DEMENTIA MAINTENANCE COGNITIVE STIMULATION THERAPY PROGRAMME - FINAL EVALUATION REPORT

EXECUTIVE SUMMARY
FOR
AGE UK

May 2018

1 INTRODUCTION

The Dementia Maintenance Cognitive Stimulation Therapy[1] (MCST) / Reminder Finder (RF) Programme was developed by Age UK[2] to help them understand the relative benefits and acceptability of different approaches to delivering MCST based support. The pilot programme also explored the potential benefits to carers of the different approaches, as well as the practical feasibility of delivering different MCST-based models. Whilst MCST and RF sessions follow the same format, the main difference is that RF sessions are longer in duration (MCST is delivered over one to two hours, whereas RF sessions are delivered over 4 hours).

Since Age UK started its MCST programme in early 2017, six local Age UK pilot sites have completed MCST and/or RF sessions:

- Age UK Nottingham and Nottinghamshire - MCST
- Age UK Walsall - MCST
- Age UK Teesside - MCST
- Age UK Mid Devon – RF
- Age UK Wirral – MCST and RF
- Age UK North Tyneside - MCST and RF

The following provides a summary of the key findings from the evaluation detailed in the full programme evaluation report.

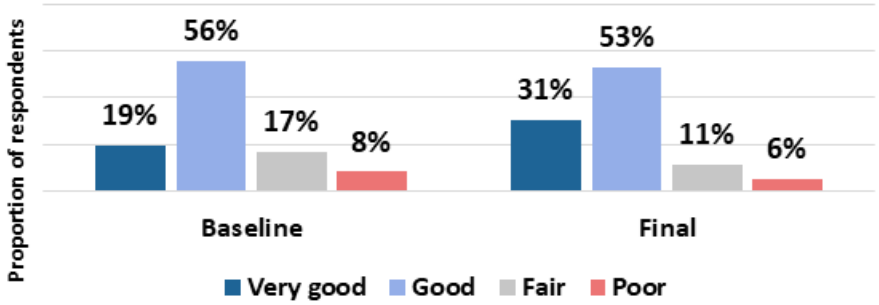
2 KEY FINDINGS

2.1 Benefits of an MCST-based approach

2.1.1 For people with dementia

At the most basic level, MCST adds to the very limited options currently available to people with dementia and their carers. The findings suggest that MCST/RF contributes to the maintenance of a range of different components of wellbeing relating to feelings, memory and everyday life, that would be expected to decrease over time for people with dementia receiving no intervention. Furthermore, the findings demonstrate that there is a positive shift in relation to participants' perceptions of their overall quality of life as demonstrated in the chart below:

Fig 1. Respondents' perceptions of overall quality of life had increased by the end of the programme



[1] CST, or 'Cognitive Stimulation Therapy', is a brief intervention, developed by researchers at University College London (UCL), for people with mild to moderate dementia. CST is an evidence-based treatment, developed following extensive evaluation of research evidence. Longer-term, or 'maintenance CST', is based on CST structures and aims to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. The effects of CST appear to be of a comparable size to those reported with the currently available anti-dementia drugs.

[2] Refers to Age UK national

Qualitative evidence from participants, along with that from carers and staff through their own observations, reinforced that the following benefits were also commonly experienced:

- ★ enjoyment, having fun and increasing levels of happiness
- ★ a sense of belonging, being part of something and making new friendships/social connections
- ★ increased confidence in participants own ability and to try other new things
- ★ improvements in communication, including reading and writing
- ★ improvements in memory and mental ability
- ★ having more energy and having the opportunity to be more active
- ★ increased levels of physical activity

> "(It) makes you start to think again and look at yourself different.."

2.1.2 For carers

Although data from carers surveys suggests that there was little change across the components of wellbeing, support and self-care being measured, qualitative evidence from carer interviews paints a different picture. Feedback from carers suggests that they have seen benefits from MCST/RF. They value the time that it provides them to do things for themselves – whether it's volunteering, running errands or spending more time with friends and family – which reduces the pressure and stresses that they experience in their caring role. It provides a welcome break from feeling that you have sole responsibility for someone.

> "I have space. I feel as if I can concentrate more on other things otherwise everything is focused on (husband) – shaving, dressing, getting his breakfast, getting him a cuppa …everything"

Another benefit for carers, which cannot be undervalued, is the improvements that they see in the person they care for. This, in some instances, has translated into an improved home life, and confidence in what the person they care for is able to do.

> "..real, tangible benefits - (participant) had lost her independence but more confident now. The stimulation makes her more alert, more aware, more functioning"

2.1.3 For local Age UKs / delivery staff

Local Age UKs have also experienced a range of benefits through their participation in the programme. At an organisational level feedback suggests it has had a positive impact reputationally, with credibility amongst partners and funders being enhanced. It has also provided the organisation with new skills, experience and learning that can be transferred, and be of benefit, to other services and provision.

