The impact of individual Cognitive Stimulation Therapy (iCST) on cognition in people with dementia: a pilot randomised control trial

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D. Clin. Psy. Thesis (Volume 1), 2019

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.

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Overview

This thesis focuses on an adapted individual Cognitive Stimulation Therapy (iCST) programme for people with dementia (PWD).

Part I is a systematic literature review exploring what qualitative studies of cognitive stimulation therapy (CST) can inform us about the acceptability and feasibility of CST, which components of CST are most desirable or important, and its key outcomes. It does so through a thematic analysis of perspectives from PWD, carers of PWD, and facilitators of CST and considers what this contributes to our understanding of both group and individual CST. Ten papers are included in the review.

Part II is a pilot randomised controlled trial that assessed the feasibility of an adapted program of iCST and explored whether it could provide benefits to cognition and quality of life (QoL) for PWD as compared to treatment as usual (TAU). This is a joint project with Lycia Forde (LF). Measures of cognition and QoL were assessed at baseline and follow-up. Both papers will consider the feasibility and acceptability of the intervention, however this paper evaluated the impact of iCST on cognition, whilst LF's paper reports on measures of QoL.

Part III is a critical appraisal of this work, with focus on Part II, which reflects on the challenges encountered whilst conducting research in a care home setting. It also reports on the experienced response to intervention and recommendations for delivering iCST to PWD.

Impact Statement

Dementia is a condition that affects approximately 800,000 people across the UK, and this number is increasing as people are living to older ages. Cognitive Stimulation Therapy (CST) is an evidence-based group therapy for people with dementia, the effectiveness of which has been supported by several trials and a Cochrane review.

The literature review attended to a gap in previous research, as it the only review of its kind which explores how solely qualitative studies across all formats of CST can expand our understanding of its implementation and how it is experienced. The review identified three overarching themes of “Acceptability and Feasibility”, “Features of CST” and “Key Outcomes”. These findings provided several new hypotheses for discrepancies between quantitative and qualitative findings, and recognised commonalities across different formats of CST, which were previously unidentified. In addition, recommendations were generated for researchers wanting to further develop or evaluate CST and for services or individuals aiming to implement CST both in group and one-to-one formats. Of note, the features identified as important or desirable provided valuable insight to which components could be central to the enjoyment and efficacy of the intervention, and this is particularly useful for services that may not have the resources to offer the full program of sessions.

The empirical paper built on findings from the literature review. The study conducted by Luke Gibbor and Lycia Forde, led by Professor Aimee Spector, developed a 14-session programme of individualised CST (iCST). The revised programme addressed difficulties encountered in previous trials including the frequency and number of sessions and difficulties with family members delivering the intervention. The intervention was found to be feasible and acceptable for people with dementia in care homes and may provide benefits to cognition. These findings indicated that further research in iCST would be well-founded, as these benefits were not found in previous trials of iCST. Despite CST being widely available in the NHS, many are unwilling or unable to attend groups, for example due to transport issues or health problems. This represents a step forward in finding an alternative intervention for these individuals. As such, iCST may offer hope to a population most in need of stimulation and at subsequently greater risk of cognitive decline. These results will be disseminated in relevant journals to support ongoing research. For example, iCST could be re-evaluated for delivery by a family caregiver, which may offer other benefits including improvements to caregiver relationships. Overall, this intervention could be an effective way to provide CST to people both in the community and at home.

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Acknowledgements

I would like to give my greatest thanks to my supervisors, Professor Aimee Spector and Dr Lauren Yates for their consistent guidance and support throughout this project, and to my thesis partner, Lycia Forde, for her hard work and the energy she brings to everything. I am especially grateful to all the care home managers and their teams who have been so welcoming and helpful, and for their interest in our research. I would also like to thank all the participants who took part in our study, who it was a pleasure getting to know.

I am grateful to Charlotte Stoner for her valuable advice on systematic reviews, and to Anna Volkmer for her support in quality rating papers. I am also thankful to Daniela Rouse, Saul Rodgers, Christina Komodromos, Stavros Orfanos and Dara Leung for all their help in collecting data.

I would like to thank my family and friends for their support, friendship and encouragement. Lastly, a heartfelt thank you for all the encouragement, understanding, patience and support from my partner Jason, who has been a constant aid and lifeline, who I could not have done this without.

Part 1: Literature Review

Cognitive Stimulation Therapy (CST) for dementia: A systematic review of qualitative research

1.1 Abstract

Introduction. CST is a well-established intervention for people living with dementia shown to improve cognition and quality of life. Past research includes development of a longer term ‘maintenance CST’ and individual CST programme. Previous reviews of CST have focused on quantitative outcomes or excluded certain formats of CST. This review aimed to attend to this gap by evaluating how qualitative studies of CST, independent of format, can contribute to our understanding of its implementation and how it is experienced.

Methods. The current systematic review explored the experience and perspectives of people with dementia, facilitators and carers. A systematic literature search retrieved 10 relevant studies using qualitative methodology. Thematic Analysis (Braun and Clarke, 2006) was used to analyse this data, alongside Thomas and Harden’s (2008) guidance on synthesising qualitative findings.

Results. Twenty themes were generated, which were grouped into three categories of “Acceptability and Feasibility”, “Features of CST” and “Key Outcomes”.

Conclusions. This is the only review to explore solely qualitative studies of CST. Findings provided insight to the shared features, outcomes and factors affecting implementation, and suggested theories for discrepancies between quantitative and qualitative findings in the literature. Some of the common themes were also in keeping with past reviews.

1.2 Introduction

In 2015, there were an estimated 46.8 million people living with dementia worldwide, with the number expected to double every 20 years. This was associated with a cost of approximately $818 billion, set to increase to $2 trillion by 2030 (World Alzheimers Report, 2015). Consequently, there is ongoing pressure to provide both medical and psychosocial treatments for people living with dementia. There is also emphasis on early intervention, especially as various memory functions remain fairly intact in early stages of dementia (Brandt & Rich, 1995; Morris, 1996, cited in Clare & Woods, 2004) and people with dementia can recruit additional neural networks to compensate for losses (Grady et al. 2003).

Cognitive interventions have been shown to provide benefits in terms of delaying further decline and improving outcomes (Batsch & Miller, 2009). Those providing ‘cognitive stimulation’ are particularly well-supported (Olzarán et al. 2010; McDermott et al. 2019) and are recommended as a treatment either in combination with medication, or as a main therapy for people in the early stages of dementia (World Alzheimer’s Report, 2011). Previously, ‘cognitive stimulation’ has been used interchangeably when describing approaches consisting of cognitive ‘training’, ‘stimulation’ or ‘rehabilitation’. However, Clare and Woods (2004) offered the following definition to support distinction between them. They proposed that cognitive stimulation is “engagement in a range of activities and discussion (usually in a group) aimed at general enhancement of cognitive and social functioning.”

