

**The impact of individual Cognitive Stimulation Therapy
(iCST) on quality of life and emotional and psychological
symptoms for people with dementia: a randomised control
feasibility trial**

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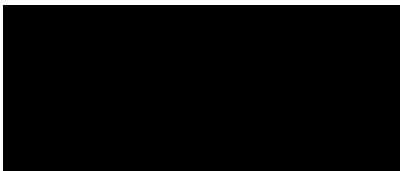
University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



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Date: 16th June 2019

OVERVIEW

This thesis was a joint thesis undertaken with my colleague Luke Gibbor (see Appendix 1 for details). This thesis contains three parts. The first part is the Conceptual Introduction that explores the background research into Cognitive Stimulation Therapy (CST) for people with dementia which formed part of the motivation for this research. The second part is the empirical paper which details our research investigating the impact of professionally-delivered individual CST. The third part is a critical appraisal of this research project.

IMPACT STATEMENT

This study has demonstrated that it is feasible for individual Cognitive Stimulation Therapy (iCST) to be delivered by a healthcare professional. Given the ease of recruitment, high attendance levels (97%), low dropout rate (0%) and absence of adverse effects, this study suggests the utility and feasibility of a larger randomised controlled trial to explore more thoroughly the impact of iCST on cognition, memory, quality of life and the emotional and psychological symptoms of dementia. This research could lead to iCST being offered to individuals with dementia who cannot or do not want to attend a CST group and ultimately mean a larger proportion of people with dementia would be able to benefit from a CST intervention.

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Part 1: Conceptual Introduction

The Efficacy of Cognitive Stimulation Therapy for Improving Quality of Life and/or Wellbeing of People with Mild to Moderate Dementia: A Conceptual Introduction

Introduction

This project aims to expand our knowledge about how to help people with mild to moderate dementia improve their mental health and quality of life by conducting a randomised-controlled trial to test out individual Cognitive Stimulation Therapy (iCST). ICST is a version of the well-evidenced group-based Cognitive Stimulation Therapy (CST) that has been adapted to be delivered on an individual basis.

Dementia is a growing public health problem which not only has a devastating impact on sufferers and those around them but also places a significant burden on public health systems across the world (Cieto et al., 2014). For now there is no cure for dementia and so the best we can offer are management strategies that may slow the rate of deterioration and ideally, enhance mood, cognition and quality of life. The current NICE guidelines recommend group cognitive stimulation sessions (NICE, 2018). However, group-delivery of cognitive stimulation means that it is likely the 61% of people with dementia who live in the community (Prince et al., 2014) do not have easy access to the intervention. In addition, the group-delivery design of CST means that individuals with poor sensory abilities, who dislike group settings and/or who have poor English without easy access to non-English groups may also be unable to access or benefit from CST.

To date one study has tested iCST (Orrell et al., 2017). This study was a single-blind randomised-controlled trial (RCT) undertaken across eight locations in the United Kingdom (UK). The participants were 356 people with mild to moderate dementia and their caregivers who were recruited via memory services, voluntary organisations and community mental health teams. Participants were randomly assigned to treatment as usual (TAU) or to iCST (75 x 30-minute sessions) over 25 weeks. The caregivers who delivered iCST were given training and support from an unblind researcher. This study found that iCST improved the quality of the caregiving relationship and the wellbeing of the carer, but found no differences between the iCST and TAU groups in their post-intervention cognitive abilities and self-reported quality of life. However, 66% of the caregiving dyads did not complete at least two sessions per week and 22% of the dyads completed no sessions. Given the low adherence, the study findings cannot be deemed conclusive evidence that iCST is not effective. In addition, it is possible the family carers did not have the necessary therapeutic skills to deliver iCST as it was intended in the protocol. This project aims to re-investigate

the effectiveness of iCST using professionally-delivered iCST so that we can be assured of protocol adherence.

If iCST is found to be beneficial in improving quality of life and/or the emotional and psychological symptoms of people with dementia, it would mean a much wider group of people with dementia would be able to benefit from the intervention. This project will test the effectiveness of iCST by carrying out a randomised control feasibility trial which, if successful, could pave the way for a larger trial. This conceptual introduction starts by exploring the background to this research before examining the existing evidence base for CST/iCST in relation to mental health and quality of life. It critically appraises the existing evidence and then outlines the rationale for the present research.

Background

Dementia

Every three seconds one person in the world develops dementia and it is estimated there were 50 million people globally with dementia in 2017 (Alzheimer's Disease International, 2018). This number is expected to nearly double every 20 years, meaning a total of 75 million people will be living with dementia in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2018). It is clear that dementia represents one of the greatest international challenges for public health and is the most common cognitive degenerative disease amongst the elderly (World Health Organisation, 2012). Dementia has multiple causal trajectories but Alzheimer's disease is deemed to be the main one, accounting for approximately 60% of cases (Thies and Bleiler, 2011). It is estimated that the global costs of dementia rose from US\$ 604 billion in 2010 to US\$ 818 billion in 2015, which amounts to an increase of 35.4% (Alzheimer's Disease International, 2015). Experts anticipate that the public cost of dementia will be \$1 trillion by 2018 and \$2 trillion by 2030 (Alzheimer's Disease International, 2015). There is no doubt it is essential to identify and deliver evidence-based effective treatments and interventions to control, manage and minimize the cognitive, psychological and behavioural symptoms of dementia and improve the mental health and quality of life of those with dementia and as a

consequence, the quality of life and mental health of their formal/informal carers (Shah, Wadoo and Latoo, 2010).

Treatment options

The main treatment options for dementia are pharmacological treatments and psychosocial interventions. To date pharmacological treatments have produced mixed results (e.g. Galimberti and Scarpini, 2012). The three most promising anticholinesterase inhibitors (AChEI) (donepezil, rivastigmine and galantamine) appear to be efficacious for mild to moderate dementia in reducing the cognitive, behavioural and psychological symptoms associated with dementia. However, it is not possible to predict which patients will benefit from these drugs and there are numerous documented negative side effects including nausea, vomiting, dizziness, headaches and confusion. In addition, researchers have been unable to identify any drugs that consistently modify the actual progression of the disease (Galimberti and Scarpini, 2012). In light of this, interest in developing psychosocial interventions to manage dementia has increased greatly in recent years. There are various types of psychosocial intervention (e.g. environmental, behavioural, social) but research suggests that those based on cognitive stimulation are the most effective (e.g. Cooper et al., 2012). Cognitive stimulation interventions are those which directly target cognitive functioning and involve engaging the people with dementia in a wide range of enjoyable activities and discussions with the aim that the effects of the intervention generalize beyond the training context (Bahar-Fuchs, Clare and Woods, 2013).

Cognitive Stimulation Therapy

Cognitive stimulation interventions are generally implemented in a group-setting and aim to provide mental stimulation by involving individuals in a diverse range of engaging activities and discussions (Woods, Aguirre, Spector and Orrell, 2012). They are mainly targeted at individuals with mild to moderate dementia and aim to improve their cognitive functioning and thereby improve their psychological wellbeing and quality of life. A recent synthesis of 22 systematic reviews which included 197 studies on a wide range of psychosocial therapies, found that group cognitive stimulation improved cognitive and social functioning and quality of life for

individuals with dementia and that Cognitive Stimulation Therapy (CST) was one of very few such types with a robust evidence base (McDermott et al., 2018).

CST is a manualised programme of structured group cognitive stimulation that was developed in the UK. It has been repeatedly evaluated (internationally), has been translated into other languages and there are readily-available guidelines about how to adapt it for different cultures and languages which has meant it is used across the world (e.g. in Italy and China) (Aguirre, Spector and Orrell, 2014). CST has been shown to improve quality of life and cognition (Spector et al., 2003; Alzheimer's Disease International, 2011; Woods et al., 2012, Orrell et al., 2014). CST is based on the principle of "use it or lose it" in which stimulation of different mental faculties may stop or slow cognitive decline by neuron activation, enhancing their function and survival (Shors et al., 2012). It is also likely that CST reduces an individual's excess disabilities – the disabilities an individual develops which are not directly due to his or her dementia. An example would be an individual losing the ability to feed himself or herself simply because their carer always feeds him or her. Research into the impact of CST on quality of life suggests improvements are mediated by improvements in cognitive domains, with the greatest impact seen in the areas of memory abilities, levels of energy, ability to do daily chores and the relationship with the individual's carer (Woods et al., 2006).

CST is designed to be delivered over seven weeks with twice-weekly 45-minute sessions. To support memory preservation, in the interests of consistency and continuity, each session should be delivered at the same time, on the same two days and in the same place each week as far as possible. The sessions all follow a similar format but each has a particular theme (e.g. food, orientation). It is designed to be a fun and enjoyable for experience and focuses on implicit rather than explicit learning, thus promoting greater participant engagement. Given long-term memory tends to be a relative strength for individuals with dementia, CST aims to use reminiscence to aid with here and now functioning. It aims to improve participant recall by using visual and tactile triggers. The facilitators are encouraged to use stimulating language as a means of supporting the language preservation and development of participants. It is known that improved confidence and motivation can aid the preservation and development of cognitive skills and therefore CST focuses on opinions rather than facts and seeks to give participants regular positive feedback (Woods et al., 2012). On the basis of the 'use it or lose it' principle (Swaab, 1991), CST seeks to provide mental

stimulation to enable participants to be challenged and retains abilities without making them feel de-skilled. It aims to help individuals maximize their potential by encouraging them to generate new thoughts, ideas and associations and exercise planning and organizational skills. The group format of CST helps individuals to build and strengthen relationships within the group. A key tenet of CST is its person-centred approach (Kitwood, 1997) in which individuals are to be valued and respected and recognized for their individuality, each with their own preferences and dislikes.

By combining a cognitive approach with psychosocial and relational aspects, CST is intended to help preserve cognitive, linguistic and executive functioning abilities, and improve dementia-related behavioural and emotional symptoms such as low mood. The aim of this review is to examine the research into CST in respect to its impact on quality of life and emotional and psychological wellbeing in order to assess the potential usefulness and value of exploring individual CST (iCST). When referring to quality of life, I am referring to the standard of comfort, contentment and health experienced by the individual (Schipper, Clinch and Olweny, 1996). When referring to emotional and psychological wellbeing, I am referring to the extent an individual experiences positive thoughts and emotions which enable them to function effectively in society and meet the demands of their everyday life (Schimmack, 2008). This contrasts with the emotional and psychological symptoms of dementia which include anxiety, depression, rapid mood swings, irritability, delusions and sleep or appetite changes (Cerejeira, Lagarto and Mukaetova-Ladinska, 2012).

Existing evidence base

Existing reviews

The following reviews have examined the evidence base for CST: Spector and Orrell (2006); Cotelli, Manenti and Zanetti (2011); Yuill and Hollis (2011); Toh, Ghazali and Subramaniam (2016) and Wang (2016). However, none of these reviews have exclusively focused on randomised-control trials or on quality of life and emotional and psychological wellbeing.

Method for identifying existing evidence

Inclusion criteria for studies in this review

1. Studies which used the manualised CST programme (either the individual, group or maintenance subtype) or the culturally adapted version based on the guidelines by Aguirre, Spector and Orrell (2014).
2. Studies with a quantitative design.
3. Randomised-controlled studies with a treatment as usual/no treatment control condition.
4. Peer-reviewed journal articles.
5. Articles published in English.
6. Articles dating from 2001 onwards, after the pilot study by Spector et al. (2001).
7. Studies which included participants with mild-to-moderate dementia as per the criteria of the fourth or fifth editions of the Diagnostic and Statistical Manual of mental disorders (DSM).
8. Studies which included measures looking at quality of life and/or emotional or psychological wellbeing.

Exclusion criteria

1. There were no specific exclusion criteria.

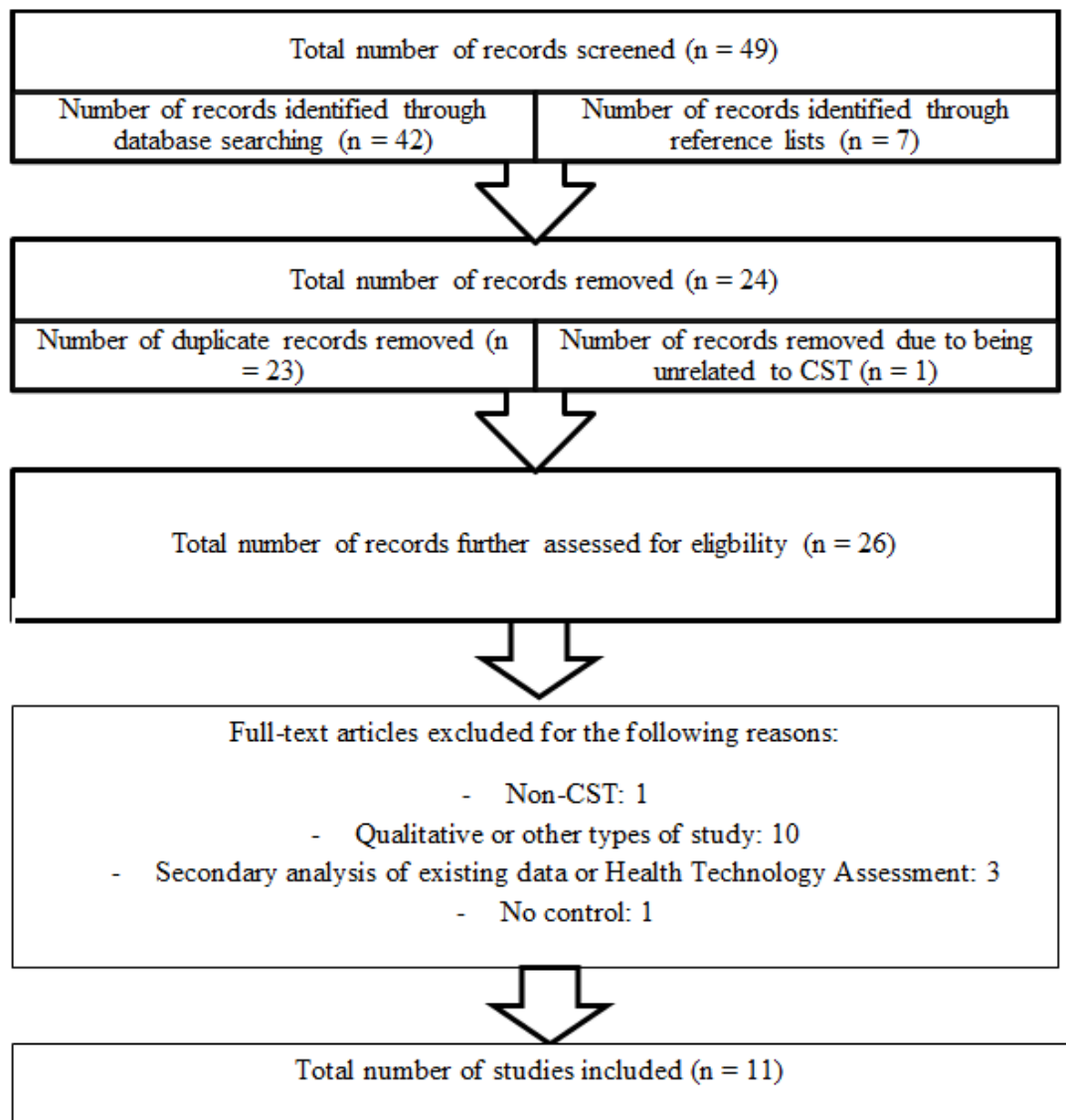
Search strategy

This review was based on a systematic search of the following databases: PubMed, PsychINFO (Ovid), Embase, SCOPUS and Web of Science. These databases were selected due to their high quality and comprehensive approach to publication.

