offered included only carers visiting a memory clinic or secondary care, and therefore our assumptions on uptake of the intervention may be inaccurate. (Some carers may be ineligible for the service; for example, because of their own dementia.)

We took this uncertainty into account through sensitivity analyses, exploring how outputs from the modelling would vary with changes in key parameters, including the decline rate. Further research is needed to estimate the effectiveness and cost-effectiveness of implementing START in other settings and with cultural tailoring to ensure acceptability among minority communities in the UK.

We were unable to assess any impact of START on amount or quality of unpaid care and support provided by family carers as no data were collected on these in the trial. Consequently, we could not include these cost estimates in our projections.

We have limited direct evidence of the impact of START on people with dementia. However, we know that the reported health-related quality of life of people with dementia did not differ between the intervention and control groups over a 2-year period. Nor was there a *significant* between-group difference in rates of transition to care homes or in death rates.

It has been suggested that START could be further adapted in various ways, perhaps delivered online, but it is not possible to speculate what the impacts would be.

4.3 | Implications

The START intervention presents an opportunity to improve the health and quality of life of family carers of people with dementia. Scaling-up START to the whole eligible population in England would improve the lives of many carers who currently receive little or no support in their caring roles. This would require commitment of additional resources, but the required investment would be much less than the service costs that would be saved. The extra expenditure necessary to establish and deliver these carer support services represents a tiny proportion of the overall cost of dementia in England. For example, the cost of scaling up START in 2040 would be £19.8 million, compared to a projected total service cost of dementia of £80.1 billion⁵—that is, roughly 0.04% of the total. The projected savings would also be modest compared to this total but should be seen alongside the considerable health and quality of life gains for carers.

Carers have always been the mainstay of dementia provision. Globally, 50% of the overall cost of dementia is accounted for by the time inputs of unpaid carers³⁸; in the UK, the proportion is 42%.³⁹ However, while the number of people with dementia is projected to increase markedly over the coming decades, the number of people available, able and willing to be carers may *decrease* as a result of demographic, social and economic trends.¹⁴ Supporting available family carers is therefore crucial. The Taskforce convened by the Alzheimer's Society a few years ago made recommendations for a dementia research 'roadmap', one element of which was 'Develop sustainable and scalable ways to support and enable family and other carers of people with dementia' (⁴⁰, p. 904). This study sought to explore this area.

Previous studies have shown that improving carer wellbeing can delay care home admission of the person with dementia,⁴¹ and there

were trends within START to suggest this may be happening.²⁰ Also, better carer mental health is associated with positive impacts on cognition, mood, quality of life, functioning and healthcare utilisation.⁹ The longer-term results in the original START trial suggest that the skills and strategies that carers learn confer health benefits for up to 6 years. By not being able to measure those effects, our modelling may again be underestimating the true gains from scaling up.

5 | CONCLUSION

START is an evidence-based intervention for dementia carers with long-term clinical and economic benefits. It improves and maintains carers' mental health, which may result in improved support for people with dementia and reduced risk of care home admission. Intervention costs are low and lead to savings in ongoing use of services. Yet START is currently available only in a few localities in England and Wales. Scaling-up START presents an opportunity to improve many people's lives affordably with long-term positive impacts.

ACKNOWLEDGEMENTS

This work was undertaken as part of the MODEM project funded by the National Institute for Health and Care Research (NIHR) and the Economic and Social Research Council (award ES/K006975/1). Gill Livingston was supported by the University College London Hospitals NIHR Biomedical Research Centre and by North Thames NIHR Applied Research Collaboration. We thank Penny Rapaport, Ramira Abbi, Eleanor Martin and Ruth Lukeman for their advice on the operation of local services.

CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest to declare for this paper.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Martin Knapp  <https://orcid.org/0000-0003-1427-0215>