1.2.1 Cognitive Stimulation Therapy for Dementia

Cognitive Stimulation Therapy (CST) (Spector et al., 2003) is a well-established intervention for people with mild to moderate dementia. The intervention is based on a variety of effective psychosocial interventions including reality orientation (Taulbee & Folsom, 1966). It also emphasises use of multisensory stimulation and implicit learning. In addition, CST is one of the only psychosocial interventions to incorporate the views of people with dementia (Kelly et al. 2017) and highlights their “personhood” (Kitwood, 1997). It involves a variety of themed activities, including music, art, word association and current affairs, usually delivered in a group. This encourages a range of cognitive skills within a social setting, providing greater stimulation and providing social benefit. Since its development, CST has been extensively supported in research with past studies indicating a positive impact on cognition and quality of life (Aguirre, Woods, Spector & Orrell, 2013; Orrell et al. 2014; Prince, Bryce & Ferri, 2011; Spector et al. 2003;). It is also cost-effective when compared to dementia medications (D’Amico et al. 2015; Knapp et al. 2006) and is the only psychosocial intervention recommended to improve cognition for people with mild to moderate dementia by the National Institute of Health and Clinical Excellence (NICE, 2018). Typically, the intervention is delivered by individuals trained in delivering CST, aided by the use of the CST manual (Spector, Thorgrimsen, Woods & Orrell. 2006).

Research from Reality Orientation suggested benefits to cognition could be lost following termination of the intervention (Gerber, Prince, Snider, Atchinson, Dubois & Kilgour, 1991). As such, longer-term maintenance CST (MCST) was developed with the aim of retaining benefits to quality of life and cognition. The pilot study of MCST consisted of 16 additional sessions once a week and led to significant improvement in cognition for those receiving MCST in addition to CST alone (Orrell, Spector, Thorgrimsen, & Woods, 2005). A longer MCST programme was subsequently published, which showed continued improvements to quality of life and activities of daily living, but no significant benefits to cognition. However, findings suggested greater improvement to cognition when CST was combined with anticholinesterase inhibitor treatment (Aguirre et al., 2011; Orrell et al. 2014).

An individual cognitive stimulation therapy (iCST) programme designed for those unable and unwilling to attend groups has also been established (Yates et al. 2015). There is evidence to suggest that family-delivered interventions in dementia can have significant benefits to memory, carer wellbeing, and reductions in care home admissions (Moniz-Cook, Agar, Gibson, Win & Wang, 1998; Onder et al. 2005; Quayhagen & Quayhagen, 2000). The iCST package was based on the CST and MCST manuals, alongside previous intervention literature. It was evaluated through a randomised controlled trial (RCT), which showed iCST improved the caregiving relationship, though evidence indicated no changes in cognition and quality of life for the person with dementia (Orrell et al. 2017).

Following its wide-spread success in the UK, there has been an increase in the adaptation and use of CST across the world. There is published guidance on cultural adaptation of CST, and it has been refined for implementation in various cultures worldwide including Tanzanian, Nigerian, Chinese, South Asian and Japanese communities (Aguirre, Spector & Orrell, 2014).

CST has also been supported by a range of systematic reviews, both individually and within broader reviews of psychosocial and nonpharmacological interventions. A Cochrane Review of reality orientation and cognitive stimulation supported evidence of benefits to cognition, self-reported quality of life and wellbeing (Woods, Aguirre, Spector & Orrell, 2012). However, it only included studies with an RCT methodology. More recently, Lobbia et al. (2018) conducted a review of CST, which further supported positive effects on cognitive function, including language, and quality of life. It was similarly focused on quantitative outcomes, and recognised limitations in the quality of included studies. In addition, outcome studies to date of CST have not controlled for potential non-specific effects of CST or iCST, for example increased social contact, which makes it more difficult to determine the key mechanisms in CST.

1.2.2 Qualitative Studies of CST

Although quantitative data gives us important evidence on the efficacy of intervention, qualitative studies provide us with better understanding of the experiences of those involved. Gibson, Timlin, Curran and Wattis (2004) observed that qualitative studies were historically under-represented and qualitative methods underutilised in clinical trial research, which in part was attributed to prevalence of RCTs. As such, there has previously been little in the way of qualitative studies of CST. This is despite qualitative studies being recommended and important in providing valuable insight into the development and refinement of complex interventions (Medical Research Council, 2008). Additionally, involving service users in research is seen as a crucial component when developing clinical practice (Trivedi & Wykes, 2002).

Dugmore, Orrell and Spector (2015) conducted a review of psychosocial interventions, which noted the benefits of qualitative studies in their ability to “draw together insights” from people with dementia, staff and carers. It investigated what qualitative research could help us to understand about “implementation, effects and processes" of psychosocial intervention in dementia. The review revealed how psychosocial interventions are influenced by several factors, such as the skills and beliefs of people with dementia and their carers. Of interest, studies indicated confidence in one's skills could affect the intervention's impact (Pullan, 2009, cited in Dugmore et al. 2015), and highlighted the importance of skills of empathy, flexibility, creativity and effective communication for facilitators (Jarrott & Gigliotti, 2011). The opinion of facilitators about the intervention could also impact willingness and motivation to deliver it (Hope & Waterman, 2004; Pullan 2009; van Weert et al., 2004, cited in Dugmore et al. 2015). The review also revealed concerns about being under skilled to implement interventions (Hope & Waterman, 2004).

Recently, Toh, Ghazali and Subramaniam (2016) conducted a review of the usefulness and effectiveness of CST, excluding maintenance CST. They concluded that CST is effective, though there were inconsistencies when comparing quantitative and qualitative findings. For example, they suggest that carers' willingness to share positive changes experienced by the person with dementia indicated improvements in caregiver wellbeing. However, a quantitative study indicated no significant improvement in caregiver wellbeing after CST (Aguirre, Hoare, Spector, Woods & Orrell, 2014; Spector, Orrell, Davies & Woods, 2001). Toh et al. therefore suggested that quantitative measures are sometimes not sensitive enough to detect effects that qualitative feedback can discover.

1.2.3 The current review

Despite there being several systematic reviews of the literature on CST, many of these focus on quantitative data, and those exploring qualitative data had a broader focus on psychosocial intervention. Although Toh et al.'s review focused on CST and incorporated qualitative literature, it excluded papers on MCST and does not include more recent developments in cultural adaptations of CST.

The current review aimed to attend to this gap and consider qualitative studies of CST, MCST, iCST and those published globally. It is the first review to consider the qualitative findings across all formats of CST and all perspectives. The key research question was: What do qualitative studies on CST reveal about its acceptability and feasibility, key features, and effects?