Search terms referring to the participant group (Alzheimer* OR dementia) were combined with search terms referring to the treatment (Cognitive Stimulation Therapy OR CST) and search terms referring to the type of study (RCT OR randomized control trial OR randomised control trial) and these were searched for in

the title and/or abstract of articles across the databases outlined. In addition, a hand search of the reference lists of each identified study was conducted to ascertain whether any additional studies should be included. The next stage involved examining titles and abstracts to determine whether each study fulfilled the review's inclusion criteria. See Figure 1. for details of the number of papers identified, excluded and included. Once all the relevant studies were identified they were read in their entirety and the relevant results were extracted.

Figure 1. Flowchart showing the number of papers identified, excluded and included.



Assessing the evidence base

Given the focus of this research relates to the potential impact of iCST on quality of life and the emotional and psychological wellbeing of participants, this review only considers those measures that consider constructs associated with quality of life and emotional and psychological wellbeing. See Table 1 for a summary of all the papers reviewed.

Table 1. Overview of all reviewed studies.

Authors / country	Experimental Design	Sample	Intervention outcome regarding participant mental health/wellbeing
Spector et al. (2001) (UK)	RCT CST treatment vs control condition	27 PWD CST group: n = 17 Control condition: n = 10 Drop out: n = 10 Mean age: 85.7 years (SD = 6.7) Living situation: at home (12); in care home (23) Setting: 3 residential homes; 1 day care centre (UK)	<ul style="list-style-type: none"> • CST group compared to controls showed significantly greater reduction in depressive symptoms (measured by the Cornell test) ($p = .02$). • No difference between groups in change in anxiety (measured by the Rating Anxiety in Dementia scale) ($p = .09$).
Spector et al. (2003) (UK)	RCT CST treatment vs control condition	201 PWD CST group: n = 115 Control condition: n = 86 Dropout: n = 34 Mean age: 85.3 years (SD = 7.0) Setting: 18 residential homes; 5 day care centres (UK)	<ul style="list-style-type: none"> • CST group compared to controls showed significantly greater increase in quality of life (measured by the Quality of Life – Alzheimer’s Disease Scale) ($p = .028$).

Niu et al. (2010) (China)	RCT CST treatment vs control condition	32 PWD CST group: n = 16 Control condition: n = 16 Dropout: n = 0 Mean age: 79.85 years (SD = 4.31) Setting: military sanatorium (China)	<ul style="list-style-type: none"> • CST group compared to controls showed significantly greater improvement in their Neuropsychiatric Inventory total score ($p < .001$).
Coen et al. (2011) (UK)	RCT CST treatment vs control condition	27 PWD CST group: n = 14 Control condition: n = 13 Dropout: not specified Mean age: 79.9 (SD = 5.6) Setting: 2 long term care facilities; 1 private nursing home (UK)	<ul style="list-style-type: none"> • CST group compared to controls showed a greater improvement in quality of life (measured by the QoL-AD) but improvement fell just short of significance ($p = 0.055$).
Aguirre et al. (2013) (UK)	RCT CST treatment vs control condition	272 PWD CST group: n = 272 Control condition: n = 86 (Spector et al. 2003 control condition results) Dropout: n = 36 Mean age: 82.6 years (SD = 8.1) Setting: half participants came from day centres, community mental health teams and voluntary sector; half participants from residential care homes (UK)	<ul style="list-style-type: none"> • CST group showed significant improvement in quality of life (measured by the DEMQOL) ($p = .004$). • No significant difference in quality of life between groups in quality of life (measured by the QoL-AD) ($p = .357$).
Yamanaka et al. (2013) (Japan)	RCT CST treatment vs control condition	56 PWD CST group: n = 26 Control condition: n = 30 Dropout: n = 9 Mean age: 83.91 years (SD = 5.98) Setting: 3 residential homes; 1 nursing home (Japan)	<ul style="list-style-type: none"> • CST group compared to controls showed significant improvement in quality of life (measured by the proxy EQ-5D) ($p = .019$) and there was a positive trend in the proxy QoL-AD ($p = .06$). • No difference between groups in quality of life as measured by the

			self-rated EQ-5D ($p = .781$) or self-rated QoL-AD ($p = .673$).
Apóstolo et al. (2014) (Portugal)	RCT CST treatment vs control condition	56 PWD CST group: $n = 27$ Control condition: $n = 29$ Dropout: $n = 8$ Mean age: 81.65 (SD = 5.64) Setting: nursing homes (Portugal)	<ul style="list-style-type: none"> No significant difference between groups in depressive symptoms change (measured by the GDS-15) ($p = .302$).
Cove et al. (2014) (UK)	RCT CST plus carer training vs. CST treatment vs control condition	68 PWD CST plus carer training group: $n = 21$ CST group: $n = 24$ Control condition: $n = 23$ Dropout: $n = 18$ Mean age CST plus carer training group: 75.4 years (SD = 5.56) Mean age CST group: 76.8 years (SD = 6.62) Mean age control condition: 77.8 years (SD = 7.47) Setting: 1 supported living; 1 sheltered housing; 63 private homes (UK)	<ul style="list-style-type: none"> No significant differences between three groups in quality of life (measured by the QoL-AD) ($p = .44$).
Orrell et al. (2014) (UK)	RCT Maintenance CST vs control condition	236 PWD Maintenance CST group: $n = 123$ Control condition: $n = 113$ Drop out by 3 months: $n = 18$ Further drop out by 6 months: $n = 19$ Mean age maintenance CST group: 82.7 (SD = 7.9) Mean age control condition: 83.5 (SD = 7.2)	<ul style="list-style-type: none"> At the 3-month end point no significant differences between groups in quality of life as measured by the self-rated DEMQOL ($p = .87$), proxy DEMQOL ($p = .95$) or proxy QoL-AD ($p = .50$). At the 3-month end point the maintenance CST group showed

		Setting: 9 care homes; 9 community services (UK)	<p>significantly improved quality of life compared to the control condition as measured by the self-rated QoL-AD ($p = .03$).</p> <ul style="list-style-type: none"> • At the 6-month end point no significant difference between the groups in quality of life as measured by the self-rated QoL-AD ($p = .54$) or self-rated DEMQOL ($p = .54$). • At the 6-month end point the maintenance group showed significantly improved quality of life compared to the control condition as measured by the proxy QoL-AD ($p = .01$) and proxy DEMQOL ($p = .03$).
Orrell et al. (2017) (UK)	RCT iCST treatment vs control condition	273 caregiving dyads iCST dyads: n = 134 Control dyads: 139 Dropout: n = 83 Mean age: 78.20 years (SD = 7.49) Setting: private homes (UK)	<ul style="list-style-type: none"> • No significant differences between the groups in quality of life as measured by the self-report DEMQOL ($p = .79$), self-report QoL-AD ($p = .45$), proxy DEMQOL ($p = .15$) or proxy QoL-AD ($p = .97$). • No significant differences between the groups in depressive symptoms (as measured by the GDS-15) ($p = .94$) or in psychological symptoms (as measured by the Neuropsychiatric Inventory) ($p = .79$).

Capotosto et al. (2017) (Italy)	RCT CST treatment vs control condition	39 PWD CST group: n = 20 Control condition: n = 19 Dropout: n = 5 Mean age of CST group: 88.25 years (SD = 5.15.) Mean age of control condition: 86.52 years (SD = 5.55) Setting: 2 residential homes (Italy)	<ul style="list-style-type: none"> • CST group compared to controls showed a significant improvement in depressive symptoms (measured by the Cornell Scale) ($p = .001$), loneliness (measured by the Social and Emotional Loneliness Scale) ($p = .014$) and quality of life (measured by the self-reported QoL-AD) ($p = .014$).
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Quality of life

There is very mixed evidence on whether CST (group/individual/maintenance) improves quality of life for people with mild to moderate dementia. Out of the eleven reviewed studies, eight explored quality of life. Of those, two found clear evidence in support of CST improving quality of life (Spector et al., 2003; Capotosto et al., 2017), two found no evidence of CST improving quality of life (Cove et al., 2014); Orrell et al., 2017) and four found mixed results. In the Orrell et al. (2017) study 66% of the dyads allocated to iCST did not complete at least two sessions per week and 22% completed no sessions at all and so it is possible the participants with dementia did not have enough exposure to iCST in order for the analysis to show if there was indeed any significant benefit of iCST. In addition, it is possible that the family carers did not have the therapeutic skills to deliver iCST as the protocol intended. Cove et al. (2014), contrary to the original CST protocol, explored CST delivered on a once-weekly rather than twice-weekly basis. They found that once weekly does not appear to be an effective dose. Given the memory difficulties of people with dementia, it is possible that having CST sessions only once a week meant that participants were less able to recall the contents from one session to the next, were less able to enjoy the pleasure that is inherent in familiarity and consistency and had less exposure to a predictable environment that supports memory difficulties by relying on implicit orientation, memory and learning.

Of the studies that found mixed findings, one obtained results that suggested CST does improve quality of life but the results fell just short of significance (Coen et al., 2011) and the three others found inconsistent results between different measures they used (Aguirre et al., 2013; Yamanaka et al., 2013; Orrell et al., 2014). Interestingly the Coen et al., (2011) study also found no evidence of improvements in the CST group in cognitive abilities as measured by the ADAS-Cog (Rosen, Mohs and Davis, 1984) (a measure that has been used in previous CST studies and demonstrated the positive cognitive impact of CST e.g. see Spector et al., 2003) which may suggest that the small sample size of this study (27 participants) was potentially not large enough for the QoL-AD to be sensitive enough to detect any potential benefit of CST on quality of life.

When one considers the measures individually there are a range of findings, with some studies finding evidence of improvements in quality of life as measured by

the self-rated QoL-AD (Logsdon et al., 1999; Logsdon et al., 2002) (e.g. Spector et al., 2003) and others finding no evidence for improvements in quality of life when using the same measure (e.g. Aguirre et al., 2013).

It is worth noting that in the Yamanaka et al. (2013), Orrell et al. (2014) and Orrell et al. (2017) papers there is no mention of whether the same caregivers were used to complete the proxy quality of life measures. Given that this has not been specified it is possible that different caregivers may have been used between the baseline and follow-up assessments. This may be significant as quality of life measures are subjective so the use of different responders between baseline and follow-up may partly or fully explain the lack of significant findings.

Psychological and emotional symptoms

There are also mixed findings regarding whether CST has a significant positive impact on psychological and emotional symptoms of dementia. Whilst Niu et al. (2010) found evidence of a significant benefit of CST on patients' psychological symptoms as measured by the Neuropsychiatric Inventory, using the same measure, Orrell et al. (2017) found no such evidence. However, it appears Orrell et al. (2017) did not use the same carers at baseline and follow-up and so this could explain their lack of significant finding. In addition, given the low adherence rates in the Orrell et al. (2017) iCST study, it is possible the participants with dementia were not given enough exposure to the iCST for any positive impact of the iCST on psychological symptoms to be detected at follow-up. It is also possible, as outlined above, the family carers did not have the requisite therapeutic skills to deliver the iCST as intended by the protocol. Spector et al. (2001) found no impact of CST on anxiety scores as measured by the Rating Anxiety in Dementia scale (Shankar, Walker and Frost, 1999). Capotosto et al. (2017) found that CST had a significant positive impact on participants' loneliness ratings as measured by the Social and Emotional Loneliness Scale (Di Tommaso and Spinner, 1993).

With regards to depression, two studies which used the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988) found a positive impact of CST on depressive symptoms (Spector et al., 2001; Capotosto et al., 2017). However, the two studies which used the Geriatric Depression Scale (Yesavage et al., 1982) found no impact of CST on depressive symptoms (Orrell et al., 2017; Apóstolo et al., 2014).

However, as discussed above, due to the low iCST adherence in the Orrell et al. (2017) study, care must be taken when considering any results from that study. In addition, Apóstolo et al. (2014) report that 21% of participants were taking anti-depressants during the research and so it is possible that for participants suffering from clinical depression, CST is less able to positively enhance mood. This is a hypothesis that would need to be further tested with future research. Apóstolo et al. (2014) report that 83% of the participants in the study had a very low level of education (0-4 years). Given research that shows the protective impact of higher education levels and young adult IQ (Leibovici et al., 1996), it is possible that having such limited education meant that participants were less able to benefit from CST.

It is also of relevance that all the studies analysed used participants with a range of anxiety and depression baseline scores. If participants are not anxious or depressed at baseline then there is less scope for improvement and so the measures might not be sufficiently sensitive to detect any significant improvements.

Gaps in the literature and further research needed

There is mixed evidence as to whether CST helps people with mild to moderate dementia improve their emotional and psychological symptoms and wellbeing therefore this is something that needs to be further investigated. In addition, the evidence is inconclusive as to whether cognitive stimulation delivered on a one-to-one basis can benefit people with dementia. One study which examined cognitive stimulation delivered by a partner found evidence this method can be helpful for verbal fluency, problem-solving, and immediate memory (Quayhagen and Quayhagen, 2001). As referred to above, more recently, Orrell et al. (2017) developed and investigated whether home-based family caregiver delivered iCST, a delivery method that would be cost-effective and practical, benefited people with dementia and/or their carers. However, this study had various limitations that could explain, at least partly, the findings. Sixty percent of the dyads allocated to iCST did not complete at least two sessions per week and 22% completed no sessions at all and this could mean that the participants with dementia did not have enough exposure to the iCST in order to benefit from it. Also, it is possible that sessions being delivered by a family caregiver, an individual with whom the person with dementia may well have a complicated relationship and/or who felt insufficiently skilled and/or who lacked motivation due

to exposure to the dementia deterioration, could have impacted the level of engagement by the person with dementia (Leung et al., 2017). In addition, it is very likely the family carer lacked the requisite therapeutic skills to deliver the iCST as it was intended in the protocol. Given the low adherence, possible low engagement, possible lack of requisite therapeutic skills in the carer and fact this study only examined home-based iCST delivery, this Orrell et al. 2017 iCST trial does not definitively show that iCST is not effective.

Rationale for present research

Although CST is becoming increasingly available in the UK and internationally, group delivery of CST does not suit all people with dementia due to for example transport, geographical or health issues or personal preference. It is known that 61% of people with dementia live at home (Prince et al., 2014) and so for these people simply accessing group CST can be challenging. In addition, in order for participants to take part in group CST they need to be able to see and hear well enough to be in a group and be able to remain in an activity for 45 minutes. If iCST were found to be effective it would mean that those participants who do not meet the group CST criteria (i.e. those who lack the sensory capacities to be in a group setting or who do not have the required attention span) would be able to benefit from CST. In future, delivery by a professional of iCST in patients' homes could also be further explored as this would mean that patients remaining at home, something considered to beneficial where possible (Olsen et al., 2016), could also benefit from CST. If iCST was found to be an effective intervention it would mean many of those without current access to CST would potentially also be able to benefit from this intervention. It is therefore important to establish whether iCST, when delivered by a professional and non-carer, is an effective intervention.