Raphael Wittenberg  <https://orcid.org/0000-0003-3096-2721>

REFERENCES

- World Health Organization. *Global Status Report on the Public Health Response to Dementia*. WHO; 2021. <https://www.who.int/publications/i/item/9789240033245>
- UN Women. *Families in a Changing World*. United Nations; 2020. <https://www.unwomen.org/sites/default/files/Headquarters/Attachments/Sections/Library/Publications/2019/Progress-of-the-worlds-women-2019-2020-en.pdf>
- Nichols E, Steinmetz JD, Vollset SE, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*. 2022;7(2):e105-e125. [https://doi.org/10.1016/s2468-2667\(21\)00249-8](https://doi.org/10.1016/s2468-2667(21)00249-8)
- Kingston A, Robinson L, Booth H, Knapp M, Jagger C. Projections of multi-morbidity in the older population in England to 2035: estimates from the population ageing and care simulation (PACSim) model. *Age & Ageing*. 2018;47(3):374-380. <https://doi.org/10.1093/ageing/afx201>
- Wittenberg R, Hu B, Jagger C, et al. Projections of care for older people with dementia in England: 2015 to 2040. *Age & Ageing*. 2020;49(2):264-269. <https://doi.org/10.1093/ageing/afz154>
- Cunningham NA, Cunningham TR, Roberston JM. Understanding and measuring the wellbeing of carers of people with dementia. *Gerontol*. 2019;59:e552-e564.
- Farina N, Page TE, Daley S, et al. Factors associated with the quality of life of family carers of people with dementia: a systematic review. *Alzheimer's & Dementia*. 2017;13(5):572-581. <https://doi.org/10.1016/j.jalz.2016.12.010>
- Daley S, Murray J, Farina N, et al. Understanding the quality of life of family carers of people with dementia: development of a new conceptual framework. *Int J Geriatr Psychiatr*. 2019;34(1):79-86. <https://doi.org/10.1002/gps.4990>
- Stall NM, Kim SJ, Hardacre KA, et al. Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: a systematic review. *J Am Geriatr Soc*. 2019;67(3):609-617. <https://doi.org/10.1111/jgs.15690>
- UK Government. Care Act 2014. <http://www.legislation.gov.uk/ukpga/2014/23/section/42/enacted>
- Department of Health. *The Prime Minister's Challenge on Dementia 2020: Implementation Plan*. Department of Health; 2016.
- National Institute of Health and Care Excellence. *Supporting Adult Carers. NICE Guideline [NG150]*. London: NICE; 2020. <https://www.nice.org.uk/guidance/ng150>
- National Institute of Health and Care Excellence. *Dementia: Assessment, Management and Support for People Living with Dementia and Their Carers. NICE Guideline [NG97]*. London: NICE; 2018. <https://www.nice.org.uk/guidance/ng97/evidence>
- Brimblecombe N, Fernandez J-L, Knapp M, Rehill A, Wittenberg R. Review of the international evidence on support for unpaid carers. *Journal of Long Term Care*. 2018;0:25-40. <https://doi.org/10.31389/jltc.3>
- Walter E, Pinquart M. How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *Gerontologist*. 2020;60(8):e609-e619. <https://doi.org/10.1093/geront/gnz118>
- Pelone F, Jacklin P, Francis JM, Purchase B. Health economic evaluations of interventions for supporting adult carers in the UK: a systematic review from the NICE Guideline. *Int Psychogeriatrics*. 2022;34(9):839-852. <https://doi.org/10.1017/s1041610220004111>
- Livingston G, Barber J, Rapaport P, et al. Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial. *Br Med J*. 2013;347(2):f6276. <https://doi.org/10.1136/bmj.f6276>
- Knapp M, King D, Romeo R, et al. Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START [STRategies for RelaTives] study): a pragmatic randomised controlled trial. *Br Med J*. 2013;347(2):f6342. <https://doi.org/10.1136/bmj.f6342>
- Livingston G, Barber J, Rapaport P, et al. Long-term clinical and cost-effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomized, controlled trial. *Lancet Psychiatr*. 2014;1(7):539-548. [https://doi.org/10.1016/s2215-0366\(14\)00073-x](https://doi.org/10.1016/s2215-0366(14)00073-x)
- Livingston G, Manela M, O'Keefe A, 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. *Br J Psychiatry*. 2020;216(1):35-42. <https://doi.org/10.1192/bjp.2019.160>
21. Matthews FE, Stephan BC, Robinson L, et al. A two-decade dementia incidence comparison from the cognitive function and ageing studies I and II. *Nat Commun*. 2016;7(1):11398. <https://doi.org/10.1038/ncomms11398>