1.3 Methods

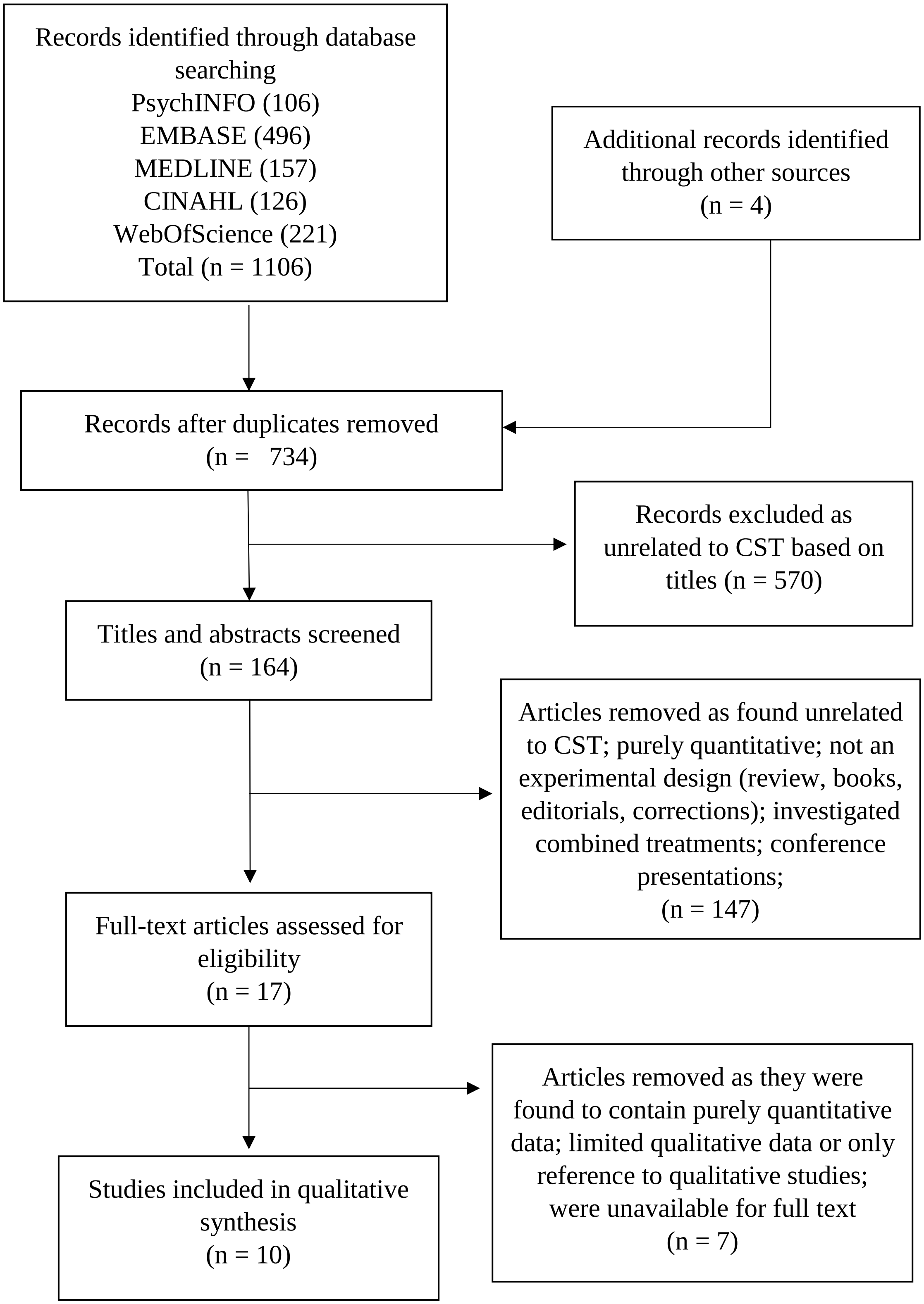
1.3.1 Search Strategy

A systematic literature search was conducted in January 2019 across 5 electronic databases covering several disciplines. These were PsychInfo (psychology and psychological aspects of related disciplines), EMBASE (biomedical and pharmacological), MEDLINE (medicine, nursing, healthcare system and preclinical sciences), CINAHL (nursing and allied health professions) and Web of Science. For each database, search terms relating to dementia were combined with terms associated with CST (see Appendix A).

1.3.2 Selection Criteria

Titles were reviewed, and only studies with a primary focus on CST, MCST, iCST or cultural adaptations were shortlisted. Studies meeting this criterion were retrieved for more detailed evaluation, with those relating to interventions offering cognitive training or rehabilitation excluded. Search terms did not specify a qualitative methodological approach. However, it was necessary that studies employed qualitative or mixed methodology and were published in English. Studies were not excluded based on demographics, qualitative methodology, or results. This search process is illustrated in Figure 1.

Figure 1. Flow chart of study selection process



1.3.3 Study quality appraisal

Systematic reviews of qualitative literature require assessment of the quality of studies included. Study quality was assessed using the Critical Appraisal Skills Programme Qualitative Checklist (CASP-QC) (CASP, 2018) (see Appendix B), which is widely used in reviews of qualitative studies including a past review of interventions for dementia (Dixon-Woods et al., 2007; Dugmore et al. 2015). Article quality was established as a score indicating how many of the 10 criteria it had met. Critical appraisal of studies was initially conducted by the author, and subsequently performed by a second independent quality rater (AV) for a random selection of four studies. The checklist was limited at times by yes or no outcomes, and as such it was agreed with the secondary rater to allow allocation of "half" points. For each study, it was established whether the item on the checklist was relevant. Subsequently, studies were evaluated for each criterion and were given a "yes" if they met a substantial number of the required points, "half" if it met some of them, and "no" if it met none or minimal features. Raters were also able to rate a criterion as "Can't tell" if there was not enough information in the study to make a decision. Items were given a score of 1 for "yes", ½ for "half", or 0 if "no" or "can't tell", which provided a score out of 10.

Any disagreements about ratings within the four articles were discussed and amended, and discussion points were used to establish a baseline for meeting criteria for the remaining articles to ensure consistency.

1.3.4 Method of analysis

Thematic Analysis (Braun & Clarke, 2006) was used to analyse articles in this review, with additional guidance on synthesising qualitative research from Thomas and

Harden (2008). This approach allowed a level of flexibility given the range of studies included. As there are a limited number of qualitative studies in the field, the aim was to give a thorough review of the available literature.

Studies were initially read in full, to allow familiarisation with the data, however for the purposes of this review, only text labelled as “results” were considered data. Studies were then re-read, and coded line-by-line in an inductive manner. Extracts for each of them were then reviewed, and the coding system was refined through reviewing extracts and themes for their relevance to the study questions. This was an iterative process resulting in a hierarchy of descriptive themes and sub-themes that contributed to the review questions. The papers were then re-read to establish if any further data was available and relevant.

1.4 Results

The literature search retrieved 734 results once duplicates were removed. Titles and abstracts of studies were read and compared with inclusion and exclusion criteria. Seventeen articles were identified as potentially relevant, which were read in full where possible. Seven were excluded as they were found to have no available qualitative data, the qualitative element of the study did not provide sufficient information to be useful and was excluded due to being of poor quality, or the full text was unavailable. The final review included nine peer reviewed articles and one doctoral thesis. The doctoral thesis was included as it met most quality criteria and provided relevant qualitative data for the research question. For those studies that were mixed methodology, quality rating was based only on the qualitative elements of the study. The final 10 articles were reviewed and summarised in terms of aims, study sample, the format of CST in focus, qualitative methodology, and quality assessment (Table 1).