The aim of this study is to investigate whether iCST is effective when the factors that may explain the absence of effect on cognitive abilities and quality of life found in the Orrell et al. (2017) trial are adjusted. This is a joint research project being undertaken by Luke Gibbor ('LG') and Lycia Forde ('LF'). Given the common lack of stimulation found in care homes (Harper-Ice, 2002; Bates-Jensen et al., 2004) and the fact that of the majority of group CST research, where CST has been found to be effective, has been carried out in care homes (e.g. Spector et al., 2003), we primarily

plan to test iCST in a care home setting. In addition, due to time constraints and logistical difficulties, it would not be very feasible at this stage to undertake this research in patients' private homes.

Given that the needs of care home populations tend to be greater than those remaining in their private homes, due to the common lack of stimulation in care homes (Harper-Ice, 2002; Bates-Jensen et al., 2004), positive findings from this study would hopefully lead to care home providers offering iCST to individuals with dementia who cannot or do not want to participate in group CST. These people would include those who do not meet the group criteria (e.g. a person with a partial hearing difficulty who struggles in environments with multiple auditory signals) or those who for social/emotional reasons feel uncomfortable in a group setting. In the same way that group CST research undertaken in care homes was generalised to memory clinics, it is considered that our findings would generalise to a private home setting, provided the delivery was also by a professional and the dosage and format were identical.

Previous research on 'dose' of CST suggests that twice rather than once weekly delivery is required to see a cognitive benefit, (Cove et al., 2014). In light of this and that when iCST was developed, patients and carers have indicated that twice weekly is acceptable (Yates et al., 2016), we will deliver the iCST on a twice-weekly basis. As group CST, which has the evidence base, runs over 14 sessions, and the low adherence in the Orrell et al. (2017) which could have been due to the length of the trial, we intend to deliver the iCST over 14 sessions across seven weeks. Given the aforementioned possible difficulties with delivery by a family caregiver, it is possible that staff/healthcare professionals may be more suitable than family members at delivering iCST and so this study will investigate iCST delivered by a professional (trainee clinical psychologists).

There are various reasons why we hypothesise that iCST delivered twice weekly (primarily) by a professional in a care home will benefit participants' cognitive abilities and quality of life. iCST is based on the same principles as CST which has a strong evidence base, is recommended by the NICE guidelines and is offered widely across the NHS (NICE, 2006; Woods et al., 2012). Like CST, iCST focuses primarily on implicit memory which is usually preserved for longer than explicit memory and also responds well to stimulation (van Tilborg, Kessels and Hulstijn, 2011). ICST will be delivered in an environment that facilitates learning (Hall et al., 2013). In addition, in our study one to one delivery will allow for the sessions to be tailored to

provide individually-adapted cognitive challenges which should enhance the degree of stimulation offered and result in greater concentration of input compared to the group-based intervention. In our study delivery by a professional/iCST-trained psychology student/graduate at two fixed times each week should result in greater engagement and adherence to the programme compared to delivery by a caregiver when time for the session has to be carved out of a normal life pattern (Yates et al., 2016). In the Orrell et al. (2017) it is possible that the emotionally invested carers with no clinical training lacked the necessary therapeutic skills to adhere to the iCST protocol. Finally, in contrast to Orrell et al.'s (2017) where some caregivers reported not feeling skilled enough to deliver the iCST, this trial will involve delivery by trainee clinical psychologists or trained psychology students/graduates who feel sufficiently skilled to deliver the iCST. Using trainee clinical psychologist or trained psychology students/graduates means they will have the necessary therapeutic skills to ensure the iCST protocol is adhered to in terms of how the therapy is delivered e.g. providing positive feedback, boosting participant self-confidence etc.

This study will include the self- and proxy-reported Quality of Life Alzheimer's Disease scale ('QoL-AD') (Logsdon et al., 1999; Logsdon et al., 2002). This measure includes 13 questions about varying aspects of quality of life, each with a four-point Likert response scale, that are administered via an interview. This study will endeavour to use the same carer for the proxy-reported QoL-AD at baseline and follow-up to avoid the individual's subjective views distorting findings. It will also analyse the Engagement and Independence in Dementia Questionnaire ('EID-Q') (Stoner et al., 2017). This measure includes 26 questions about an individual's degree of independence and engagement with others, each with a five-point Likert response scale, that are administered via interview. It will also analyse the Positive Psychology Outcome Measure ('PPOM') (Stoner et al., 2017). The PPOM includes 16 questions about an individual's sense of positivity, each with a five-point Likert response scale, that are administered via interview. The PPOM consists of an adaptation of the Herth Hope Index (Herth, 1992) and a resilience scale that was developed with people with dementia using prominent resilience theories. The latter two measures were selected as they have been developed using rigorous methods and show acceptable internal consistency and convergent validity (Stoner et al., 2017). They were developed by identifying salient positive psychology themes from across the qualitative dementia research and were deemed easy to use and acceptable by those with dementia with

whom they were tested. Given the positive impact of group CST on patient's quality of life, it is likely that any positive effects on quality of life would be detected by these scales and could provide a more detailed picture of the nature of these effects. In addition, we have chosen to include the PPOM due to the possibility that previous lack of significant findings in relation to emotional and psychology wellbeing may have related to the lack of difficulties at the outset. Unlike the GDS-15, RAID, NPI etc. the PPOM does not focus on difficulties and so it is thought to have greater sensitivity to any improvements even if the participant is not experiencing high levels of anxiety and/or depression at the outset of the study. The EID-Q and PPOM were developed and validated for people with dementia living in a range of settings and so there is no clinical rationale why they would be unsuitable for this research.

This study aims to investigate whether iCST delivered by a professional or trained psychology student/graduate (14 sessions, twice weekly over 7 weeks) a) improves cognitive function in people with dementia when compared to controls (as measured by the ADAS-Cog) and b) improves self-reported quality of life (as measured by the self-reported QoL-AD), proxy reported quality of life (as measured by the proxy-report QoL-AD), self-reported positive psychology (as measured by the PPOM) and/or self-reported engagement and independence (as measured by the EID-Q) in people with dementia when compared to controls.

Conclusion

It is clear that dementia represents a growing challenge for public health systems across the globe and therefore the need for effective therapies to help manage the condition has never been greater. The review incorporated into this introduction suggests that although the evidence is mixed, CST does appear to be generally effective at improving the emotional and psychological wellbeing and quality of life of people with mild to moderate dementia. Given that this review did not use a quality assessment tool it has not been possible to know how to place differential importance on particular findings based on the quality of the particular study. Using a quality assessment tool may have assisted in the analysis and comparisons of the studies examined. A further difficulty is that none of the reviewed studies controlled for the non-specific effects of CST or iCST (e.g. social contact) and so it is not possible to ascertain what component of the CST/iCST was responsible for any observed effects.

If individual professionally-delivered CST were found to be effective and therefore made publically available, this would vastly increase the number of people with dementia who are able to access this intervention. Based on the evidence for group CST and reasons outlined above, there is a rationale to further investigate the effectiveness of professionally-delivered iCST at improving the quality of life and mental health of people with mild to moderate dementia. This study is a pilot trial and it is hoped that any findings suggestive of the effectiveness of iCST would result in a larger trial being undertaken.

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Part 2: Empirical Paper

The impact of individual Cognitive Stimulation Therapy (iCST) on quality of life and emotional and psychological symptoms for people with dementia: a randomised control feasibility trial

The impact of individual Cognitive Stimulation Therapy (iCST) on quality of life for people with dementia: a randomised control feasibility trial

Abstract

Aims

Cognitive Stimulation Therapy (CST) is a well-established psychosocial intervention for individuals with dementia that improves cognition and quality of life. However, a large clinical trial on individualised CST (iCST) delivered by family carers found iCST to be ineffective. The current study aimed to explore whether it is feasible for healthcare professionals to deliver iCST. Feasibility criteria included; (1) ease of recruitment, (2) attendance and (3) drop out/attrition. It also aimed to explore whether the intervention improves quality of life and the psychological and emotional symptoms of dementia.

Method

Twenty-nine participants were randomly allocated to the iCST group or control (treatment as usual) group. The iCST group participants were offered 14 twice-weekly 45-minute iCST sessions delivered by trainee clinical psychologists. The following measures were administered for all participants pre- and post-intervention: self- and proxy-reported Quality of Life Alzheimer's Disease scale, (QoL-AD) Positive Psychology Outcome Measure (PPOM) and Engagement and Independence in Dementia Questionnaire (EIDQ).

Results

The feasibility criteria for delivery of iCST by non-family carers (healthcare professionals) were fulfilled. There were no barriers to recruitment as care homes and eligible residents readily expressed interest and were willing to consent to take part. Engagement was high with a 0% dropout for participants who received the iCST and 97% session attendance. There were no significant differences between participants who received iCST and treatment as usual in self- and proxy-reported quality of life and self-reported psychological wellbeing.

Conclusion

This study suggests that it is feasible for non-family carers (healthcare professionals) to deliver iCST by non-family carers. The absence of barriers to recruitment suggests this therapy would be popular and the low dropout and high attendance rates indicate good engagement by participants. The study does not support iCST improving quality of life or the psychological and emotional symptoms of dementia. The lack of findings regarding improved quality of life and the psychological and emotional symptoms of dementia could be explained by insufficient statistical power due to the small sample size. It is also possible that the group component of CST is a key factor in its effectiveness and hence the lack of findings from iCST with its one-to-one format.

Introduction

Dementia

Dementia represents one of the largest global challenges for public health and is the most common cognitive degenerative disease amongst the elderly (World Health Organisation, 2012). It is one of the major causes of dependency and disability in the elderly population across the world with an estimated 5-8% of the general population aged above 60 years with dementia at any given time (World Health Organisation, 2017). Currently there are 50 million individuals in the world who have dementia and there are approximately 10 million new cases each year (World Health Organisation, 2017). The number of people with dementia is predicted to rise from 50 million in 2018 to 152 million in 2050, a 204% increase (World Health Organisation, 2017). Dementia has an enormous and devastating physical, psychological, cognitive, social and economic impact on not only the individuals diagnosed with dementia but also on their families, carers and the wider society (Cieto et al., 2014).

Dementia is a syndrome which typically has a chronic or progressive nature (World Health Organisation, 2017). It involves a deterioration in cognitive ability above and beyond what would be expected in normal ageing. Although consciousness is not affected, dementia negatively impacts upon memory, thinking, orientation, ability to learn, calculation, linguistic abilities and judgement (World Health Organisation, 2017). Dementia also typically involves a reduction in emotional control and motivation and degeneration of social behaviour.

A presentation of dementia results from a range of injuries and diseases that either directly or secondarily impact the brain. Alzheimer's disease is the most typical form of dementia (around 60-70% of cases) (World Health Organisation, 2017). The other main types of dementia are vascular dementia, dementia with Lewy bodies and a collection of diseases that contribute to deterioration of the frontal lobes of the brain. An example of an injury that would indirectly result in dementia is a stroke.

Treatment options

Despite extensive research, at present there is no medical treatment available to cure dementia or change its progressive course (NHS, 2017). Although there is no cure for dementia, there are various things that can be offered to improve the lives of individuals with dementia and those around them (NICE, 2018). These include: diagnosing as early as possible to facilitate early and optimal management, maximising physical health, cognition and psychological wellbeing, detecting and managing/treating any physical illness, identifying and managing challenging psychological and behavioural symptoms and providing clear information and ongoing support to families and carers.

There has been growing interest in developing psychosocial therapies to manage dementia. There are numerous types of psychosocial interventions (e.g. social, environmental, behavioural) but research to date suggests those based on cognitive stimulation are the most effective (McDermott et al., 2018). Cognitive stimulation therapies aim to exercise cognitive functioning and socially engage the individual with dementia with the objective that the benefits of the intervention generalise outside the training context (Bahar-Fuchs, Clare and Woods, 2013). Interventions can be offered that in the best-case scenario, slow the deterioration and ideally, enhance cognition, psychological wellbeing and quality of life. One principal intervention is Cognitive Stimulation Therapy (CST) and it is recommended by the current NICE guidelines (NICE, 2018).

Cognitive Stimulation Therapy (CST)

CST is a well-established structured group psychosocial intervention for people with dementia. It is based on the principle of “use it or lose it” in which stimulation of different mental faculties may stop or slow cognitive decline by neuron activation, enhancing their function and survival (Shors et al., 2012). CST was designed to be delivered for 45-minutes, twice weekly for seven weeks. Ideally there should be five to eight participants and two facilitators in each CST group. Where possible group members should have similar levels of functioning so that activities can be designed and targeted accordingly.

The delivery of CST is guided by key principles (Spector et al., 2001). The idea is for the sessions to be stimulating and maximise potential, but not so difficult such that the participants could feel distressed or deskilled. Continuity and consistency across sessions is emphasised so all sessions should be undertaken in the same location and ideally at a similar time of day. In addition, each session follows the same structure (introduction, theme song, discussion about current affairs, main activity, suggested home activities, closure). However, each session has its own main topic (e.g. food, childhood). CST takes a person-centred approach and each session has a choice of activities so that the different interests and abilities of the group members can be catered for. Orientation is a key aspect of all sessions but should be included sensitively and implicitly rather than being experienced as a test by participants. CST focuses on opinions rather than facts and implicit rather explicit learning. This is to avoid creating a didactic teaching environment and thereby help boost participants' self-confidence in their existing and developing abilities.

Given the typical dementia profile in which long term memory remains largely intact for longer than short term memory (Duong, Patel and Chang, 2017), CST aims to use reminiscence as a way of helping here-and-now functioning. CST also provides participants with triggers to aid their recall. CST involves using stimulating language and aims to help participants build new ideas, thoughts and associations. Key to CST is that all participants should feel respected, involved and valued. It is essential that each participant feels they have choice over the session activities and that they enjoy each session. A final important principle of CST is that the sessions should provide an opportunity for participants to build and/or strengthen relationships with other participants and the facilitators.

Whilst there is robust evidence that CST improves cognition (Spector et al., 2003; Prince, Bryce and Ferri, 2011; Woods et al., 2012, Orrell et al., 2014), there have been mixed findings regarding whether CST improves quality of life and the psychological and emotional symptoms of dementia (Lobbia et al., 2018). Lobbia et al. (2018) carried out a systematic review of 12 quantitative studies of CST. Of the nine studies that examined quality of life, four found significant improvements, four found no improvements in overall quality of life, and one study found improvements in quality of life on some measures, but not others. Research into the impact of CST on quality of life suggests improvements (when they are indeed found) are mediated by improvements in cognition with the greatest impact seen in the domains of energy

level, memory, ability to do chores and the relationship with the individual's carer (Woods et al., 2006).

Research to date

Whilst the evidence for group CST is strong, there is mixed evidence as to whether cognitive stimulation delivered on a one-to-one basis can benefit people with dementia in a similar way. One study which examined cognitive stimulation delivered by a partner found evidence this method can impact verbal fluency, problem-solving, and immediate memory (Quayhagen and Quayhagen, 2010). More recently, Orrell et al. (2017) developed a home-based one-to-one version of CST delivered by family caregivers called iCST. It was considered that this method of delivery method would be the cheapest and most practical (Orrell et al., 2012).

A single-blind randomised control trial ('RCT') was undertaken across eight locations in the United Kingdom to investigate the effectiveness of iCST. The participants were 356 people with mild to moderate dementia and their caregivers who were recruited via memory services and community mental health teams. Participants were randomly assigned to treatment as usual ('TAU') or to iCST (75 x 30-minute sessions) over 25 weeks. The caregivers who delivered iCST were given training and support from an unblind researcher. The study found that iCST improved the quality of the caregiving relationship and the wellbeing of the carer, but there were no differences between the iCST and TAU groups in their post-intervention cognitive abilities and self-reported quality of life.