For the staff involved in delivery it has given them a new and rewarding opportunity to work with clients, whilst developing new skills and taking on new responsibilities. Being able to directly see the benefits of their work on people affected by dementia and their carers is motivating and had a positive impact on morale.

> "Seeing clients regain their confidence; wanting to go out and wanting to achieve again"

2.2 Comparison between MCST and Reminder Finders

2.2.1 Effectiveness

For people with dementia

Feedback from participants was largely consistent across both models of delivery (MCST and RF) in terms of their experience of participation and what they get from it. Likewise, observations from delivery staff and carers relating to experience and benefits for participants suggest little difference.

Similarly, changes between the baseline and final DEM-QOL surveys, where the majority of measures showed a slight increase or a maintained level, shows very similar shifts for both MCST and RF participants.

Based on our findings, we conclude that both models provide effective support for people with dementia with no apparent differences between them in terms of experience and outcome.

For carers

When looking at the survey responses from carers of MCST and RF participants separately the findings suggest that there is a slight improvement from baseline to final survey across the majority of measures for RF participant carers and a slight decrease for MCST participant carers. Qualitative evidence from carers suggests that the type of benefits experienced are similar regardless of the delivery format. However, what does seem to be different is the extent of the benefit, with carers of RF participants reporting a more pronounced level of benefit for themselves.

In addition, benefits realised for the carer appeared to be related to the intensity of their caring responsibilities. For those that did not have full time caring responsibilities the pressures and stresses were not as pronounced. The most important thing for them was that their loved one was having a positive experience and were benefitting from the sessions.

The findings suggest that carers of those people who participated in RF sessions, and those that had full time caring responsibilities, experienced a more profound benefit from the longer respite time provided.

2.2.2 Acceptability

Feedback from participants, carers and project staff has been overwhelmingly positive about the structure and format of both MCST and RF sessions.

Initial assessment and selection of participants of similar abilities plays a crucial role in ensuring appropriateness and acceptability. RF participants appeared to have a higher starting point in terms of baseline DEM-QOL measures, which may suggest a more moderate level of dementia and therefore longer sessions being more appropriate and acceptable.

Going forward there are examples of projects that have opted to change from MCST to RF or vice versa based on their experience, with one project feeling that the length of MCST sessions made things feel rushed, whilst another felt that the longer sessions of RF was too intense for staff delivering.

The findings do not suggest any differences in acceptability or appropriateness between MCST and RF, however at a local level one model may be preferred over the other by the delivery organisation.

3 LEARNING FOR FUTURE DELIVERY

3.1 Critical success factors and enablers

A number of critical success factors and enablers have emerged through the learning and experience of the pilot projects:

- **Opportunities in local area** – there need to be sufficient gaps in local provision that can be addressed through MCST/RF provision and/or can complement what already exists. Accessibility (location of venue, transport etc) is also a key consideration.
- **Relationships** – developing and/or strengthening relationships with local organisations and promotion of MCST/RF provision to ensure sustainable referral pathways. This is important for people entering the service but also for referring to other support when groups come to an end.
- **Referral pathways** – linked to the above, the time required to develop referral pathways should not be underestimated and sufficient lead in time should be considered.
- **Staff** – ensuring delivery staff are equipped with the necessary skills, experience and resources to conduct group facilitation with this client group is essential. Furthermore, confidence and willingness to embrace a new opportunity is also important.
- **Balancing continuity with resilience** – Continuity of delivery staff is an important aspect of developing trust and familiarity/understanding of the participants. It also contributes to the ongoing development of staff through experience. However, resilience of the service can depend on having other staff that can also support/deliver the sessions.
- **Funding** - Whilst at least one local Age UK expressed concerns about charging for the service and used Age UK funding to provide support free of charge, all felt that it was important to find ways to fund MCST/RF sustainably. All the pilot projects have looked at detail costings and identified appropriate charges for their second round of delivery.
- **Participant selection** – effective assessment of participants plays a vital role in ensuring the acceptability and appropriateness of MCST/RF, and in selecting/pitching activities at an appropriate level. Furthermore, understanding the preferences of individuals can help to inform the balance of the group (e.g. gender mix)
- **Adherence to format** – the evidence base developed in regard to the benefits on cognitive function are based on the delivery format set out in the training and user manuals. Adherence to the defined format is important.
- **Post participation** – having referral routes/signposting options for participants and carers when the sessions come to an end needs to be considered and planned from the outset.

Overall, the findings from this evaluation suggest that MCST-based approaches can be delivered effectively by local Age UKs in a way that is acceptable, appropriate and generates benefits for all involved.