1.4.1 Quality Analysis

Seven studies employed purely qualitative design (Aguirre et al. 2011; Bertrand et al. 2018; Dickinson et al. 2017; Leung et al. 2017; Spector et al. 2011; Streater, 2015 Yates et al. 2015). The other three studies used a mixed methodology and reported quantitative and qualitative findings (Bailey et al. 2017; Kelly et al. 2017; Wong et al. 2018). On average, 7.5 out of 10 quality criteria were met by the included articles, with a range of 4.5 to 9. Of note, only one study reflected on the relationship between the recruited members of a focus group (Aguirre et al. 2011), however none of the studies reflected on the impact of researcher identity on the process, nor did any studies utilise respondent validation to support the credibility of findings.

Table 1. Summary of article characteristics and quality assessment

Author & Country	Code	Aims	CST Format	Sample (N)	Qualitative Methodology	Quality Assessment
Bertrand et al. (2018) **Brazil**	BE	Understand issues of implementing CST for Brazilian population	CST Cultural adaptation	HCP (9) Carers (15) PWD (13)	Focus groups Individual interview (Semi-structured) FA	Met 7/10 criteria +ve: Detailed description of how focus groups and interviews were conducted including reasoning for individual interview use with PWD -ve: Participants had no prior experience of CST
Wong et al. (2017) **Hong Kong**	W	To investigate feasibility and cultural appropriateness of CST -HK	CST Cultural adaptation	Facilitators (12) Carer (13)	Focus groups Individual interview (Semi-structured) FA	Met 6/10 criteria +ve: Clear indication of topic guide, map of cultural issues and associated amendments to program -ve: Missing main participant group of PWD; not clear on how many attended focus groups versus interview
Kelly et al. (2017) **Ireland**	K	To explore personalised account of the impact of CST (supplement quantitative data)	CST Cultural adaptation	PWD (4) Carers (6) Facilitators (4)	Individual interview (Semi-structured) Unclear analysis methodology	Met 4.5/10 criteria. +ve: Clear topic guide for interview -ve: Qualitative methods not justified; No information on why

						some participants did not take part in interviews; only brief description of analysis process.
Bailey et al. (2017) **UK**	BA	Investigate impact of CST on PWD and impact of carer support group	CST	Carers (20)	Individual interview (semi-structured) TA	Met 5/10 criteria +ve: Some description of analysis process; topic guided provided for interviews -ve: Recruitment strategy unclear; qualitative design not justified; ethics process unclear
Leung et al. (2017) **UK**	L	Understand perspectives of PWD and carers on mental stimulation and experiences of participating in iCST	iCST	PWD and Carer dyads (23)	Semi-structured interview FA	Met 9/10 criteria +ve: Separation of PWD and carer for interview and clear recruitment strategy; transparent interview guide; consideration of implication of recruitment strategy; more than one analyst -ve: Does not explicitly justify semi-structured interview use
Dickinson et al. (2017) **UK**	D	Explore views and experiences of staff running CST in terms of barriers and facilitators	CST	Facilitators (24)	Individual interview TA	Met 8.5/10 criteria +ve: Clear recruitment strategy and reasons for not participating; setting described and justified; consideration of changing topic guide depending on facilitators experience of CST; consent

						clearly outlined; multiple analysts -ve: Methodology not justified clearly
Yates et al. (2015) **UK**	Y	Gain insight into perception of mental stimulation from view of carers and PWD	iCST	PWD (28) Carers (24)	Focus group Individual interview (semi-structured) TA	Met 8.5/10 criteria +ve: Clear topic guide and description of data collection; Continued assessment of consent regarding recordings; examined role of interviewer experience; thorough analysis -ve: specific methods not clearly justified
Aguirre et al. (2011) **UK**	A	To improve MCST manual by attuning to attitudes and perceptions of user needs	MCST	PWD (17) Carers (18) Facilitators (13)	Focus groups TA	Met 8.5/10 criteria +ve: Clear description of recruitment strategy; justification of interview methodology; reflection on interaction between focus group members; discussed contradictory data. -ve: Not clear how consent was gained; no provision of ethics committee reference.
Spector et al. (2011)	SP	To investigate the experience of CST as	CST	PWD (17) Carers (14)	Focus group Individual interview (semi-structured)	Met 8.5/10 criteria

UK		expressed in day to day life		Facilitators (7)	FA	+ve: Data saturation discussed; data collection methods clear; clear analysis procedure -ve: Interview methodology not explicitly justified; singular analyst.
Streater et al. (2015) **UK**	ST	To investigate staff's perceptions on delivery of MCST and provide more in depth understanding of group processes and outcomes.	MCST	Facilitators (15)	Focus groups TA	Met 9/10 criteria +ve: Justification of analysis methodology and thorough description of analysis procedure; clear outline of interview methodology; -ve: Saturation of data not discussed, sample majority female; only one analyst

Key: PWD = Person(s) with dementia; HCP = Health Care Professionals; +ve = Positives; -ve = Negatives; CST = Cognitive Stimulation Therapy; MCST = Maintenance Cognitive Stimulation Therapy; iCST = Individual Cognitive Stimulation Therapy
FA = Framework analysis (Ritchie & Spencer, 1994); TA = Thematic analysis (Braun & Clarke, 2006)
Codes are allocated to each study based on initial of first author.

1.4.2 Description of Themes

The analysis generated three overarching themes which contributed to the research question: ‘Acceptability and Feasibility’, ‘Features of CST’ and ‘Key Outcomes’. 20 sub-themes were generated across the included articles. The hierarchy of themes and sources are summarised within Table 2. Where appropriate, ellipsis (…) have been used to isolate relevant quotations for themes.

Table 2. Hierarchy of themes and coverage within the reviewed articles

Themes			**BE**	**W**	**K**	**BA**	**L**	**D**	**Y**	**A**	**SP**	**ST**
Acceptability and feasibility	Fitting service needs		x					x				x
	Facilitators and barriers	Carer engagement	x		x						x	x
		Resources			x			x	x	x		x
		Training and experience					x	x	x			x
		Patient motivation	x				x		x			x
		Time for facilitators					x	x	x			x
Features of CST	Mental stimulation		x				x		x	x		
	Adaptability			x		x				x		x
	Being with others		x			x	x	x	x	x	x	
	Practical activities			x			x		x	x		
	Relaxed environment							x	x	x	x	
	Shared experience					x				x	x	
	Difficulty of sessions				x	x	x		x			x
Key outcomes	Cognition				x	x	x		x		x	x
	Confidence				x	x	x	x		x	x	x
	Enjoyment				x	x	x				x	x
	Mood			x	x	x	x	x	x		x	x
	Continued stimulation				x	x	x				x	x
	Relationships					x	x				x	
	Making a difference				x		x				x	x

Key: Checked boxes indicate that the study contributed to the corresponding theme.

1.4.2.1 Acceptability and feasibility

Most of the studies included observations or experiences relating to the acceptability and feasibility of the different formats of CST. This generated two themes of “Fitting service needs” and “Facilitators and Barriers”. Eight sub-themes were expressed as either facilitators or barriers to implementation or enjoyment of CST.