This study had various limitations that may explain, at least partly, the findings. Sixty percent of the dyads allocated to iCST did not complete at least two sessions per week and 22% completed no sessions at all (Yates et al., 2016). This could mean that the participants with dementia did not have enough exposure to the iCST in order to benefit from it. Also, it is possible that sessions being delivered by a family caregiver meant the person delivering the iCST felt insufficiently skilled and/or lacked motivation. The lack of motivation could have arisen due to exposure to the deterioration of the person with dementia. The possible feeling insufficiently skilled and/or lack of motivation in the person delivering the iCST could have impacted the level of engagement of the person with dementia. Given the low adherence, possible

low engagement and fact this study only examined home-based iCST delivery, this study does not definitively show that iCST is not effective.

The aim of the current study was to investigate whether iCST would be effective when the factors that may explain the absence of effect on cognitive abilities and quality of life found in the Orrell et al. (2017) trial were adjusted. This study was set up experimentally in the same way as previous trials of group CST (e.g. Spector et al., 2003). However, the programme was delivered on an individual rather than group basis and following an amended iCST manual.

Rationale for research

Although CST is becoming increasingly available in the UK (via the NHS) and internationally, group delivery of CST does not suit all people with dementia due to transport, geographical or health issues or personal preference. If iCST were found to be effective it may mean that those participants who do not meet group CST criteria (i.e. those who lack the sensory capacities to be in a group setting, who do not have the required attention span or who do not have the requisite language skills) would be able to benefit from CST. If iCST was found to be an effective intervention it may mean many of those without current access to CST would potentially also be able to benefit from this intervention. It is therefore important to establish whether iCST, when delivered by a professional and non-family-carer, is an effective intervention.

There were various reasons why it was hypothesised that iCST delivered twice weekly by a professional in a care home would benefit participants' cognitive abilities and quality of life. iCST is based on the same principles as CST which has a robust evidence base, is recommended by the NICE guidelines and is offered widely across the NHS (Woods et al., 2012). Like CST, iCST focuses mainly on implicit memory which tends to remain more preserved than explicit memory and also responds well to stimulation (van Tilborg, Kessels and Hulstijn, 2011). It was hypothesised twice weekly sessions would be effective as this was the frequency of sessions in the trials of CST where it has found to be an effective intervention (e.g. Spector et al., 2003). It was considered that delivery by healthcare professionals would be suitable as they would feel sufficiently skilled to deliver the iCST and remain motivated which in turn may potentially lead to high levels of engagement from the participants with dementia. Finally, it was deemed that delivery in a care home setting would not be problematic

given this is where many trials of CST have been undertaken when CST has been found to be effective (e.g. Spector et al., 2003).

Research aims

This study aimed to investigate whether delivering iCST by a non-family carer (healthcare professional) was feasible in relation to ease of recruitment, attendance and dropout. The study also aimed to assess whether iCST compared to treatment as usual improves self-reported quality of life, proxy-reported quality of life, self-reported positive psychology and/or self-reported engagement and independence in people with dementia.

Methods

This was a joint thesis undertaken by Lycia Forde (LF) and Luke Gibbor (LG). LF focused on quality of life and psychological wellbeing and LG focused on cognition.

Development of adjusted iCST manual

The original CST manual and iCST manual from the Orrell et al. (2017) study were used as the starting point for the design of the programme of iCST delivered in this study. We then examined the qualitative feedback from participants in this study regarding which elements of the iCST had been the most enjoyable (Leung et al., 2017). This feedback revealed how much participants had enjoyed the musical elements of the sessions and so we ensured this was given proper allocated time at the start of each session and also a dedicated session. The feedback also showed how much participants had valued the conversations and so we ensured each session facilitated conversations and that the guidance in our manual enabled the person delivering the iCST to add their own questions as appropriate so that follow-up questions could be asked and conversation could develop naturally. Besides using the qualitative feedback, there was also a consultation with our two supervisors in order for a new 14-session iCST manual (see Appendix 2) to be designed.

Design

This study was a single blind multi-centre randomised controlled feasibility study. Given this was a feasibility study looking at ease of recruitment, attendance and dropout rates, a sample size was selected that was typical for a feasibility study and which was pragmatic given the practical constraints of the researchers. With a sample size of 32 (the intended sample), using a G*Power calculation it was expected that with power set at 0.80 and $\alpha = .05$, this study would be able to detect an effect size of 1.02 or above.

Ethics

Ethical approval was obtained from the UCL/UCLH Joint Research Office (see Appendix 3). It was ensured that all participants scored a minimum of 10 on the Standardised Mini-Mental State Examination (SMMSE) (Folstein, Folstein and McHugh, 1975) and were able to provide informed consent in accordance with the Mental Capacity Act (2005). All participants were provided with clear information about what the study would involve prior to obtaining their informed consent. All care homes were provided with information booklets to share with the carers/families of potential participants (see Appendix 4). It was ensured that all participants understood they could withdraw their participation from the study at any time. Participants and their carers were offered the opportunity to ask any questions about the study before they signed a consent form (see Appendix 5). All data collected during the study was anonymised and will continue to be kept confidential.

Participants

The managers of 26 care homes were contacted via email and telephone. The initial email (see Appendix 6) provided preliminary information about the study and the subsequent telephone call enabled further details of the study to be discussed. When care homes confirmed their interest in taking part in the study they were provided with information booklets to share with participants and their families/carers. The six interested care homes provided a list of potentially willing participants and LF and LG then met with these individuals to explain the study and what participation

would involve. Care homes were given £10 for each participant who took part in the study. The recruitment process took approximately six months. All participants were required to fulfil the following eligibility criteria, determined through previous CST research (Spector et al., 2003):

- Meet criteria for dementia of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000);
- Have mild to moderate dementia as derived from the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005);
- Score a minimum of 10 on the Standardised Mini-Mental State Examination (Folstein, Folstein and McHugh, 1975);
- Able to communicate, understand, see and hear well enough to participate in iCST activities;
- Have the capacity to provide informed consent as per the Mental Capacity Act (2005);
- Have no major health issues which would affect participation.

Participants were screened using the SMMSE and only participants who scored at least 10 were included. This functioned as a secondary check to ensure participants had the cognitive capacities to provide informed consent. When all interested participants were met with to obtain informed consent, it was ensured that they understood they could withdraw their participation at any time. Throughout the study each participant was monitored to ensure they continued to have the capacity to provide informed consent (as per the Mental Capacity Act (2005)) for their participation.

Consent to Participation

In order to ensure participants were able to give informed consent, prior to meeting with participants, they were provided with an information booklet about the study. We asked the care home staff to discuss what the study would involve with potential participants. We also asked the care home staff to share the information booklets with any family members or carers of potential participants so that they too could discuss study participation with potential participants. To ensure all participants had the required mental capacity to provide informed consent in line with the Mental

Capacity Act (2005), we only included participants who scored a minimum of 10 on the SMMSE (Folstein, Folstein and McHugh, 1975). When obtaining informed consent we went through each section of the form with each participant and when the participant either could not read or chose not to, we read the particular section to them and explained any uncertainties.

With regard to the ongoing capacity of participants to provide informed consent, at each session we observed participants to ascertain whether the participant had experienced a significant deterioration in their mental capacity.

Procedure

iCST sessions took place in the six London care homes where the participants were residents. The sessions took place in the same quiet location within the care home, either the participant's bedroom or an allocated room made available each week. Sessions were delivered by LG and LF individually. Of the 29 participants, 14 were randomly allocated to receive iCST and 15 were randomly allocated to receive treatment as usual (TAU) to act as controls. For the randomisation, each participant was assigned a number and a computer randomizer (<https://www.randomizer.org/>) was used to generate two sets of numbers and allocate one set to each condition. To ensure assessment blinding for the participants, a different researcher administered the tests from the researcher who delivered iCST. However, levels of blinding were not checked.

At the outset of the study each participant completed the full battery of tests. After this, participants in the iCST treatment group received seven weeks of twice weekly 45-minute sessions of iCST. At the end of the intervention (within a week after completing the final iCST session), the same battery of tests was administered to all participants.

Measures

The following tests were administered: self- and proxy-reported Quality of Life Alzheimer's Disease scale, (QoL-AD) (Logsdon et al., 1999; Logsdon et al., 2002), Positive Psychology Outcome Measure (PPOM) (Stoner et al., 2017) (see Appendix 7) and Engagement and Independence in Dementia Questionnaire (EID-Q)

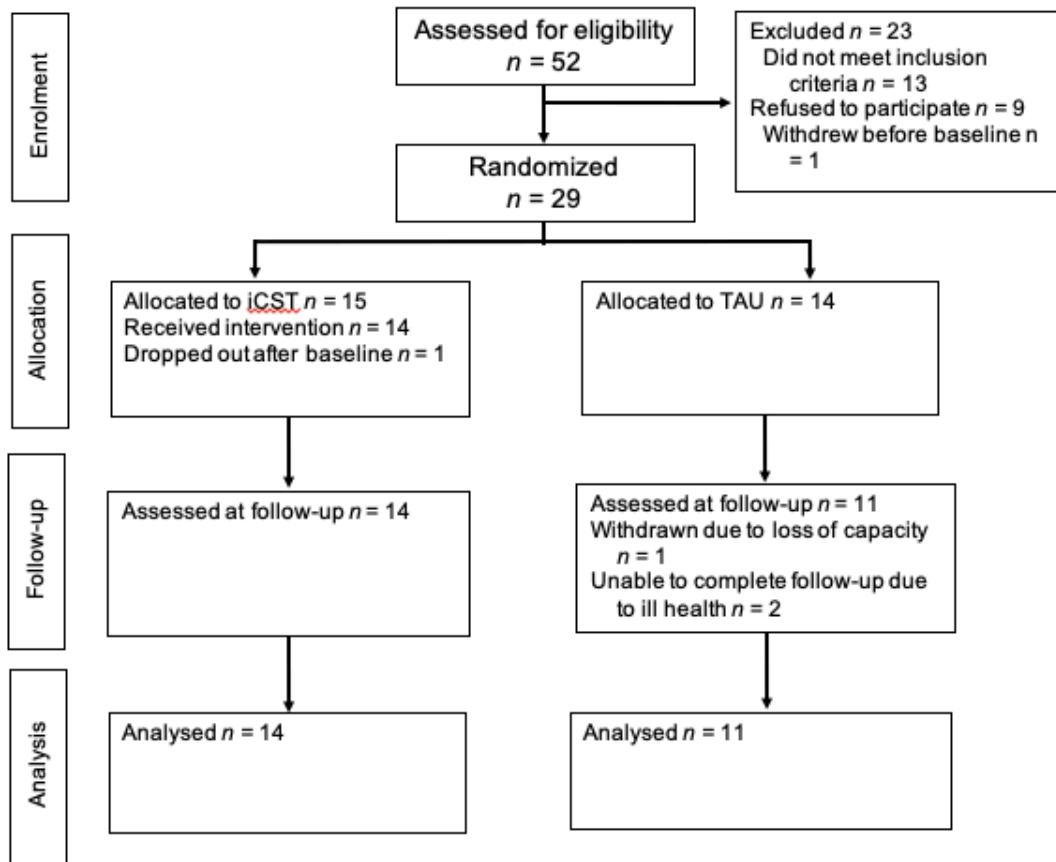
(Stoner et al., 2017) (see Appendix 8). The QoL-AD includes 13 questions about varying aspects of quality of life (e.g. physical health, energy, mood), each with a four-point Likert response scale, that are administered via an interview. The QoL-AD has good internal consistency, reliability and validity (Thorgrimsen et al., 2003). The PPOM includes 16 questions about an individual's sense of positivity (e.g. I have a positive outlook on life), each with a five-point Likert response scale, that are administered via interview. The PPOM consists of a hope subscale which is an adaptation of the Herth Hope Index (Herth, 1992) and a resilience subscale that was developed with people with dementia using prominent resilience theories. The EID-Q includes 26 questions about an individual's degree of independence and engagement with others (e.g. I can look after myself as much as I need to), each with a five-point Likert response scale, that are administered via interview. The latter two measures have good internal consistency and convergent validity (Stoner et al., 2017).

Results

Participants

Of the 52 participants screened, twenty-three were excluded and twenty-nine were randomised. See Figure 1 for full details of the participant flow.

Figure 1. Consort diagram showing participant flow



There were 29 participants who completed baseline assessments. Participants were randomly allocated to iCST (15) and TAU (14). Table 2 outlines details of their basic demographic information at baseline.

Table 2. Participant demographic information at baseline.

Characteristic	iCST (n = 15)	TAU (n = 14)	All participants (n = 29)
Gender (%)			
Female	6 (42.9)	10 (66.6)	16 (55.2)
Male	8 (57.1)	5 (33.3)	13 (44.8)
Age (years)			
Mean (SD)	86.20 (1.43)	75.57 (3.30)	81.07 (10.74)
Range	75 - 98	56 - 94	56 - 98
Ethnicity (%)			
White British	12 (80)	11 (78.6)	23 (79.3)
White Other	2 (13.3)	0 (0)	2 (6.9)
Asian	1 (6.7)	2 (14.3)	3 (10.3)
Black British	0 (0)	1 (7.1)	1 (3.4)
SMMSE Score			
Mean (SD)	20.73 (3.07)	22.21 (4.04)	21.45 (3.58)
Range	14 - 25	14 - 27	14 - 27

Feasibility results

Once interested care homes had been identified, there were no barriers to recruit the 29 participants. Out of the 196 iCST sessions offered, 6 (3%) were missed entirely (due to feeling unwell, tired or not in the mood) and three sessions (5%) were incomplete (due to feeling tired or not in the mood). There was a 0% dropout rate for those who received iCST, suggesting that iCST delivered by the same healthcare professional twice weekly for 45-minute sessions was acceptable to participants. In addition, there were no adverse effects of iCST observed throughout the trial.

Descriptive statistics

Due to four participants struggling to maintain concentration for the test time, there was only complete data for 25 participants. The mean baseline SMMSE score for the 25 participants was 21.68 (indicating mild cognitive impairment). The mean changes in scores of the measures from before and after the course of iCST sessions

for the treatment and control conditions are reported in Table 3. Table 3 also shows the number of participants whose data was available for analysis.

Table 3

Mean changes in measure scores

Measure	Group	N	Mean score change
Self-reported QoL-AD	iCST	14	+2.93
	TAU	11	+ .83
Proxy-reported QoL-AD	iCST	14	-.36
	TAU	10	+7.6
PPOM	iCST	14	+7.07
	TAU	11	+1.07
EID-Q	iCST	14	-5.36
	TAU	11	-2.21

Positive mean score changes indicate an improvement and negative mean score changes indicate deterioration.

Analysis

An independent samples t-test was conducted to compare the changes in scores across all the measures and their subscales (where applicable) between the iCST group and TAU group. Levene's Test for Equality of Variances was not significant for any of the outcomes and so equal variances were assumed. There was no significant difference in score changes between the iCST group and TAU group in the self-reported QOL-AD, $t(24) = -0.95, p = 0.35$. There was no significant difference in score changes between the iCST group and TAU group in the proxy-reported QOL-AD, $t(22) = 1.83, p = 0.08$.

