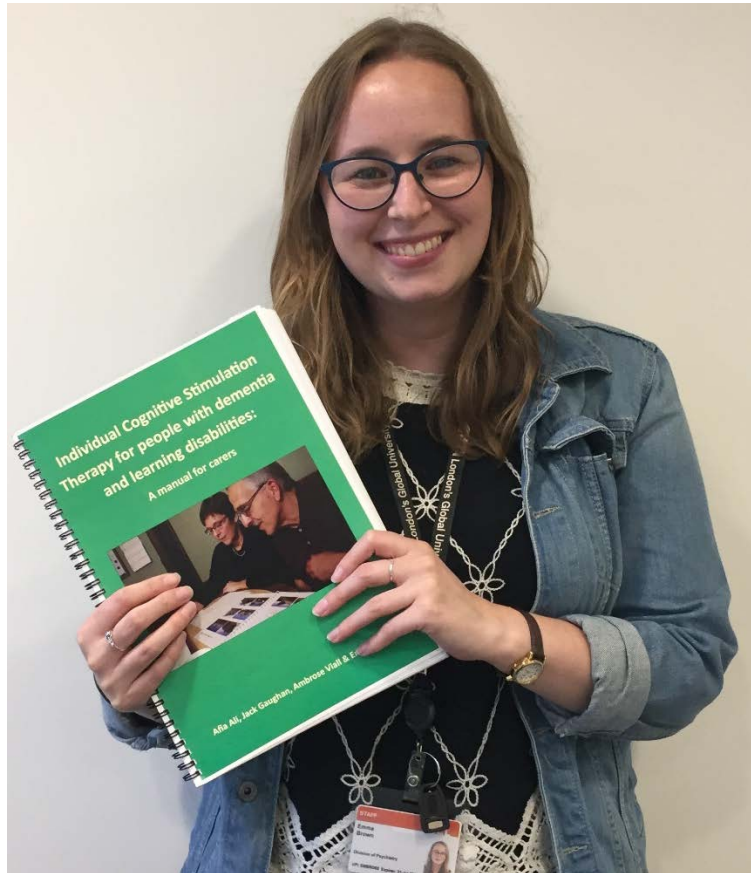




UCL

Individual Cognitive Stimulation Therapy study for people with dementia and learning disabilities: study feedback



THANK YOU!

From all the researchers working on the study into individual Cognitive Stimulation Therapy for people with an intellectual disability and dementia, we wanted to say a big thank you for your involvement in the research. From answering all Emma's questions, to completing the activities together, we appreciate the time you have given to help us complete the research. Below is a summary of what we found so you can hear more details about what you have been involved with!

The Research

Our study has been a 'feasibility randomised controlled trial'. This means that our primary interest has been finding out whether this sort of research is acceptable, feasible, interesting and potentially helpful for the target audience. We have also been interested to see if there was any difference between those who completed the manual of activities (what we call the 'intervention') and those who did not initially complete the activities (what we call the 'control' group) on the range of questionnaires you completed with Emma.

Taking Part

Our aim when starting the study was to recruit 40 pairs of people, with 20 pairs initially completing the intervention and 20 pairs to go into the control group. We are happy to say we managed to hit our target and recruit 40 pairs, and even ended up with too many people by the end!

Thank you for your patience and time when meeting with us throughout the study and answering our questions. We managed to keep in touch throughout the 20 week process and almost everyone kept going with the study until the very end.

Results

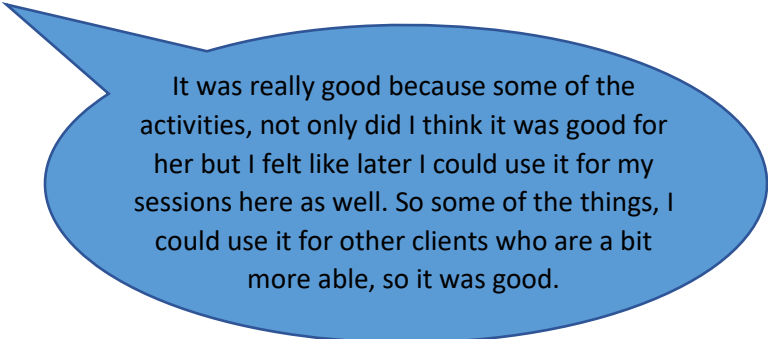
The fact we managed to recruit the number of people we needed suggested to us there was enough interest from people to take part. Those who completed the intervention managed to complete a high number of sessions out of the 40 activities, suggesting carers were able to find the time to do them and the service users were able to sit down with them and complete them. Positive feedback from those who completed the activities also suggested that most of the activities were manageable and enjoyable.

When comparing the results on the questionnaires you completed, on most things we asked about we did not find what we call a 'significant difference' between those who completed the intervention and the control group. As the number of people taking part in our research was relatively small compared to most research studies, it can be difficult to find a significant result. However, we did notice a significant difference between those completing the intervention and those in the control group on the 'Quality of Life' questionnaire. This suggested that carers of those who completed the intervention thought the people they worked with had a higher quality of life after completing the activities than carers of those who had not completed any activities at the end of the same 20 week period. This could suggest that completing the activities may help improve the quality of life of the service user.