Fitting service needs

Three studies spoke about how CST might fit with their service needs. Bertrand et al. (2018) noted that treatment options for dementia are not well known in Brazil, with little to be done following diagnosis. Facilitators understood CST to be evidence-based and recommended by NICE, which contributed to perceiving it as a good fit for the UK model of care. It was also seen to contribute to care beyond that of other psychosocial interventions, and observation of benefits motivated service managers to provide CST (Dickinson et al. 2017). Facilitators implementing MCST found it “not difficult to run” but raised concerns that length of the programme meant they could not offer sessions to others (Streater, 2015).

> *“If we hadn’t been doing the long programme, we could have got other new people in and through the CST programme thus making the waiting list shorter.” (Facilitator) (ST)*

Facilitators and barriers

Nine studies reported observations or experiences relating to facilitators and barriers of CST. This included themes of “Carer engagement”, “Making a difference”, “Resources”, “Shared experience”, “Training and experience”, “Difficulty of sessions,” “Patient motivation” and “Cultural differences.”

Carer engagement. Facilitators saw the support of carers as vital, as attendance often relied on them transporting people to centres for the groups. This was also associated with financial and time cost on carers to support this travel (Bertrand et al. 2018; Streater, 2015). However, carers in Kelly et al.'s (2017) study stated they were "relieved" to have the group available and were willing to travel for it. Facilitators said that depending on locality, people without a carer may have no means of getting to a group (Streater, 2015).

> *"If you've got someone to bring their mum in, which has taken them an hour and a half in the car, it could have taken them two hours to get them ready, you know, where is benefit in dropping them off for ninety minutes, there isn't." (Facilitator) (ST)*

Some carers found it frustrating when they heard little about the content of sessions (Spector et al., 2011). Facilitators in Bertrand et al.'s (2018) study suggested providing entertainment or psychoeducation for carers to better engage them.

*Resources***.** Facilitators of all formats of CST noted the value and availability of resources in the relevant manuals (Dickinson et al. 2017; Streater, 2015; Yates et al. 2015). These were raised as an important facilitator of the intervention (Dickinson et al. 2017; Aguirre et al., 2011), and family carers in iCST felt the manual was accessible and had appropriate activities (Yates et al. 2015). Streater (2015) noted facilitators felt the manuals and DVD were sufficient to deliver the intervention.

However, some facilitators felt that the manuals provided some less appropriate suggestions (Streater, 2015). Facilitators of CST highlighted additional resources beyond the manual, including people, time and physical resources which are needed to run sessions (Dickinson et al. 2017; Kelly et al. 2017).

> *"It's a huge volume of work setting up the process as well, it's not just doing a group… you've got to have the resources; people, time and the practical things that you take to the different sessions". (Facilitator) (D)*

Training and experience. Four studies discussed how the experience and skills of facilitators can affect the intervention. Training was crucial for engaging facilitators in CST, as it demystified it as an intervention (Dickinson et al. 2017). Dickinson et al. (2017) also highlighted supervision and experience of working with dementia as necessary for adequate running of groups. Healthcare staff felt appropriate communication skills were necessary to facilitate a group environment. There was emphasis on support from staff with more experience or who had attended training (Streater, 2015).

Family carers facilitating iCST experienced difficulties in delivering CST attributed to communication skills and wanted more support (Leung et al. 2017). Carers wondered if intervention would be delivered more effectively by professionals, unless further support could be provided (Yates et al. 2015).

> *"I'm not saying it's wrong to have a member of staff, but I think the person, like me and Eric, would do it quite nicely together." (Carer) (Y)*

*Patient motivation***.** Four studies spoke about patient motivation. Bertrand et al. (2018) associated this with increased difficulty for carers getting people with dementia to the group, whilst facilitators saw it as a barrier to engagement. Family carers delivering iCST felt decreased motivation was linked to emotional and physical health problems (Leung et al. 2017).

> *"Only the period when he was reluctant, and I suppose that was also tied to him having an emotional response to his condition." (Carer) (L)*

Resistance from people with dementia fluctuated, suggesting a need for flexibility when scheduling sessions (Yates et al. 2015). Facilitators also found it difficult to retain engagement during MCST (Streater, 2015).

Time for facilitators. Four studies highlighted the time necessary to facilitate CST. Facilitators linked the additional time needed to prepare for CST sessions to being able to offer fewer groups (Dickinson et al. 2017). Time needed to deliver the intervention was also a barrier for family carers in iCST, including time to organise for the sessions (Leung et al. 2017). People with dementia in iCST held concerns about whether carers would have time to complete activities with them (Yates et al. 2015).

> *"We can't offer as many groups because we haven't got the resources from staff really to put that much time aside." (Facilitator) (D)*

Facilitators delivering MCST noted that the longer timeframe of intervention was potentially too much for staff to commit to (Streater, 2015).

1.4.2.2 Features of CST.

Most studies reported on features of CST that are desirable, or key elements of the intervention. This generated five sub-themes including "Mental stimulation", "Adaptability", "Being with others", "Practical tasks", "Relaxed environment", "Shared experience" and "Difficulty of sessions".

Mental stimulation

Four studies talked about mental stimulation. People with dementia felt mental stimulation encouraged concentration, reflection and alertness, as "if you do not use it, you lose it", whilst carers suggested it kept people with dementia in the present and supported learning (Leung et al. 2017).

> *“It gives an opportunity to think, reflect, review words and understand them, to reflect on what you want to say and what you’re hearing somebody else saying and about the whole situation.” (Person with dementia)* (L)

Music, quizzes, and keeping up to date with newspapers were highlighted as stimulating activity. Mental stimulation was experienced as meaningful by people with dementia, though they reported a dependence on carers or facilitators to support them with stimulation (Yates et al. 2015).

“May I just say I believe that we are all crying out for help and stimulation, but we can’t, haven’t so much got ideas in our own head as we hope other people can encourage us.” (Person with dementia) (Y)

However, carers in Bertrand et al.’s (2018) study worried the Brazilian population were not ready for mental stimulation, and Aguirre et al. (2011) found carers were less confident about the “use it or lose it” hypothesis, and raised concerns that mentally challenging people with dementia would emphasise deficits to them.

Adaptability

Four studies discussed adaptability within CST. Carers suggested flexibility in session topics allowed better engagement of people with dementia (Bailey et al. 2017). Service providers noticed benefits of adaptability when managing people with different stages of dementia and differing symptoms, as it allowed a person-centred approach.

> *“Sometimes you have to modify it and do different things to fit with the group. The books don’t always fit the pattern. I suppose the book is giving you guidance to what the activities are, but then just have to adjust that to the patients’ level of concentration, physical health or mobility.” (Facilitator)* (D)

Both carers and facilitators voiced the importance of not asking people with dementia to do something they are unable to and considering individual preferences (Aguirre et al. 2011). Facilitators in MCST felt it was important to adapt in line with choices made by the group (Streater, 2015). Facilitators in two studies recognised that people can be less interested in certain topics or sessions (Streater, 2015; Wong et al. 2018).

Being with others

The benefits of doing activity with others was highlighted both within a group and individual CST contexts. People with dementia and carers linked being with others with opportunities to be heard, whilst also gaining other perspectives on matters (Aguirre et al. 2011; Leung et al. 2017; Spector et al. 2011). For carers facilitating iCST, the structure of CST encouraged communication from the person with dementia (Leung et al. 2017).