There was no significant difference in score changes between the iCST group and TAU group in the PPOM, $t(26) = -1.03, p = 0.31$. There was no significant difference in score changes between the iCST group and TAU group in the PPOM

Hope Subscale, $t(23) = -0.63, p = 0.53$. There was no significant difference in score changes between the iCST group and TAU group in the PPOM Resilience Subscale, $t(23) = 0.99, p = 0.33$.

There was no significant difference in score changes between the iCST group and TAU group in the EID-Q, $t(26) = 0.68, p = 0.50$. There was no significant difference in score changes between the iCST group and TAU group in the EID-Q Activities of Daily Living Subscale, $t(22) = -1.68, p = 0.11$. There was no significant difference in score changes between the iCST group and TAU group in the EID-Q Decision Making Subscale, $t(22) = -0.26, p = 0.80$. There was no significant difference in score changes between the iCST group and TAU group in the EID-Q Activity Engagement Subscale, $t(22) = -1.5, p = 0.15$. There was no significant difference in score changes between the iCST group and TAU group in the EID-Q Support Subscale, $t(22) = -0.11, p = 0.92$. There was no significant difference in score changes between the iCST group and TAU group in the EID-Q Reciprocity Subscale, $t(22) = -0.53, p = 0.60$.

Discussion

Summary of results

This study found that iCST delivered by a non-family carer (healthcare professional) in twice-weekly 45-minute sessions over seven weeks fulfilled the feasibility criteria of ease of recruitment, good attendance and low dropout. There were no barriers to recruit the participants and the high levels of attendance (97% of sessions attended) and low dropout rate (0%) suggest participants felt engaged with and enjoyed the iCST sessions. This study did not demonstrate any significant impact of iCST on quality of life or the emotional and psychological symptoms of people with dementia.

Interpretation of results

The results of this study do not show that professionally delivered iCST has a positive impact on quality of life or the psychological and emotional symptoms of

people with dementia. There are a number of possible explanations for this finding. Given that this was a feasibility study, the lack of findings could be explained by the limited sample size which was not sensitive enough to detect what may be a small effect size. Spector et al. (2003) found an effect size of 0.78 for the improvements in QoL-AD following group CST but a G*Power calculation suggests that this study with 28 participants would only be able to detect effect sizes of 1.1 or greater. Besides only having 28 participants, due to ill health, carers not feeling they knew the patients well enough to complete the proxy QoL-AD, low mood of the participants etc. in some instances there was only complete data for 10 out of the 14 participants in the TAU group.

The research is mixed as to whether group CST has a positive impact on quality of life (Coen et al., 2011; Aguirre et al., 2013; Yamanaka et al., 2013; Cove et al., 2014; Orrell et al., 2014; Orrell et al., 2017) and the psychological and emotional symptoms of people with dementia (Spector et al., 2001; Apóstolo et al., 2014; Orrell et al., 2017). However, it is possible that any positive findings on the impact of group CST on quality of life (Spector et al., 2003; Capotosto et al., 2017) and the psychological and emotional symptoms of people with dementia (Spector et al., 2001; Niu et al., 2010; Capotosto et al., 2017) are largely explained by the group format of CST. It is likely that the group format helps the participants to build friendships and these friendships may extend outside of the CST group. It is known that loneliness is a risk factor for dementia (Holwerda et al., 2014) and that having a rich social network reduces the likelihood of developing dementia (Crooks et al., 2008). Research by Ballard et al. (2018) shows that one hour of social interaction each week has a positive impact on quality of life, levels of agitation and antipsychotic use amongst patients with dementia. Although iCST allows the participant to develop a relationship with the facilitator, this relationship is largely a professional relationship and cannot extend outside the remit of the iCST sessions. It is therefore possible that this key difference between individual and group CST, namely the ability of group CST to facilitate increased socialisation within and outside the group and possible increased stimulation within the group setting, explains the lack of findings of any benefit of iCST on quality of life and the psychological and emotional symptoms of people with dementia.

Another possible explanation for the current findings is that during its course, iCST sessions did improve patients' quality of life and psychological wellbeing but that these benefits did not continue after the iCST sessions had ceased because the

individuals were disappointed their twice-weekly sessions had stopped. Although at present there is no direct qualitative evidence to support this hypothesis, there is qualitative research that shows participants tend to enjoy iCST sessions (Leung et al., 2017) and it is therefore conceivable they would feel disappointed when such sessions have ceased.

It is plausible that the quality of life benefits of group CST can still be detected after the course of group CST sessions have finished whilst those of iCST cannot be detected given that the friendships that can be nurtured within the group CST format can persist and thrive even after the course of group CST sessions have finished. Support for this theory comes from research by Orrell et al. (2014) that showed that when patients received six months of maintenance group CST after an initial course of group CST, when they were tested three months into this therapy, there were improvements for proxy-rated quality of life using the QoL-AD, Dementia Quality of Life Scale (DEMQOL) and activities of daily living that were not found when the patients were tested after the six month course of maintenance CST had finished. It is conceivable participants felt disappointed to no longer be receiving the maintenance CST and this is why the benefits of maintenance CST were no longer detectable at the six-month testing point after the course of maintenance CST had concluded.

Strengths of current research

One of the strengths of this study was the design replicated the original group CST study in which CST was found to be effective (e.g. Spector et al., 2003). Previous research on 'dose' of CST suggested that twice rather than once weekly delivery was required to see a cognitive benefit, (Cove et al., 2014). In light of this and the fact that when iCST was developed, patients and carers indicated that twice weekly is acceptable (Yates et al., 2016), in this study the iCST was delivered on a twice-weekly basis. As group CST, which has a consistent effect on cognition and quality of life, runs over 14 sessions, the iCST programme in the current study was delivered over 14 sessions across seven weeks. Another strength of this study is that the iCST was delivered by trainee clinical psychologists who, unlike many family carers, felt sufficiently skilled to deliver the iCST and therefore closely adhered to the iCST manual and delivered the iCST in line with the key principles. They delivered iCST as consistently as possible, referring to the manual before and during each session, and

delivered the iCST at a fixed time each week. This was helped by the fact that the trainee clinical psychologists were delivering the iCST as part of their paid work rather than as an additional task as would have been the experience of family carers. The high levels of attendance and low dropout rates suggest using non-family healthcare professionals rather than family carers to deliver iCST results in higher levels of engagement from participants. This also means that the participants in the study received a full dosage of iCST and that the iCST was delivered in a way that adhered closely to the manual design.

Another strength of this study was that it had a good ratio of males to females (46% of participants were male). This meant that the findings could be fairly said to apply to both genders but also suggests that iCST is appealing to both genders. Aguirre et al. (2013) found that CST seems to particular benefit females and most CST research samples have been predominantly female (e.g. in the Spector et al. (2003) study only 21% of the sample were male) and so it is possible that a strength of iCST is that it attracts both genders. This requires further exploration before any conclusions can be drawn. A further strength of this study is that although the sample was predominantly white British, it managed to attract participants with a wide range of ages (56-98 years) and a range of ethnicities (Asian, black British, white other, white British).

The iCST manual was designed to be easy to follow and allowed for flexibility so the sessions could be adapted to the varying interests and needs of participants. A further strength of this study was the range of measures used to test for improvements in participants' quality of life and the emotional and psychological symptoms of the people with dementia. This means that different aspects of quality of life and emotional and psychological dimensions could be explored.

Limitations of current research

Although the sample size was suitable with regards to exploring the feasibility of delivering iCST by a non-family carer (healthcare professional), it does limit the conclusions that can be drawn regarding the impact of iCST on quality of life and the psychological and emotional symptoms of people with dementia. A further limitation of this study relates to the fact that the only assessment to investigate whether iCST had impacted quality of life and the psychological and emotional symptoms of the

people with dementia took place during the two weeks after the iCST sessions had concluded rather than during the course of the trial.

One of the major limitations of this study is that it involved using seven different researchers to administer the baseline and follow-up measures. Despite the clear guidance in the measures to minimise the impact on results of using different researchers, it is likely there was some variation between the researchers in their administration and scoring style and also in regards to what they elicited from the participants. There were no systems in place to check inter-rater reliability. Similarly, in various instances it was not possible to administer the proxy-rated QoL-AD to the same carer at follow-up who had completed the measure at baseline. In addition, by virtue of the carers being present in the care home when the iCST sessions were being delivered, it was not possible to blind the carers as to which participants had received TAU or iCST. This lack of blinding could have resulted in unconscious favourable or unfavourable bias, depending on the carer's view of the iCST programme, when responding to the questions in the proxy QoL-AD.

Although the PPOM and EID-Q were deemed suitable for use with people with dementia (Stoner et al., 2017), during our study both questionnaires presented some limitations. It is possible the EID-Q and PPOM were validated with a sample with a milder cognitive impairment than the participants in the present study. The EID-Q includes some statements which appeared difficult for participants to understand either due to unclear language (e.g. People take decisions away from me) or length (e.g. I can make changes to my life to match my abilities). The PPOM also includes some of the statements which some participants found unclear (e.g. I can bounce back) and the guidance preventing researchers from rephrasing the statements. This lack of clarity in the questionnaires may have limited understanding of the participants, particularly those who are lower functioning.

Even though the study managed to attract participants with different ethnic backgrounds, the participants were predominantly white British and this does limit the generalisability of the findings to the wider population. In addition, researchers were unable to consult the medical notes of participants and so were forced to rely on care home staff testimony that all participants put forward to take part in the study had been diagnosed with dementia by a medical professional. In light of the high SMMSE scores of participants and the inability of researchers to consult participants' medical notes, there remains a question whether all participants truly did have a dementia

diagnosis. Therefore this does call into question the extent to which all participants adhered to item 2 of the inclusion criteria: “Have mild to moderate dementia as derived from the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005).”

Implications for future research

The feasibility results suggest that a full-scale RCT is now recommended to look at the effectiveness and cost effectiveness of iCST in this format (as opposed to previously tested formats). This full scale RCT should also assess the participants at a point when the participants have received enough sessions to have built a relationship with the facilitator but before the course of sessions has finished, such as at the midpoint (i.e. after seven sessions). Given all the feasibility parameters suggested the iCST offered was appealing and engaging for participants and has no adverse effects, there are no ethical reasons for not further investigating iCST delivered by a non-family carer (healthcare professional). A future full trial should use formal measures of fidelity to ensure the iCST is being delivered consistently. Future research could explore the effectiveness of delivering iCST using different types of non-family healthcare professionals such as clinical psychologists or care home staff. As far as possible the future research should use the same researcher to undertake the baseline and follow-up measures with each particular participant. It would also be useful to undertake qualitative research alongside the quantitative research in order to explore why the follow-up assessment undertaken after the iCST had concluded may not have detected the positive impact of the iCST on quality of life and the emotional and psychological symptoms of the people with dementia. The qualitative research could explore what participants think about each session and explore their levels of enjoyment during and after each session. If research were undertaken using for example clinical psychologists and also care home staff to deliver the iCST, the qualitative (and quantitative research) could explore how delivery by these two types of healthcare professional impacts the participants and the efficacy of iCST. If research showed that care home staff were able to deliver an effective iCST and delivery by care home staff was acceptable to participants, this would be a much more cost-effective way of delivering iCST on a wider scale.

It should be noted that this study did not restrict participation to only those participants who would otherwise have been unsuitable for CST (e.g. due to hearing

difficulties). Future research should consider whether to include participants who would in principle be suitable for CST. It may be that even though some individuals are suitable to take part in CST, iCST may be preferred such as for example if the model of iCST fit better with the culture of the care home.

If a larger trial were to find that iCST as delivered in this study were effective in improving participants' quality of life and/or emotional and psychological symptoms of people with dementia, iCST could then be assessed being delivered twice weekly using family carers. In future, delivery by a professional of iCST in patient's homes could also be further explored as this would mean that the 61% of patients with dementia who remain living at home (Prince et al., 2014) could find it easier to benefit from CST as iCST could be delivered in their homes. It would be useful to offer CST to patients living in their home environment as research shows that where possible, continuing to live in the home environment is beneficial for individuals with dementia (Olsen et al., 2016).

Implications for practice

The cognitive impairments of care home populations tend to be greater than those who remain in their private homes and this is likely contributed to by the frequent lack of stimulation in care homes. High levels of unoccupied time are common with one study finding that 65% of residents reported they "do nothing" 65% of the time (Harper-Ice, 2002) and another finding that some residents can spend up 17 hours a day in bed when awake and not receiving treatment (Bates-Jensen et al., 2004). The common lack of stimulating activities offered by care homes is particularly problematic given the difficulties of people with dementia to engage in self-directed activities (Tak et al., 2015). With all of this in mind, it was hoped positive findings from this study would lead to care home providers offering iCST to individuals with dementia who cannot or would not want to participate in group CST. This might include those who do not meet group inclusion criteria (e.g. a person with a partial hearing difficulty who struggles in environments with multiple auditory signals) or those who for social/emotional reasons feel uncomfortable in a group setting. In the same way that group CST research undertaken in care homes was generalised to memory clinics, it is hoped that our findings might generalise to private home settings, provided the delivery is by a professional and the dosage and format are identical.

Conclusions

The present study has shown that it is feasible (with regard to ease of recruitment, attendance and drop out) to deliver iCST by non-family carers (healthcare professionals). Results indicated no impact of iCST delivered by non-family carers on quality of life and/or the emotional and psychological symptoms of people dementia but due to the small sample size of this study, further research is required to more systematically explore this.

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Part 3

The Critical Appraisal

Research preparation

The preparation for this research was greatly aided by discussions with our main supervisor, Professor Aimee Spector, who has extensive experience of researching group CST. Professor Spector was able to guide Luke Gibbor (LG) and I as to how best to design our study, undertake the recruitment and execute the research. There was a clear consensus amongst the researchers designing this trial that it would be feasible and appropriate to undertake a randomised control trial but the decisions as to the exact nature and format of the iCST were more challenging. Although the original iCST was designed to be delivered over 25 weeks in 75 sessions of 30 minutes each, we considered that, given the absence of significant findings in the Orrell et al. (2017) study, it may be more useful to follow more closely the original group CST format, where CST had consistently been found to be effective, of 14 sessions delivered over seven weeks.

When designing the iCST programme we used the iCST manual from the Orrell et al. (2017) study as our starting point but then used the qualitative feedback from this study (Leung et al., 2017) and discussions with Professor Spector and our other supervisor, Dr Lauren Yates, to make further adjustments. The qualitative feedback was very useful and gave us information such as the fact that participants in the Orrell et al. (2017) study particularly enjoyed the music element of the sessions and so we ensured our manual allowed for proper time for this. In addition, being able to work jointly and in consultation Professor Spector and Dr Yates helped us make good use of the qualitative data. For example, the qualitative feedback revealed how participants had found the discussions very enjoyable. We were mindful of wanting our iCST manual to enable delivery of a standardised therapy whilst also wanting to

ensure it allowed sufficient flexibility to be tailored to the individual and allow for fluid conversations. From Dr Yates's experience she was able to reassure us that including a note in the Introduction to the manual that would enable the person delivering the iCST to add their own questions as appropriate would not undermine how standardised the iCST and would likely make the conversations more natural and enjoyable for the participants.