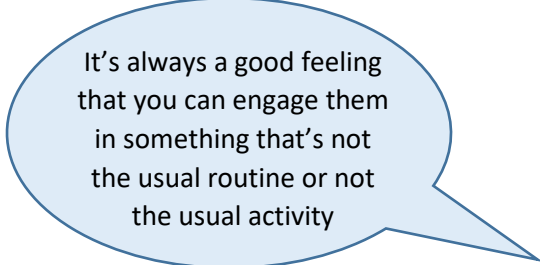
Feedback

Thank you very much to those of you who have provided feedback to us along the way, through diaries, comments, questionnaires or interviews. Any feedback we have had is really helpful for us to understand your experiences and what we could improve. If you have not had the opportunity to provide us with feedback and would like to, please do not hesitate to contact the study team.

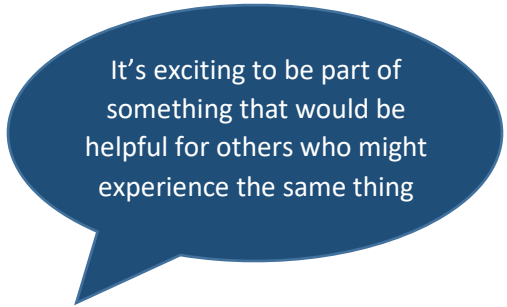
Generally, we have received very positive feedback about the manual, with people saying they liked the range of activities, the use of pictures and the support they had from the study team. We also valued feedback on specific activities that may have been too difficult for some people or not interesting enough. Here are a few examples of some of the feedback we received:



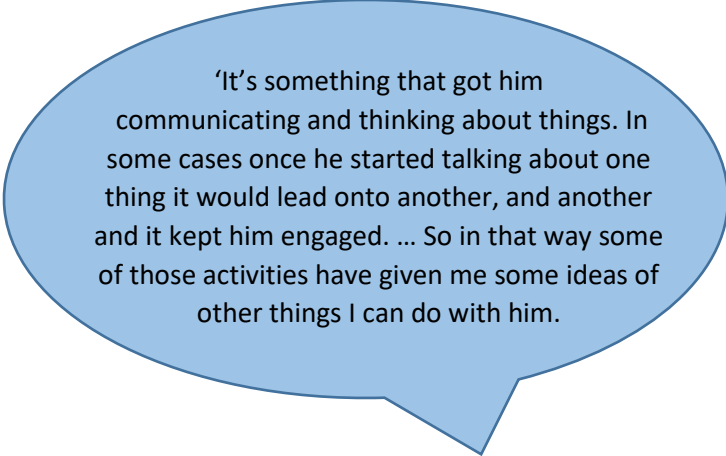
It was really good because some of the activities, not only did I think it was good for her but I felt like later I could use it for my sessions here as well. So some of the things, I could use it for other clients who are a bit more able, so it was good.



It's always a good feeling that you can engage them in something that's not the usual routine or not the usual activity



It's exciting to be part of something that would be helpful for others who might experience the same thing



'It's something that got him communicating and thinking about things. In some cases once he started talking about one thing it would lead onto another, and another and it kept him engaged. ... So in that way some of those activities have given me some ideas of other things I can do with him.

In Future

You should hopefully all now have a copy of the individual CST manual, which is for you to keep and use as you like. If you were already completing the intervention, feel free to continue completing the activities together if you enjoyed them or found them helpful. If you were in the control group that did not initially get a copy of the manual, we hope you have fun and enjoy completing the activities. If there was anyone in the control group who did not initially have access to the manual and has still not had a copy, please get in touch with Dr Ali and she can provide you with the manual and training.

The plan for our research now is that we will write up our findings into a research paper that will then be published in a scientific journal. We do not yet know where it will be accepted and some journals vary in whether they need a subscription to access them. However, if you would like to be sent a copy of our paper you can check our website where we will post updates regarding when it will be published. You can then contact Dr Ali and she can send you a copy. The publication process does take a long time so it may be a while before the paper is available.

We are unable to comment on the possibility of future research at this stage. While we are unsure if a larger trial will go ahead, the work we have done will help inform any future research on individual CST for people with intellectual disabilities.

When speaking with some of you, we heard feedback that you thought individual CST could be helpful for other residents or people you work with as well. There is also discussion by other researchers regarding providing group CST for people with an intellectual disability (but without dementia).

Contact Details

While we hope we have been able to keep you informed of our research findings, if you did have any follow up questions or queries you are still able to contact the research team. Emma will no longer be working on the project, but the Chief Investigator of the study, Dr Afia Ali is still contactable on the details below. We will also be posting any other news or updates on the individual CST Study website.

Individual CST Study Website:

www.ucl.ac.uk/psychiatry/research/epidemiology-and-applied-clinical-research-department/icst-study

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