> *"…Just opening topics of conversations, maybe listening to her, encouraging her to express herself and talk about things." (Carer)* (L)

Having CST with others allowed people with dementia to help each other and be supported by facilitators (Bertrand et al. 2018; Spector et al. 2011). Discussion with others increased chances for learning (Aguirre et al. 2011). People with dementia also felt they needed support to do activities at home (Yates et al. 2015).

> *"The idea of activities (in the home) is good, people with dementia just need assistance with it." (Person with dementia)* (Y)

Carers, facilitators and people with dementia also noted the opportunities for socialising (Bailey et al. 2017; Bertrand et al. 2018; Dickinson et al. 2017). For one participant in Bailey et al.'s (2017) study, it provided opportunity to re-engage socially having previously cut-off from social interaction. Some people with dementia saw the importance of companionship and somebody to discuss things with (Spector et al. 2011). Chatting together also offered opportunities to share memories, providing further stimulation (Aguirre et al. 2011).

Practical activities

Four studies noted a preference from people with dementia for practical activities. Wong et al. (2018) observed a preference of Chinese people with dementia for practical tasks, though this was mirrored by a culture non-specific desire for outdoor and physical activities (Aguirre et al. 2011; Leung et al. 2017). Both carers and people with dementia saw keeping the body active as important as the mind (Yates et al. 2015).

> *"I like making things with my hands, just to keep my mind stimulated."*
>
> *(Person with dementia) (L)*

Activities highlighted by the studies included "Being Creative" (Wong et al. 2018), games/puzzles (Leung et al. 2017), games such as cards or dominoes and physical activities including gardening (Yates et al. 2015), and dancing, singing, painting, drawing, cooking and knitting (Aguirre et al. 2011).

Relaxed environment

Four studies spoke about how environment impacts CST. A supportive and friendly environment was seen as crucial by people with dementia (Spector et al. 2011). It was important that people around them were kind and provided "human courtesies" (Aguirre et al. 2011). Facilitators tried to ensure group composition avoided conflict and encouraged a supportive environment (Dickinson et al. 2017). In iCST, family carers were concerned that involvement might require a more "formal setting", but this could be managed with the right approach (Yates et al. 2015).

> *"(Sessions should be) more subtle, so no one feels testy. It's more of a conversation and discussion rather than "it's therapy time now."" (Carer)* (Y)

Shared experience

Three studies suggested benefits of a group setting as it involved people with shared identity and experience. People with dementia felt that that this provided support (Spector et al. 2011). Carers felt that having similar difficulties meant those taking part in the group could feel safe (Bailey et al. 2017).

> *"… People who are suffering with the same memory losses, my mum doesn't feel so scared to make a fool of herself or things like that." (Carer)* (BA)

Carers in one study suggested people within groups should be of comparable cognitive abilities or share interests (Aguirre et al. 2011).

Difficulty of sessions

Five studies noted the difficulty of sessions. People with dementia experienced some sessions as childish or too easy (Leung et al. 2017). This was observed by carers and facilitators who were told the same by people with dementia or had observed negative reactions to sessions (Bailey et al. 2017; Streater, 2015). Facilitators noticed some struggled with tasks as they declined, which could make facilitating harder (Streater, 2015). However, some people with dementia experienced tasks as difficult, but acceptable (Kelly et al. 2017). Family carers facilitating iCST raised concerns about activities being experienced as childish but suggested they would be enjoyable once started (Yates et al. 2015), which was noted by carers in Bailey et al.'s (2017) study.

> *"… I am so pleased with this group… I didn't expect to say that after the first week, because the first week [name] said it was a bit childish, but he has carried on and he has come, and he enjoyed it…" (Carer)(BA)*

1.4.2.3 Key outcomes

Most studies explored the outcomes of participating in CST, which generated several sub-themes including ‘Cognition’, ‘Confidence’, ‘Mood’, ‘Enjoyment’, ‘Relationships’ and ‘Continued stimulation’.

Cognition

Six studies discussed the effect of CST on cognition, most of which described a positive impact (Bailey et al., 2017; Kelly et al., 2017; Leung et al., 2017; Spector et al., 2011; Streater, 2015; Yates et al., 2015) from the view of all participant groups. However, some carers had perceived minimal, or non-sustainable improvement (Bailey et al. 2017).

> *“…the week before, I felt… he was doing a bit better. But this last week, he seems to have slipped back again.” (Carer) (BA)*

Four studies (Kelly et al., 2017; Leung et al., 2017; Spector et al., 2011; Streater, 2015) referred to specific improvements in attention and concentration, some of which connected this with a related sense of alertness (Spector et al., 2011; Streater, 2015).

> *“Their family, the people that brought them in were feeding back on how interactive the person was… how alert they were, how engaging they were…” (Facilitator) (ST)*

Three studies reported observed improvement to memory either in retaining new information and events (Spector et al., 2011), or non-specific memory improvements (Kelly et al., 2017). People with dementia found CST provided new ways of improving memory, which was maintained over time (Kelly et al. 2017). Facilitators noticed that people with dementia also exhibited some benefits to spontaneous verbal fluency (Spector et al. 2011).

> *"At the beginning they would take ages to think of names (ball activity) but at the end they were flying through it'." (Facilitator) (K)*

Confidence

Seven studies (Aguirre et al. 2011; Bailey et al. 2017; Dickinson et al. 2017; Kelly et al., 2017; Leung et al. 2017; Spector et al. 2011; Streater, 2015) observed improved confidence in people living with dementia. This was associated with reduction in anxiety and improved self-esteem, confidence outside of the group setting, and participants being more verbal in the group.

> *"It was such a difference to see people at the end of CST, their confidence levels had totally increased" (Facilitator) (K)*

> *"It's made me a bit more confident; you know at the beginning I was a bit hesitant to say much, well you just think well if I've got something to say then I'll say." (Person with dementia) (SP)*

Several studies (Bailey et al. 2017; Kelly et al. 2017; Leung et al. 2017) observed positive changes in persons with dementia's relationship to their diagnosis and associated difficulties. Bailey et al. (2017) connected this to the enjoyment experienced.

> *"I think that's probably why he enjoyed it so much, he wasn't made to feel, you know, silly?" (Carer) (BA)*

Enjoyment

Five studies (Bailey et al. 2017; Kelly et al. 2017; Leung et al. 2017; Spector et al. 2011; Streater, 2015) spoke about a general sense of enjoyment from participating in the groups, which was reflected from all participant groups. People with dementia reported looking forward to CST each week and were sorry to end the group (Spector et al. 2011). Leung et al. (2017) highlighted that the sense of enjoyment persisted beyond memory of the specific sessions.

> *“Yeah even though like things might not stay with me …, but it’s brilliant.” (Person with dementia) (L)*

Mood

Eight studies recognised an improvement in the mood of people taking part in CST. Carers observed people with dementia being in better mood overall (Kelly et al. 2017; Streater, 2015; Yates et al. 2015). People with dementia described feeling more relaxed and wanting to continue with the group (Spector et al. 2011). This was associated with increased interest in activity at home, and better communication with others (Bailey et al. 2017). Facilitators recognised an improvement in self-esteem which indicated the intervention was valuable (Dickinson et al. 2017).