Recruitment

The recruitment process involved LG and I individually approaching various care homes. LG lives in north London and I live in south London and so we each approached separate care homes. I initially used Google to identify 22 care homes within three miles of where I live. I started by emailing the managers of the 17 closest care homes and following up these emails with a telephone call. There were two care homes that expressed an interest in our feasibility research and so I went to visit each of these and speak to the managers. Following these meetings, the smaller care home was happy to proceed but the larger one requested that I do a presentation to all the managers within the care home who are responsible for the various different units of the care homes. Despite being intimidated at the prospect of giving such a presentation, it was a useful learning experience and went as well as I could hope because the head manager confirmed that all the managers were keen to offer the opportunity to the residents within their units. I followed up the presentation with emails to all the unit managers and then awaited replies. It took various follow-up emails before I was given a list of potential names.

From a logistical point of view, it was certainly much easier running the research in the very large care home as it meant being able to see multiple participants during one visit. For any future research I would certainly recommend starting recruitment by approaching very large care homes.

Working in care homes

Running our research in care homes brought with it various advantages and challenges and gave me an insight into some of the systemic issues that could influence future delivery of the original group CST or iCST whether in a research or clinical context. A key advantage of delivering CST in a care home context is that routine forms an inherent part of care home life (Paddock et al., 2018) and this meant that participants were always available at the appropriate time and did not have other needs that prevented the sessions from proceeding on time and for the full 45 minutes. It is likely that were participants in a home context there would be times when the clinician would arrive to deliver the iCST but the participant would not be available for example because they have forgotten about the session, have visitors over or have yet to wash and have breakfast.

Another benefit of running the research in a care home context is that one can be fairly confident that each week the allocated room where the CST is to be delivered will be in a clean and hygienic state. Similarly, it is probable that the participant will have had their primary physical needs taken care of (e.g. being fed and washed) and so these areas will be less likely to act as obstacles to the CST proceeding.

One of the key challenges of working in a care home context that I encountered was managing the other residents. Often when I would go to collect one of the iCST

participants, other residents would ask to join the session. It was challenging and felt unkind to be excluding other residents when often they had very little activity to keep them occupied. Linked to this I also experienced one of my participants express resentment that I was delivering iCST to other residents and not just him. I did my best to reassure him that even though I visited other residents, each participant was equally important to me.

An important part of delivering CST in a care home context relates to how to manage relations with the care home staff. I was very conscious that by virtue of my role, visiting twice a week to deliver a fun activity for 45 minutes and thereby experience the more positive and hopeful side of the residents, could lead to resentment in the staff. With this in mind, I always made a concerted effort to articulate my respect for the work of the care home staff and invested time in building good working relationships with all the members of the team. Ensuring that participants are available for their allocated sessions depends largely on staff organisation and willingness and so building solid working relationships with all care home staff is an essential part of delivering CST, whether for research or clinical purposes. In addition, given the importance of staff morale on their own ability to deliver person-centred care (Kadri et al., 2018), I considered it important to do what I could to make the staff feel respected and valued for their essential and worthwhile work.

Obtaining consent

Obtaining consent was a fairly time-consuming and challenging task. Our consent form was relatively long and so this required participants to concentrate for a prolonged period of time. Even though we tried to make the process as enjoyable as

possible, including allowing breaks, it is likely that the process of obtaining consent from the participants was tiring and dull for them.

Delivering the iCST programme

Delivering the iCST programme entailed various challenges but overall was a rewarding and enjoyable activity. It was extremely useful to keep the key principles of iCST in mind at all times (Spector et al., 2001). In particular I ensured that each session took a person-centred approach and this meant not only adjusting to the individual broadly, in terms of for example preferences they had expressed in previous situations, but also adjusting to their mood and circumstances during each individual session. As part of the warm up during each session I would endeavour to gauge the mood of the participant so the session pace and contents could be tailored accordingly. At every opportunity I gave the participant choice as to what the session would include and I believe this helped the participants to feel engaged with the sessions.

In keeping with the iCST principle of aiming to strengthen a relationship with the participant and ensuring to make each session enjoyable and fun, I always presented with an energetic and optimistic persona and where appropriate, incorporated humour into our sessions. To show how much I valued the participants and in so doing, strengthen our relationship, I made a particular effort to remember details shared by the participants in previous sessions and would try to incorporate these into the present session. In order to maximise the participants' confidence in themselves and in so doing, maximise their potential, I always ensured to listen very carefully, validate any comments made by the participants and in line with a further iCST principle, focussed on opinions rather than facts during the sessions. Carrying

out the orientation activities was always done sensitively such that if a participant was unable to say the date or share details of their daily routine, I would try to give them clues and triggers to help them but would never simply tell them they were wrong. I found that the iCST principle of using reminiscence as an aid to the here and now, not only achieved this purpose but also served the function of improving the participants' confidence in their own cognitive abilities and memories. Many participants voiced their concerns about having a poor memory but when they were able to share details of for example their childhood etc. and I was able to validate this, this greatly improved their confidence.

I was mindful of trying to use stimulating language and communication and do feel that this combined with adopting a lively demeanour helped to engage the participants. When participants were tired or feeling a little unwell it was more challenging to support them to come up with new thoughts, ideas and associations. In such situations, where possible I would simplify the questions and tasks involved. If ever I noticed a participant doubting their own abilities I would try to remind them of some of the activities they had successfully completed either during that particular session or in previous sessions.

One challenge I encountered with four participants was that they were hard of hearing. With these participants I did what I could to enunciate clearly and where possible accompany what I was saying with gestures or visual clues. Another challenge I came up against was when participants were very keen to share with me a particular grievance or positive experience of their week and were reluctant to move off this topic and onto the session topic. To manage this, at the start of each session I would remind participants of the session plan and at each change of activity I would signpost the participant gently.

A further challenge that I experienced was managing the disappointment that clients expressed when I reminded them that the course of sessions was time-limited. During their final session many participants expressed sadness that they would not continue to have sessions. This experience did prompt me to consider the ethical implications for participants taking part of such a time-limited trial and then having life resume as normal afterwards.

It seemed that having the Life History session as the first session was a particularly helpful way of building that initial rapport with the client and thereafter having some details about the participant that could be referred back to during all future sessions. I also think that having physical games as the second session worked well as this meant introducing fun and enjoyment early on during the programme and functioned well as being a good advertisement as to what was to come in future sessions. Finally, I think that participants particularly enjoyed the Childhood session. This was the session where I found participants to be especially chatty and animated.

At various times during the course of delivering the iCST sessions, participants made comments outlining their concerns about their memory difficulties. Given that one of the principles of CST is to boost participant confidence and also given that the main focus of CST is to provide stimulation, when participants expressed such concerns I tended towards offering reassurance and returning to the task in question. In hindsight it may have been more helpful in some instances to offer more empathic and exploratory comments.

Strengths and limitations

One of the main strengths of this study was its design. The study was a single blind randomised control trial which ensured a fair assessment of the impact of the iCST and avoided researcher bias impacting assessments. In addition, the study followed previous research regarding CST dosage which suggested two weekly sessions are required to see a cognitive benefit (Cove et al., 2014) and research showing that patients and carers considered twice weekly sessions acceptable (Yates et al., 2016). Given that group CST which has a consistent impact on cognition of people with dementia is designed to be delivered over 14 sessions and the low adherence in the iCST trial run by Orrell et al. (2017) that could have been due to the length of the trial (25 weeks), this study involved sessions being delivered in 14 sessions over seven weeks.

To avoid potential problems of caregivers delivering the iCST (e.g. them feeling insufficiently skilled or unmotivated due to regular exposure to the deterioration of the person with dementia; them finding it hard to carve out the time for the sessions out of their normal life; them finding it hard to deliver the sessions consistently due to having an emotional relationship with the person with dementia), this study involved the iCST being delivered by trainee clinical psychologists. They felt sufficiently skilled to deliver the iCST, were motivated, delivered the iCST as consistently as possible and the sessions were run at two fixed times each week. They ensured to refer closely to the iCST manual and this ensured good adherence. Given they were delivering the sessions as part of their paid work rather than as an additional job, as would be the case with family carers, it is considered this helped with ensuring good adherence to the iCST manual and consistency. In addition, albeit hard to

quantify, it is plausible the trainee clinical psychologists approached the sessions with more energy than family carers given they were not being continually exposed to the deterioration of the participants which in itself could be demotivating. This study had high attendance levels and no participants receiving the iCST dropped out which suggests the way the iCST was delivered was effective at engaging participants.

Another strength of this study is the nature of the iCST manual. The manual is easy to follow and does not rely on the person delivering the iCST to obtain difficult resources. All the activities can be administered using items that would be found in a typical house or care home. The manual also allows for each session to be tailored so that it can be matched to the interests, personality and abilities of the person with dementia. It is likely that this level of tailoring also helped lead to such high levels of engagement amongst participants.

Even though this study was primarily a feasibility study and so was intentionally not very high powered, the small sample size does limit the conclusions that can be drawn regarding the impact of iCST on quality of life and the psychological and emotional symptoms of dementia. The main limitation of this study is that the only assessment regarding whether iCST had an effect on quality of life and the emotional and psychological symptoms of dementia took place two weeks after the course of iCST sessions had concluded. It is possible that any positive effect of the iCST on quality of life and/or the emotional and psychological symptoms of dementia which would have been detected whilst the sessions were still ongoing, was not detected due to participants' disappointment the sessions had ended by the time the follow-up assessment took place. A further limitation of this study relates to the number of different researchers used to administer the measures. Using different researchers means that despite the detailed guidance of how to administer the

measures, there could have been some variation in measure administration. In addition, different researchers may have unwittingly elicited different responses from the participants due to for example their gender, demeanour etc. These potential effects of using different researchers do mean that the results may have marginally less reliability. Finally, no formal fidelity measures were used in this study and so level of manual adherence cannot be quantified.

Reflections

Running this research project has offered a great learning opportunity. It has helped me develop my recruitment, experimental design and analysis skills. Whilst it was quite tiring administering the iCST sessions back-to-back, it was a rewarding and enjoyable process and represented ongoing learning opportunities for developing my ability to deliver iCST. It is important that the effectiveness of iCST is systematically researched in a future full-scale trial because, if found to be effective, it would enable more people with dementia to access the benefits of CST. This feasibility study represents a stepping stone towards this process.

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Appendices

Appendix 1: joint thesis details

In this joint thesis Luke Gibbor (LG) and Lycia Forde (LF) were jointly and individually responsible for different aspects of the thesis. LG and LF jointly adapted the iCST and CST manuals to create an iCST manual designed to be delivered over 14 sessions. LG and LF individually recruited 17 and 11 participants respectively. LG and LF each delivered the iCST to seven participants over 14 sessions (seven weeks). LG and LF were jointly responsible for undertaking and arranging for the participants to be assessed at the start and end of the trial. LG and LF each recruited a research assistant to assist with this task. LG and LF analysed the data independently with LG focusing on the cognitive measures and LF focusing on the quality of life and psychological wellbeing measures. LG and LF wrote their theses independently.

Appendix 2: iCST manual

INTRODUCTION

- iCST consists of 14 sessions, delivered twice weekly.
- Each session will be 45 minutes long.
- This manual is not intended to be followed word-for-word and is instead provides a guide. Please pick and choose from the questions and activities suggested, tailoring this to the person, and add any of your own questions and materials that you think would be suitable and fit within the theme of the session.

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

General tips

The resources provided are meant as guidance. Please feel free to add to any of the resources specified for each session.

Ideally sessions should be held in a quiet, comfortable room, and in the same place each week if possible. Ensure the room is easily accessible, and has appropriate space to complete the activities safely.

KEY PRINCIPLES

1. Mental Stimulation

The principal aim of iCST is to get people's minds active and engaged. There is strong evidence that following a diagnosis of dementia, people often withdraw from stimulating activities. This leads to further impairment, due to both loss of skills and confidence. You might explain to people that, like any part of the body, the brain needs to keep exercised to remain active. The aim of iCST is to pitch activities so that tasks are not too easy, meaning that people have to make some effort. Equally, pitching things too high can make people feel uncomfortable. Pitching the level of mental stimulation often involves some trial and error to get it right!

2. Developing new ideas, thoughts and associations

Often with people with dementia, we tend to talk about things from the past. Whilst this can be enjoyable, it often involves recalling information which has been over-rehearsed. This may therefore be less mentally stimulating than thinking about things in new ways and making new meaningful connections.

The aim of CST is to continually encourage new ideas, thoughts and associations, rather than just recall previously learned information. A good example of this technique is within the 'faces' exercise. Rather than looking at one face and asking the person what they remember or think about the face, show more than one face and ask questions such as 'What do they have in common?' 'How are they different?' 'Who would you rather be?' Similarly, rather than introducing discussion topics likely to have been covered before, such as "What do you think of the Royal family?"; encourage discussions about new topics such as "Is modern art really art?" or "What do you think of same sex weddings?" These techniques enable people to apply their knowledge, yet develop thought sand ideas that they may not have had previously, increasing the level of stimulation within the activity.

3. Using orientation in a sensitive manner

Orientation is an important goal of CST, but the way that people are orientated is key. Rehearsal of orientation information (such as the date) and putting the person on the spot with direct questions (e.g. what is the address) can be demoralising. Orientation needs to be done in a subtle way at the beginning of each session, for example through conversation about forthcoming festivals, important dates or the weather. Orientation can also be introduced into the topic (such as using summer fruits in a 'food' session).

4. Focusing on opinions rather than facts

An important aim of iCST is focusing on the person's strengths. If we focus on 'facts' too much, there is the risk that people will often be wrong. If we ask people for their opinions, then they may be amusing, sad, unusual, controversial or puzzling, but they cannot be wrong. Everyone is entitled to their own opinion, of course. So, rather than say 'Where did you go on holiday when you were a child?' (a memory question), ask 'What is your favourite place to go on holiday?' or 'Where would you advise a young family to go on holiday?'. Rather than ask 'Who is the Prime Minister', ask 'What do you think of politicians?' or 'Who has been the best leader of the country?', by giving a range of names, backed up by photographs. The activities should never feel like a memory test, and we should avoid asking direct questions of memory such as 'Can you remember...?' Reducing the demands of an activity creates an environment that promotes involvement and success.

5. Using reminiscence as an aid to the here and now

Using past memories is very useful during the sessions and can be an enjoyable activity. We can use reminiscence to celebrate the person's family life, personality, career, hobbies and achievements. We need to remember though that sometimes people may have unhappy (even traumatic) memories of their earlier life, and some sensitivity is needed not to push our relative/friend into exposing painful memories. The better we know the backgrounds and life stories of the person, the less likely this is to occur. However, reminiscence can also be a useful tool towards orientation, which is a key goal of iCST. Many iCST sessions allow you to compare old and new, thinking about how things have changed over time. For example, old and new coins and the changes in value of goods can be discussed in 'money' sessions.

6. Providing triggers to support memory

Multi-sensory cues are really important, as memory works much better if you do not rely on just one sense. Try to have a mix of activities involving vision, touch, hearing, taste and smell. Often it is a combination of senses that is most effective. For example, the 'food' session is enhanced if the person can taste, smell and feel food with interesting textures. Words in a discussion may soon be lost when memory is limited. Having an object, a photograph or picture keeps the person's attention on the activity and encourages a focus. Using stimuli, objects, and the paper-based activities provided in this programme will allow us to create an environment that promotes success.

7. Stimulate language and communication

There is evidence that language skills improve when engaging in mentally stimulating activities. Many of the sessions stimulate language, for example naming people and objects (e.g. in categorisation), thinking about word construction and word association. An important goal of iCST is to enhance communication, and make time to listen. It is important to consider if your relative/friend has any hearing or vision problems or if English is not their first language. Sitting next to them whilst engaging in the activities, and making sure they have their glasses and hearing aid, is very important.