 22. Office for National Statistics (ONS). *National Population Projections: 2014-based*. Statistical Bulletin. London: ONS; 2015.
 23. Comas-Herrera A, Knapp M, Wittenberg R, et al. MODEM: a comprehensive approach to modelling outcome and costs impacts of interventions for dementia. Protocol paper. *BMC Health Serv Res*. 2017;17(1):25. <https://doi.org/10.1186/s12913-016-1945-x>
 24. National Institute for Health and Care Excellence. *Dementia Guideline CG42*. NICE; 2006.
 25. Gallagher-Thompson D, Solano N, McGee JS, et al. *Coping with Caregiving: Reducing Stress and Improving Your Quality of Life*. Stanford University School of Medicine and VA Palo Healthcare System; 2002.
 26. Sommerlad A, Manela M, Cooper C, Rapaport P, Livingston G. START (STrAtegies for RelaTives) coping strategy for family carers of adults with dementia: qualitative study of participants' views about the intervention. *BMJ Open*. 2014;4(6):e005273. <https://doi.org/10.1136/bmjopen-2014-005273>
 27. Reed C, Barrett A, Lebec J, et al. How useful is the EQ-5D in assessing the impact of caring for people with Alzheimer's disease? *Health Qual Life Outcome*. 2017;15:16.
 28. Curtis L, Burns A. *Unit Costs of Health and Social Care 2019*. PSSRU at the University of Kent; 2019.
 29. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67:361-370.
 30. Williams A Euroqol—a new facility for the measurement of health-related quality-of-life. *Health Pol*. 1990;16:199-208.
 31. Knapp M, Bauer A, Wittenberg R, et al. What are the current and projected future cost and health-related quality of life implications of scaling up cognitive stimulation therapy? *Int J Geriatr Psychiatry*. 2022;37. <https://doi.org/10.1002/gps.5633>
 32. Fossey J, Charlesworth G, Fowler JA, et al. Online education and cognitive behavior therapy improve dementia caregivers' mental health: a randomized trial. *J Am Med Dir Assoc*. 2021;22:1403-1409.
 33. Henderson C, Knapp M, Fossey J, et al. Cost-effectiveness of an online intervention for caregivers of people living with dementia. *J Am Med Dir Assoc*. 2022;23:1468-1473.
 34. Cooper C, Vickerstaff V, Barber JA, et al. A New psychosocial goal-setting and manualized support intervention for Independence in Dementia (NIDUS-Family) versus goal-setting and routine care: a single-masked, phase 3, superiority randomised controlled trial. *Lancet Healthy Longevity*. 2024;4(1):e12-e22.
 35. Chen Y, Bandosz P, Stoye G, et al. Dementia incidence trend in England and Wales, 2002-19, and projection for dementia burden to 2040: analysis of data from the English Longitudinal Study of Ageing. *Lancet Public Health*. 2023;8(11):e859-e867.
 36. Webster L, Amador S, Rapaport P, et al. Tailoring STrAtegies for RelaTives (START) for Black and South Asian dementia family carers in the United Kingdom: a mixed methods study. *Int J Geriatr Psychiatry*. 2023;38(1):e5868. <https://doi.org/10.1002/gps.5868>
 37. Amador S, Rapaport P, Lang I, et al. Implementation of START (STrAtegies for RelaTives) for dementia carers in the third sector: widening access to evidence-based interventions. *PLoS One*. 2021;16(6):e0250410. <https://doi.org/10.1371/journal.pone.0250410>
 38. Wimo A, Jönsson L, Bond J, Prince M, Winblad B. The worldwide economic impact of dementia 2010. *Alzheimer's & Dementia*. 2023;9(1):e13-11. <https://doi.org/10.1016/j.jalz.2012.11.006>
 39. Wittenberg R, Knapp M, Hu B, et al. The costs of dementia in England. *Int J Geriatr Psychiatry*. 2019;34(7):1095-1103. <https://doi.org/10.1002/gps.5113>
 40. Pickett J, Bird C, Ballard C, et al. A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *Int J Geriatr Psychiatry*. 2018;33(7):900-906. <https://doi.org/10.1002/gps.4868>
 41. Dickinson C, Dow J, Gibson G, Hayes L, Robalino S, Robinson L. Psychosocial intervention for carers of people with dementia: what components are most effective and when? A systematic review of systematic reviews. *Int Psychogeriatrics*. 2017;29(1):31-43. <https://doi.org/10.1017/s1041610216001447>

How to cite this article: Knapp M, Lorenz-Dant K, Walbaum M, et al. Scaling-up an evidence-based intervention for family carers of people with dementia: current and future costs and outcomes. *Int J Geriatr Psychiatry*. 2024;e6059. <https://doi.org/10.1002/gps.6059>