> *“After the sessions, she came out to me a brighter, happier person.” (Carer) (K)*

People with dementia also gained a sense of success and providing recognition of their attendance of sessions was associated with happiness (Wong et al. 2018). For some people with dementia, the sense of achievement was retained beyond the content of the sessions (Leung et al. 2017).

Continued stimulation

Five studies observed that participating in CST led to increased activity and stimulation outside of the intervention (Bailey et al. 2017; Kelly et al. 2017; Leung et al. 2017; Spector et al. 2011; Streater, 2015). Carers associated this with renewed discovery of the interests of the person with dementia (Bailey et al. 2017) and observed people with dementia engaged in more acts of personal care and social activity (Spector et al. 2011). People with dementia reignited value in life, and recognition of their abilities encouraged them to continue seeking stimulation (Leung et al. 2017). Facilitators also noticed that individuals sought involvement in their communities (Streater, 2015).

> *"It's made me start thinking about doing what I used to do which was painting… I think I could do more painting, and that might make me better, you know, and I can get up and do things more easily." (Person with dementia)* (L)

Relationships

Several studies observed changes to the relationships people with dementia had with others. People with dementia became closer with others (Bailey et al 2017; Spector et al. 2011) and carers experienced improved relationships with people with dementia associated with increased conversation (Bailey et al. (2017).

> *"…we are interacting now, more than me trying to reach him, and me make conversation and him talk to me. He is actually talking to me first… we chat and that…" (Carer).*

Facilitators of iCST found the structure of sessions supported them to reconcile and improve relationships with people with dementia (Leung et al. 2017)

> *"It's keeping the relationship going and although I can see that there can be changes in the relationship, doing this kind of activities together cements it and makes you stay involved in each other's lives." (Carer)* (BA)

Making a difference

Four studies reported discernible improvements in those taking part in CST. Facilitators saw the benefits of CST (Kelly et al. 2017). For some facilitators, what people with dementia were capable of was surprising (Streater, 2015).

People with dementia experienced CST as worthwhile, and carers observed that though they may not know what sessions were about, they could see the benefits (Spector et al. 2011).

> *"... it was just good to be able to go and discuss the things, so you felt that at least you'd done something you know I wasn't wasting my time." (*Person with *dementia) (SP)*

However, some carers facilitating iCST held beliefs that dementia is unchangeable (Leung et al. 2017).

1.5 Discussion

The current study aimed to explore what qualitative studies can reveal about the acceptability and feasibility of CST, its key features and experienced effects. Qualitative research can be especially important as it offers several benefits not directly explored by RCTs, including information for further development of interventions, exploration of implementation processes and understanding responses to interventions (Lewin, Glenton & Oxman, 2009). This study aimed to build on past reviews, which have typically focused on studies with quantitative methodology, excluded certain formats of CST or involved a range of psychosocial interventions. As such, the current study benefited from inclusion of several studies previously not integrated into systematic reviews. Thematic Analysis (Braun & Clarke, 2006) was used alongside recommendations by Thomas and Harden (2008) to review the 10 studies included. This generated 20 sub-themes, which were grouped into three overarching themes of 'Acceptability and Feasibility', 'Features of CST' and 'Key Outcomes'. Current findings revealed commonalities in themes across both group and individual CST and globally. These were previously unidentified in the literature and may provide greater understanding of core processes independent of CST format.

1.5.1 Interpretations and Comparisons

1.5.1.1 Acceptability and Feasibility

Resources contained within the CST manuals were perceived as helpful, important and sufficient for facilitating intervention (Aguirre et al. 2011; Dickinson et al. 2017; Streater, 2015; Yates et al. 2015). However, facilitation also required time, physical resources, and available staff or carers to successfully run sessions. Moreover, preparation for sessions in addition to frequency of them meant that fewer groups could be offered in some services (Dickinson et al. 2017; Streater, 2015). Time was similarly a barrier for carers delivering iCST, which led to poor treatment adherence (Orrell et al. 2017). Additionally, several studies raised the importance of facilitators having enough experience and communication skills to facilitate the intervention (Dickinson et al. 2017; Leung et al. 2017; Streater, 2015). This is in keeping with past reviews of psychosocial interventions that found skills and qualities of carers affected implementation (Dugmore et al. 2015). This review also identified the importance of carer engagement. Carers can be essential for the success of groups, as people with dementia may rely on carers to bring them to groups depending on locality and availability of transport, which is harder when patients are less motivated to attend. Bertrand et al. (2018) raised the potential benefit of providing something for carers, as they can be left waiting at services whilst groups are in progress.

1.5.1.2 Features of CST

There were several common features identified in the data. Primarily, 'Being with others' was most broadly represented, and was not only identified in group CST but in iCST. This suggests that sessions with carers could be experienced as additional or of different quality to other interactions with them. Social disengagement has long been associated with increased risk for cognitive impairment, whilst social interaction protects from decline (Bassuk, Glass & Berkman, 1999; Yeh & Liu, 2003). Of interest, findings suggest that being with others was associated with opportunities to be heard (Aguirre et al.; Leung et al. 2017; Spector et al. 2011), encouraging communication between people with dementia and others (Leung et al. 2017), and providing support for them to take part in activities (Bertrand et al. 2018; Spector et al. 2011). These benefits may mediate improvements in relationships with caregivers identified by quantitative outcomes in iCST (Orrell et al. 2017). For group CST, one of the other features seen as important was friendliness and "human courtesy" which could be an important factor when considering group dynamics. Similarly, shared experience is inherent in group CST and was felt to provide support and maintain a sense of safety.

Adaptability was similarly broadly reported. This is in keeping with the way in which manuals are devised, as they offer choices and levels of difficulty for each session. One study referred to the manuals as giving guidance, but that it was the job of facilitators to adjust it to the patients' abilities. In relation to this, the difficulty of sessions presented in group and individual CST was experienced variably, with some experiencing sessions as too easy and others as too difficult. Whilst more difficult sessions could make facilitating harder (Streater, 2015), sessions being too easy could result in negative reactions or poorer motivation from people with dementia (Bailey et al. 2017; Leung et al. 2017; Streater, 2015). This reinforces how adaptation and adjustment is an essential process of CST, which they should hold in mind both whilst planning and during sessions It also lends further support to facilitators needing sufficient training and experience. Wey (2006) raised how the zone of proximal development and scaffolding (Vygotsky, 1978, cited in Wey, 2006) could be applied in dementia rehabilitation. This refers to the difference between what someone can do without help and what is possible with encouragement, support and guidance. Similarly, "distributed cognition" (Saloman, 1993) suggests a person with greater capability can support someone in an area they have less capability. As such, with appropriate support, harder tasks may offer greater challenge and stimulation. Conversely, a study of group CST, and a study of iCST indicated easier sessions could still hold value by providing enjoyment as time goes on (Bailey et al. 2017; Yates et al. 2015). This suggests that facilitators should ensure a balance of enjoyment and stimulation.