8. Stimulate everyday planning ability

Skills in planning, organising and sequencing – also known as 'Executive functioning' skills, are often very impaired in dementia. Several sessions exercise these skills, for example planning and carrying out stages of a task (making a cake in 'being creative', selecting food for a meal in 'food'). Mental organisation skills are exercised through the discussion of similarities and differences, and through organising items into categories. These subtle tasks should encourage people to use skills which may have become under-used.

9. Using a 'Person-centred' approach

In a person-centred approach, we see the person first and foremost, the unique qualities of the individual as determined by their life history. The experiences that have shaped their personality and attitudes lead to a variety of skills, interests, preferences and abilities. The main purpose of iCST is to increase the person's pleasant experiences, by focusing on their strengths, and not concentrating on areas of difficulty. We show respect to the person by getting to know what is important for them, value the diversity of their views, opinions and beliefs, and therefore allowing the person to be different.

10. Offering a choice of activities

This programme is fairly detailed, primarily to make it more user-friendly. It is important that you offer your relative / friend several choices and alternative activities if those described in this manual do not suit their preferences, likes or dislikes. Offering choice allows people to become involved in making the programme their own. We propose that you work together to identify activities that suit the person's interests. For each session, we have suggested a choice of activities (described as Level A and Level B). Usually Level B activities are more demanding on the person's memory and other cognitive skills. Chose the level that is most appropriate and enjoyable for your relative/ friend, or mix activities from the two levels and add your own ideas! There is space in the manual to note activities you have tried for each session, so that next time around they can be among the choices open to you.

11. Enjoyment and fun

If you find people commenting that 'this is like being back in school', something is going wrong! This may imply that they are being made to work hard in a strict and serious atmosphere. The activities should provide a learning atmosphere which is fun and enjoyable. Yes, peoples' brains should be stimulated, but so should their laughter muscles! If the person makes comments about 'school', ask them what they liked and disliked about school, and reflect on whether you are taking on the role of 'teacher' too readily. A key principle of the programme is that activities should lead to your relative / friend feeling enabled and empowered.

12. Maximising potential

There is evidence that people with dementia can learn, with the right encouragement and support. We should be careful therefore not to assume a person is unable to contribute or carry out an activity because they were not able to yesterday or last week. People with dementia often function below their full potential, due to a lack of stimulation or opportunity. An important goal of iCST is that it works by building on the memory and cognitive skills of the person, providing them the opportunity to practice these skills. This involves giving the person time, being careful not to overload or overwhelm them with information, and providing just enough prompting to enable them to carry out the activity themselves. This will increase exposure to success, which will aid learning and enjoyment. People are more likely to achieve their potential by doing rather than sitting passively and watching.

13. Strengthening the relationship by spending quality time together

The sessions will help strengthen relationships – especially if we do not become 'teachers', but assist the person, to join in, and have fun. An important aspect of iCST is that it enables other family members or friends an opportunity to feel at ease, and enjoy quality time together. The true focus is not about the activity itself, but the quality and joy of the interaction. You are also encouraged to set time aside to celebrate your role as a carer. Providing a caring, happy and fulfilling environment for your relative/friend is a rewarding experience and we hope this programme helps carers to achieve this.

SESSION 1: LIFE HISTORY

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

The idea of this session is for you and the participant to get to know one another better. Below are some ideas to guide your questioning

LEVEL A

- Tell me about your family.
- Tell me about your family traits.
- Do you have any photos of your family/childhood/life that you would like to show me?
- What music do you like/dislike? Is there a song that you would like to listen to at the start of each session?
- What things do you like/dislike?
- Who in your life is important to you?
- What things do you enjoy/not enjoy?
- What physical games do you enjoy? What physical game would you like to play in our next session? (ideas include boules, mini-bowling, throwing ping pong ball into a cup)

My Life History game (optional). Flip a coin onto the board, and answer the life question in the box.

LEVEL B

Use the topics above (Level A) to generate discussion alongside the guidance below.

- Make a family tree. You can include birthdays and more complex details about people on tree. E.g. marriages, how people are related, place of birth or where they are living now.
- Do you like to be part of a group or prefer one to one company?
- Who are the most important people in your life at the moment?

Resources

- My Life History game board

SESSION 2: PHYSICAL GAMES

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Spend the session playing a physical game. Some suggestions for activities have been provided below:

- See how long you can keep a balloon in the air for
- Make a bowling alley with plastic bottles or objects and a ball and see how many you can knock down
- DIY throwing games: collect objects from around the home, such as cups, bowls, pans and use these as 'goals' and a ball (ping pong ball). Place the objects at a reasonable distance and see if you can throw the ball into your goals.
- Boules

Tips

These activities can be done standing up or sitting down depending on the physical abilities of the person. Please make sure you have enough space to do the physical activity you choose, and take care to make the area safe to avoid any accidents.

Resources

- chosen physical game(s)*

SESSION 3: SOUNDS

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Listen to clips of music, and have a discussion about them using the suggested questions below. If the person does not like music, an alternative is to listen to clips of known sounds found on the Sounds Activity sheet.

LEVEL A

- What do you think of the music you hear?
- Does the music remind you of anything?
- Where might you hear this music?
- Can you play any musical instruments or would you have liked to learn?
- What styles of music do you like?

LEVEL B

- Listen to the clips of music, and try to match these with the styles on the activity sheet. Use the topics provided above in Level A to generate discussion.

Tips

You might need to play each track more than once to identify the styles of music.

Resources

- Music clips of: classical, blues, country, waltz, rock, world, reggae, funk, salsa, jazz, etc. You could also use a mixture of well-known classics.
- Styles of Music Activity Sheet*
- Sounds Activity Sheet*

SESSION 4: CHILDHOOD

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Look at childhood photographs alongside those of friends and family members, and photographs of childhood toys (or real old and new toys) and have a discussion about them using the following questions as a starting point.

LEVEL A

- What were you like as a child? What kinds of things did you like to do?
- Do the photos have a story behind them?
- Can you see a family resemblance in the photos of your relatives as children?
- What was school like?
- (Using photos or real toys) Which of the toys seem like the most appealing or fun?
- How do you think these toys work? What games might you play with them?
- Did you play with any of the toys and games as a child?
- Do you think children nowadays play with toys like these?

LEVEL B

Have a discussion about your childhood prompted by the following questions, though you could also use some of the topics as above (LEVEL A).

- What were your favourite hobbies as a child?
- Did you have any pets?
- Did you have a best friend when you were a child?
- Where did you play, and what games were your favourite? (This could be a chance to take out some of the photos and/or real toys).
- Can you identify the toys and games that you see?*
- What do you think the rules of each game are? (You can then try playing some of them).
- What was the area you grew up in like?
- How did you get to school when you were a child?
- Do you have any stories from your childhood?

Tips

- You could write the questions on slips of paper, put them in a pot and pick them out randomly.

Resources

- Pictures of old toys (see activity sheet*), or if available, old or new childhood toys
- Names of old toys (see work sheet*)
- Childhood photos of friends and family if available

SESSION 5: FOOD

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A

Look at the pictures of different foods, or you may bring in some samples of food. These and the questions below can be used to guide discussion. You could also plan your dream menu using the activity sheet. You might also sort the real food/pictures into categories (e.g. sweet, salty).

- What do you think of the food in the pictures (or the real food samples)?
- Are there any particular foods you would like to try?
- If you were planning a dream meal, what would you have for each course?
- What drinks would you choose to go with the meal?
- If you were having a dinner party, who would you invite and why?

If the person prefers not to do this activity, then discuss food adverts instead. You could compare old and new adverts for the same product.

- Which advert do you prefer and can you think of a different way of advertising the product?
- Do you prefer the old or the new advert, and why?
- What is your favourite advert?
- Have you ever bought a product because of the advertisement?

LEVEL B

Use the topics above (LEVEL A) to generate discussion alongside the guidance.

- Do you like to try new foods?
- What would you need in order to prepare your dream meal?
- What do you think about foods from around the world?
- What kind of foods do you like or dislike?
- Do you think your tastes have changed over the years?
-

For slogans and adverts, you might add the following questions.

- Do you watch TV, listen to the radio and/or use the internet? Do you think that adverts are more effective on TV, over the radio, in the paper or on the internet?
- Do you have any favourite or least favourite adverts?

Resources

- Dream menu activity sheet*
- Pictures of food and ingredients
- Food adverts sheet (optional)*

SESSION 6: FACES

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Discuss the images of faces on the activity sheet using the following points as a guide.

LEVEL A & B

If the person spontaneously recognises any of the faces, you might ask them to tell you about them, otherwise try to steer away from fact-based questions in this activity. The goal is not to identify or recall facts about the faces shown.

- What can you tell about a person just by looking at their face?
- What sort of character do you think each person has (e.g. friendly, outgoing)?
- What are each face's best/worst features?
- Do any faces stand out to you and why?
- If you were to choose one as a friend, which would it be and why?
- Who is the most or least attractive?
- How do you think these people are feeling?
- In what ways are these people similar, or different?

Tips

You could use images of people from recent newspapers or magazines.

Resources

Faces activity sheet*

SESSION 7: WORD ASSOCIATION

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A

Think of words associated with the words shown on the activity sheet. There are many possible associations so see how many you can think of. You can either discuss your answers or write them on a separate piece of paper. Add pairs of your own if you wish.

LEVEL B

You could complete some of the activity from LEVEL A as a warm-up, then complete the well-known proverbs provided in the activity sheet. Discuss the proverbs as you match them. For example, discuss the meaning of the proverbs, or whether you have been in a situation where they applied to you.

Alternatively, have a game of free association. Begin with an agreed word and each take turns to say a word related to the last word said. For example, you might agree that 'dog' is your first word. The first player might say 'walk', the second might say 'run', and the first player takes another turn and so on. Before you begin, agree when the game will stop (e.g. after you have thought of 20 words, or run out of words).

You could also think about writing the words down, and seeing how far you get from the original word.

Resources

- Associated pairs activity*
- Proverbs word game*

SESSION 8: BEING CREATIVE

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Discuss your thoughts and ideas about works of art (e.g. paintings, sculptures, photography). You may also wish to use the self-portraits activity which could involve matching the artists to their portraits, discussing the styles of portraits and the person's thoughts about them (e.g. Are they flattering? Would you like the artist to paint a portrait of you? What do you think they are trying to say about themselves?)

LEVEL A

- Which of the works of art do you like?
- Which would you like to have?
- Where would you hang this art in your home/room?
- Are there any you dislike and why?
- How do the pictures make you feel?
- Do you prefer the classical or modern (old or new) works of art more?
- Do you consider all of the examples to be pieces of art?
- Discuss your thoughts about self-portraits (optional).

LEVEL B

Use the topics above (LEVEL A) to generate discussion alongside the guidance below.

- Can you identify any particular styles of art?
- Do you think the artists who painted these pictures are talented?
- What makes something art?
- How do you value art?
- Do you think there is a message behind the painting?

Resources

- Images of classical and contemporary paintings, photographs or other artwork*
- Self-portraits activity*
- Architecture sheet

SESSION 9: CATEGORISING OBJECTS

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A

Think of categories and list as many examples as you can in each category. For example, if you chose 'fruit' as a category, you might list apples, pears, oranges etc. Some other suggestions are below.

- Things you might find in the kitchen, garden, bathroom etc.
- Things you might take on a picnic or find at the seaside
- Countries
- Girls' / boys' name
- Famous landmarks
- Colours
- Famous novels
- Things to do on a sunny day

LEVEL B

Complete the categories game as in LEVEL A, but make the game more challenging by setting a timer. See how many examples you can come up within the time set. You could also think of more specific categories, such as those shown below.

- Countries beginning with a vowel/consonant (or for a challenge, beginning with a specific letter)
- Animals beginning with a vowel/consonant (or a particular letter)
- Foods from Italy
- Famous landmarks in London

If there is time, you could look at the odd one out series to discuss. Choose a selection, and think about the following topics.

- What are the differences between the items?
- What are the similarities?
- Can you find more than one association between the items?

Tips

Discuss reasons for your answers, and see how many differences, similarities, and connections you can think of between the items in each series.

Resources

- Odd one out series*

SESSION 10: ORIENTATION

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A

Look at and discuss different scenes and landscapes in the scenes activity sheet. Feel free to add your own images from magazines, photos or postcards of different places. You could also draw an outline of the UK, and draw in different towns and places, then discuss how to get from one place to another.

- What kind of place do you think this is?
- Which scene do you like best and why?
- Can you think of any similarities? How about differences?
- Which scenes look like they could be from faraway places? Which look closer to home?
- What sort of people might live, work in or visit these places?
- How would you expect to spend your time if you were visiting the place in the picture?
- Would you need to take anything in particular? E.g. sunglasses, a warm jacket.

LEVEL B

Use the topics above (LEVEL A) to generate discussion alongside the guidance below.

Bring a world map, and ask the individual to match each scenes to where in the world they think it may have come from. You could use pins or tabs on the map to do this. You might also do the same with images of famous landmarks and cities.

- What area of the world might these be from?
- Have you ever visited any places like this?
- Would you like to visit any of these places?

Resources

- World map
- Scenes activity sheet*
- Famous landmarks sheets*

SESSION 11: USING MONEY

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A

- If you found £5 on the street, what would you spend it on?
- What would you do if you won the lottery?
- Are you a saver or a spender?
- Should children be given pocket money? Were you given pocket money?
- Do you think we should have a minimum wage, what should it be?
- What kinds of things do you like to spend your money on?
- Look at photos of items, and ask the individual how much they think each item costs now, and how much it cost in the past?

LEVEL B

Use the topics above (LEVEL A) to generate discussion alongside the guidance below.

- Do you think purchasing items on credit is a good idea?
- Do you agree with the saying 'Health is better than wealth' or 'Money is the root of all evil'?
- What is your opinion on betting and gambling?
- Would you ever lend money to anyone?
- Do you agree with the saying 'Look after the pennies and the pounds will look after themselves'?
- Do you have a favourite charity? If so, why did you choose to support it?
- Do you think some professions deserve to earn more?
- What kind of things should the government spend money on? (e.g. NHS, schools)

Resources

- Have access to website or app that shows you old and new prices, or bring a worksheet with this information
- Prices of items in the photos

SESSION 12: NUMBER GAMES

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Spend the session playing number games. Some activities and ideas are detailed below.

LEVEL A & B

- Card games (e.g. Snap!, Pontoon, higher or lower).
- Dominoes
- Paper games (e.g. noughts and crosses, squares – see worksheet)
- Board games (e.g. Yahtzee, Connect 4)
- Guess how many items in a container, then count them and see whose guess is the closest (optional).

Resources

- Pack of cards, dominoes, connect 4, board games etc.
- Container filled with sweets/chocolates/other (optional)
- Squares game*

SESSION 13: WORD GAMES

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

Spend the session playing some word games. Some activities and ideas are detailed below.

LEVEL A & B

- Hangman
- Crossword
- Word Search
- Taboo: Take turns to think of a word for your partner to guess and try to describe it without using the word itself.
- 20 Questions: Think of a well-known target word. The person can ask only yes or no questions in order to guess the target word. They are allowed up to three clues.
- Go through the alphabet and think of a word for each letter. To make this more difficult, you can restrict the words to a certain category (e.g. trees and flowers, or animals).
- Scrabble

Resources

- Word games from magazines, puzzle books or newspapers (optional)
- Scrabble (optional)

SESSION 14: THINKING CARDS

Warm up

5 minutes: Discuss the date, weather, plans, what they have been doing recently etc. You might also look at their diary (or that of the care home) and discuss upcoming events.

5 - 10 minutes: Discuss a newspaper article or magazine (this could be a pre-prepared article: headline, picture, summary).

5 minutes (optional): Play participant's chosen song (with/without singing along) or discuss a thought for the day or a chosen quote.

Main Activity

LEVEL A & LEVEL B

Choose a selection of questions and topics provided in the grid, and use these as a guide to generate and encourage discussion. Think creatively and have fun exploring the ideas you come up with together. If you think of any questions of your own, incorporate these into the activity.

You could throw a coin onto the grid and answer the question the coin lands on.

Resources

- Thinking cards grids*

Appendix 3: ethics approval

Letter and subsequent email from the UCL Research Ethics Committee.

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH



25 January 2018

Dr Aimee Spector
Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Spector

Notification of Ethics Approval with Provisos

Project ID/Title: 12503/001: Individual Cognitive Stimulation Therapy for Dementia (iCST Pilot)

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that the data collection element of your study has been ethically approved by the UCL REC until **30th September 2019** subject to a satisfactory response to the following queries:

1. Will a more simplistic Participant Information Sheet (PIS) using simpler language and larger font be available for volunteers if they struggle to understand the current sheet, or is that not expected with the degree of dementia that patients who are being recruited into this study are expected to have?
2. The 'What if something goes wrong?' section of the PIS needs to be modified as you should not state that participants will have to bear the cost for legal action. UCL's insurance policy provides cover for claims against UCL for negligence by research participants and others as well as cover for non-negligent harm to study participants, i.e. compensation to participants where negligence cannot or is not proven.
3. Should a patient raise suspicion or concern to the researcher regarding the quality of care in the care home, who will the researcher escalate this to? Similarly if the patient raises a question about their medical/nursing care, who will the researcher liaise with to ensure their questions are addressed?
4. Please clarify the relevance of the GP information sheet. Is this a customary notification of patients becoming invoked in a Randomised Controlled Trials? Or to ensure follow on care if a formal diagnosis is made by the researchers which was not confirmed prior to study? The second point is important to reduce harm to participants once the study is completed.

Ethical approval is also subject to the following conditions:

Notification of Amendments to the Research

You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
<http://ethics.grad.ucl.ac.uk/responsibilities.php>

Adverse Event Reporting – Serious and Non-Serious

It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse

incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report

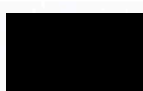
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: <http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research>
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely



Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Luke Gibbor and Lycia Forde



VPRO.Ethics

Thu 22/02/2018, 12:07



Thanks for your satisfactory responses to the Committee's comments.

With best wishes for the research, [Helen](#)

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Appendix 4: participant information sheet

Division of Psychology & Language Sciences
Faculty of Brain Sciences



Participant Information Sheet For Adults

This study has been approved by UCL Research Department's Ethics Chair [Project ID: 12503/001]

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Individual Cognitive Stimulation Therapy for Dementia (iCST Pilot)

Department: Department of Clinical, Educational, and Health Psychology

Name and Contact Details of the Researchers:

Luke Gibbor
Trainee Clinical Psychologist



Lycia Forde
Trainee Clinical Psychologist



Name and Contact Details of the Principal Researcher:

Dr Aimee Spector



1. Invitation to participate in a research study

You are being invited to take part in a doctorate research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this information sheet.

2. What is the project's purpose?

In recent years, Cognitive Stimulation Therapy (CST) groups have shown to be an enjoyable and beneficial therapy for people with memory problems. This project will show whether individualised (one-to-one) CST is effective in

improving things like memory and quality of life for people with memory problems.

3. Why have I been chosen?

You have been invited to take part because you have at some point had a memory assessment, and it is thought that you might benefit from and enjoy this opportunity.

The inclusion criteria for this study are that you meet the criteria for a mild to moderate dementia, are able to communicate, understand, see and hear well enough to participate in iCST activities, have the capacity to provide informed consent and have no major health issues which would affect participation.

In total we are hoping to recruit 32 participants to this study.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason and without it affecting the standard of care you receive. If you decide to withdraw you will be asked what you wish to happen to your data you have provided up that point.

5. What will happen to me if I take part?

This study is a randomised trial. We need to see whether iCST is better than treatment as usual, so we need to compare any changes experienced by people receiving iCST to those not receiving iCST. The fairest way of doing this is to select people for the group by chance; everyone agreeing to take part will have a 50:50 chance of receiving iCST. The decision is made by an independent computer, which will not have any identifying information about you.

If you decide to take part, your participation in the study will last for a time period of about 2 months. Following discussion of any questions you may have with a researcher, and signing the consent form, **all participants** will be asked to:

1. Meet with a researcher for between one / one-and-a-half hours for an interview and to complete some questionnaires covering your quality of life, memory and other areas of thinking. The time stated to complete

the interviews and questionnaires is an estimate; you may take as many breaks as you want or feel necessary, and even complete the process over two sessions if preferred.

2. Repeat these questionnaires with the researcher after 7 weeks. This is to see whether any of these factors change as a result of the iCST sessions.

The researcher will come to where you live to complete these assessments, and to offer the iCST sessions if you are chosen for that group.

iCST sessions will last for 45 minutes and will be led by a professional trained in CST. They will take place twice a week for 7 weeks. The activities will include, for example, discussion of food and current affairs. The idea is to keep the mind active through enjoyable activities.

6. What are the possible disadvantages and risks of taking part?

iCST aims to be stimulating and enjoyable. Sessions involve discussing themes such as food, music and current affairs and the level of risk in taking part is therefore minimal. If at any point you want to stop a session it will be ended. If the sessions really do not suit you, you are free to stop the iCST at any point. If we have any concerns that are raised during the course of the research, we may need to speak with the care home staff, but we would aim to speak with you about this first.

7. What are the possible benefits of taking part?

If you decide to take part and receive iCST, we hope that it might be enjoyable for you. We also anticipate that the stimulating activities might improve some of your skills, including memory and language, and improve your quality of life. Such changes have been demonstrated through group CST. The information that we get from this study may help us to treat people with memory problems better in the future, so you will be making a valuable contribution.

8. What if something goes wrong?

If you are unhappy or dissatisfied about any aspect of the study, we would ask you to tell us about this first, so that we can try to resolve any concerns and find a solution. Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of this study, please contact the principal investigator (see details above). If you

feel that your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

Should you have any concerns after your participation in the project, please speak with members of your care team or contact us directly.

9. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

10. Limits to confidentiality

I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified, unless during our conversations, we hear anything which makes us worried that someone might be in danger of harm. In this case, we might have to inform relevant agencies of this.

11. What will happen to the results of the research project?

The results will be published in relevant health journals. No participants will be identified in any publication arising from the study, without their written consent. We will make arrangements for participants to be informed of the progress of the research and the results through newsletters and local meetings.

Anonymised data will be stored for up to 5 years at University College London. Anonymised data may be looked at by authenticated researchers, and may be used for additional or subsequent research.

12. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ud.ac.uk.

UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ud.ac.uk.

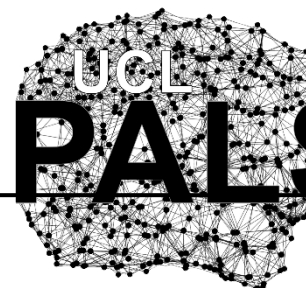
Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed only until the end of your participation in the study. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

13. Who is organising and funding the research?

The research is funded by University College London. This funding covers the running costs of the research project and is led by Dr Aimee Spector, who is a Reader in Clinical Psychology at University College London.



CONSENT FORM FOR ADULTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Individualised Cognitive Stimulation Therapy for Dementia (iCST Pilot)

Department: Department of Clinical, Educational and Health Psychology

Name and Contact Details of the Researchers:

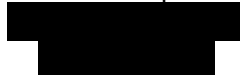
Luke Gibbor
Trainee Clinical Psychologist

Lycia Forde
Trainee Clinical Psychologist



Name and Contact Details of the Principal Researcher:

Dr Aimee Spector



Name and Contact Details of the UCL Data Protection Officer:

Lee Shailer



This study has been approved by UCL Research Department's Ethics Chair [Project ID: 12503/001]

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction, and would like to take part in (please tick one or more of the following) <ul style="list-style-type: none"> - an assessment at start and end of the study - possibility of receiving iCST or normal care 	

2.	I understand that I will be able to withdraw my data up to the time of the second assessment.	
3.	I consent to the processing of my personal information (name and date of birth) for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	
4.	<p>Use of the information for this project only</p> <p>I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified, unless during our conversations, we hear anything which makes us worried that someone might be in danger of harm. In this case, we might have to inform relevant agencies of this.</p> <p>I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.</p>	
5.	I understand that my anonymised information may be subject to review by responsible individuals from the University or monitoring and audit purposes.	
6.	<p>I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without the care I receive or my legal rights being affected.</p> <p>I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.</p>	
7.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
11.	I understand that my care home will compensated for my participation in the study.	
12.	I agree that my anonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
13.	I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
14.	I hereby confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.	
15.	<p>I hereby confirm that:</p> <p>(a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and</p> <p>(b) I do not fall under the exclusion criteria.</p>	
16.	I agree that my GP may be contacted if any unexpected results are found in relation to my health.	
17.	I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 12 months.	
18.	I am aware of who I should contact if I wish to lodge a complaint.	
19.	I voluntarily agree to take part in this study.	
20.	<p>Use of information for this project and beyond</p> <p>I would be happy for the data I provide to be archived at University College London for a period of up to 5 years.</p> <p>I understand that other authenticated researchers will have access to my anonymised data.</p>	

Name of Participant

Date

Signature

Researcher

Date

Signature

Appendix 6: care home invitation letter

RESEARCH DEPARTMENT OF CLINICAL,
EDUCATIONAL AND HEALTH PSYCHOLOGY



Care Home Manager
Address

Department of Clinical Psychology
University College London
1-19 Torrington Place
London
WC1E 7HB

DATE

Dear Care Home Manager,

Re: Individualised Cognitive Stimulation Therapy for Dementia (iCST Pilot)

You are invited to take part in a research trial being conducted at University College London, investigating the impact of individualised Cognitive Stimulation Therapy (iCST) for people with a mild to moderate dementia.

What is Cognitive Stimulation Therapy?

CST is a well-established group intervention for people with dementia that has been shown to improve quality of life and cognition. It involves a range of themed-activities, stimulating the brain and engaging people with dementia. Although there is a strong evidence base for CST, the effectiveness of iCST, when delivered in care homes, is not yet known. Our study aims to investigate the effectiveness of professionally-delivered iCST, consisting of 45-minute sessions twice-weekly over seven weeks.

If iCST were found to be effective, it would mean many individuals who cannot currently access group CST, such as those with sensory impairments or who do not have transport means to access groups, could still benefit from CST.

What will taking part involve?

Trainee psychologists will come to your care home and deliver iCST to residents for free. There would be minimal expectations of care homes, beyond referring residents. Residents interested in taking part would complete a cognitive assessment with us and questionnaires (taking approximately one hour) at the start and end of the study. We will then randomly allocate individuals to receive either iCST or care as normal.

As a token of appreciation, we are offering £10 to the care home, for each resident who takes part. Ideally, we would like each care home to put forward a minimum of four participants.

If you think that the care home may be interested in taking part in this trial or you would like to find out more, please contact us by telephone or email on the details below. Alternatively, we would be happy to meet with you and answer any questions.

We look forward to hearing from you.

Kind regards,

Supervised by

Recruiter details (Trainee Clinical Psychologist)
Tel:
Email

Dr Aimee Spector (Clinical Psychologist)

Appendix 7: The Positive Psychology Outcome Measure (PPOM)

The Positive Psychology Outcome Measure (PPOM)

Interview and Scoring Procedure

The PPOM is free to use but should be cited as:

Stoner, C. R., Orrell, M. & Spector, A. (2018). The Positive Psychology Outcome Measure (PPOM) for people with dementia: Psychometric properties and factor structure. *Archives of Gerontology and Geriatrics*, 76, 182-187. DOI: 10.1016/j.archger.2018.03.001

Participants can complete the PPOM in two ways: by interview or by self-report. Participants should always be encouraged to make a choice as to how they wish to complete the PPOM. The PPOM **should not** be completed using proxies (e.g. completed by family/ professionals on behalf of a person with dementia).

Self-Report Procedure

If a participant wishes to complete the PPOM by self-report, only page 2 of this document should be given to them.

Interview Procedure

If completing by interview, a trained researcher should always administer the interview. Each item should be read out using the one-month time frame and each Likert response should also be read out.

If a participant asks for clarification, the item should be read out again. Interviewers should not explain items and, instead, encourage participants to interpret the question in a way that makes most sense to them.

Only one response can be circled. If a participant is undecided between two responses, they should be encouraged to select the one they feel is best.

Scoring Information

Each response has a corresponding score (0-4). Responses should be summed to provide an overall score for the PPOM. There are two subscales for the PPOM: Hope (Item 1-8) and Resilience (9-16). Subscales can be summed to calculate hope scores and resilience scores.

Instructions

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

PPOM					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
1. I have a positive outlook on life	0	1	2	3	4
2. I can see positive things in difficult situations	0	1	2	3	4
3. I can recall happy/ joyful times	0	1	2	3	4
4. I have inner strength	0	1	2	3	4
5. I can give and receive care/ love	0	1	2	3	4
6. I have a sense of direction in life	0	1	2	3	4
7. I believe that each day has potential	0	1	2	3	4
8. My life has value and worth	0	1	2	3	4
9. I am able to adapt to things	0	1	2	3	4
10. I am able to deal with whatever happens	0	1	2	3	4
11. I am able to see the humorous side	0	1	2	3	4
12. I can cope with stress well	0	1	2	3	4
13. I can bounce back	0	1	2	3	4
14. I can stay focused	0	1	2	3	4
15. I am an emotionally strong person	0	1	2	3	4
16. I can handle unpleasant feelings	0	1	2	3	4

Appendix 8: Engagement and Independence in Dementia Questionnaire



Instructions

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

EID-Q (V3)					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. I am a burden to others	0	1	2	3	4
6. I enjoy conversations with others	0	1	2	3	4
7. I can make my own decisions as much as I'd like to	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I'm confident in making decisions	0	1	2	3	4
10. I am often ignored by those around me	0	1	2	3	4
11. I can do activities that are important to me	0	1	2	3	4
12. I can get in touch with friends/ family if I need to	0	1	2	3	4

13. People take decisions away from me	0	1	2	3	4
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
14. My friends/ family care about me	0	1	2	3	4
15. I can arrange my life in a way that suits me best	0	1	2	3	4
16. I can help the people I care about	0	1	2	3	4
17. I feel I am active in everyday life	0	1	2	3	4
18. I can take part in groups/ activities with others	0	1	2	3	4
19. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
20. I feel that my friends/ family want to spend time with me	0	1	2	3	4
21. I can make changes to my life to match my abilities	0	1	2	3	4
22. I can confide in my friends/ family	0	1	2	3	4
23. I can get myself food if I need to	0	1	2	3	4
24. I can help my friends/ family as much as I would like	0	1	2	3	4
25. I keep myself busy with activities/ hobbies	0	1	2	3	4
26. I feel connected to others	0	1	2	3	4