Another commonly reported feature was mental stimulation, which is a cornerstone in the theory underlying CST as it is thought to enhance functionality and survival of neurons, which is often referred to as the "use it or lose it" principle(Salthouse, 2006; Swaab et al. 2002). Findings associated it with keeping people with dementia in the present, supporting learning, and it was experienced as meaningful by people with dementia. Practical tasks, outdoor physical tasks and creative activity were identified as preferred choices for providing this stimulation.

1.5.1.3 Key Outcomes

Findings suggested several positive effects of CST beyond those indicated by quantitative outcomes. Of note, CST was associated with improved cognition in both group and individual CST. These findings are in keeping with past reviews of CST (Orrell et al. 2014; Spector et al. 2003; Woods et al. 2012;) and psychosocial interventions (Dugmore et al. 2015; McDermott et al., 2018; Olazaran et al. 2010) but was not consistent with an RCT of iCST, which indicated no cognitive benefits (Orrell et al. 2017). Findings in the current study offer several theories that may explain this discrepancy. Firstly, benefits to concentration and alertness are reported across CST, MCST and iCST (Kelly et al. 2017; Leung et al. 2017; Spector et al. 2011; Streater, 2015). Measures in dementia research typically consist of items measuring concentration and attention but do not usually evaluate them extensively, and it possible that the change is too small to be detectable by currently used assessment tools. Alternatively, perceived cognitive benefit may be associated with the reported improvements to confidence, which was represented in all formats of CST. Several studies observed a positive shift in relationship to diagnosis (Bailey et al. 2017; Kelly et al. 2017; Leung et al. 2017), and it is possible that perceiving cognitive impairment as less limiting or less significant was associated to reports of cognitive improvements. This is supported by Kelly et al. (2017)'s findings which indicated no objective change in cognition, yet improvements in self-rated subjective cognitive function and satisfaction with cognitive performance. Similarly, facilitators felt surprised at what people with dementia were capable of, and perception of cognitive improvement may be linked to modified beliefs about their abilities. The benefits to relationship with others described previously, better understanding of dementia, and improved communication could also allow people with dementia to express themselves more frequently. This is especially important when we consider the high level of unmet needs in those both living at home and in residential care (Black et al. 2013; Hancock, Woods, Challis and Orrell 2006). Additionally, they could reduce levels of malignant social psychology, which are behaviours that undermine personhood of people with dementia, and thereby increase person-centred care and subsequent wellbeing for people with dementia (Kitwood, 1999). These changes in perceptions of cognitive impairment, improved communication and reduction in malignant social psychology are likely also associated with reduction in excess disability, defined as the difference between “possible” and “actual” functioning for people with dementia (Spector & Orrell, 2010). It is therefore possible that reduction of excess disability in alternative or parallel mechanism of CST, alongside the “use it or lose it” principle (Salthouse, 2006; Swaab et al. 2002).

A general sense of enjoyment from CST groups and individual sessions was also clear in the data, and this likely corresponds with changes in mood. Improvements to mood were widely represented in the studies, in both group and individual CST. This included benefits to self-esteem, relaxation, and increased activity (Bailey et al. 2017; Dickinson et al. 2017; Kelly et al. 2017; Spector et al. 2011; Streater, 2015; Yates et al. 2015). In addition, increased activity was further reflected in themes of people with dementia engaging in more activity and stimulation outside of intervention independent of format (Bailey et al.2017; Kelly et al. 2017; Leung et al. 2017; Spector et al. 2011; Streater et al. 2015).

1.5.2 Strengths and Limitations

The main limitation in this review is the number of available studies using qualitative methods to evaluate CST. This may partially result from difficulties identifying qualitative studies due to inconsistencies in indexing, as was noted by Dugmore et al. (2015). Additionally, it is generally acknowledged that there are few qualitative studies in the CST literature, especially those including the views of people with dementia. This may relate to difficulties encountered, such as communication challenges related to cognitive impairment (Beuscher & Grando, 2009). Furthermore, several studies using qualitative methodology either during development or field testing, notably in cultural adaptation studies, lacked enough quantity and clarity of data to contribute to the review.

To some extent, this limitation is moderated by the available evidence in quantitative studies which contributed to our understanding in the current review. In addition, the overall quality of the studies included was good, with six scoring at least 8 out of 10 on the quality criteria. Of note, two studies achieved a score of 9 out of 10. One of these studies did not meet the criteria for addressing the relationship between researchers and participants (Streater, 2015), however this was ostensibly missed by all studies included. Conversely, three studies were of notably poorer quality with a lack of clarity regarding recruitment and sample and methods of data collection and analysis (Bailey et al. 2017; Kelly et al. 2017; Wong et al. 2017). With regards to the quality appraisal tool used in this review, the CASP is limited by the breadth of the questions which can sometimes be difficult to interpret. This was minimised by using a second rater to set a baseline quality for each criterion, but future research may benefit from consideration of other appraisal tools.

1.5.3 Implications for Research and Practice

The current review allows for integration of factors affecting implementation, features and outcome data to provide several suggestions for research and practice. Foremost is a need for more qualitative research in this field. Involving people with dementia in this research is also highly important, as it provides them with a sense of worth and personhood through seeking their opinion and perspectives (Bell & Troxel, 2001; Jonas-Simpson, 2001, cited in Beuscher & Grando, 2009). Second, the understanding gained in relation to facilitators and barriers to facilitation may provide several recommendations for how services can optimise the delivery of CST. Primarily, the review suggests ensuring a necessary level of training and supervision to facilitate groups or one to one sessions. Providing training in iCST not only to carers of people unwilling or unable to access groups, but carers of those currently attending CST groups, could support continued stimulation. It would provide a method of providing psychoeducation to carers as suggested by Bertrand et al. (2018), which could also address carers' frustration at hearing little about content of sessions (Spector et al. 2011).

Moreover, the common factors identified may benefit future developments, as they inform which components of CST might maximise efficacy or acceptability. This is particularly relevant for services that may not implement the entirety of CST manuals, for example services limited by staff availability. Further, services or individuals should consider the resources beyond the manuals necessary for implementation, including time for facilitators both in preparation and in delivering sessions. This may be easier for services running groups who can re-utilise resources but is an important consideration for carers considering delivering CST at home. Qualitative findings can also be useful in directing research towards appropriate outcome measures, and future studies may benefit from more specifically assessing the outcomes identified in this review. One possibility is use of Likert scales as utilised by Kelly et al. (2017) to quantitatively record changes, for example in confidence, alertness and concentration.

1.5.4 Conclusion

CST is experienced as broadly acceptable, feasible and beneficial for people with dementia. There are several common features across different formats of CST, which may correspond with common processes underlying the improvements reported in both quantitative and qualitative studies. This review has culminated qualitative findings which contributes to our understanding of these processes and suggests possible guidelines for services and carers wanting to deliver CST in services or at home. These findings also provided information for researchers aiming to further develop CST and explore its efficacy.

1.6 References

Articles included in the current review are marked with an asterisk (*).

Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell, M. (2012). Cognitive stimulation therapy (CST) for people with dementia-who benefits most? https://doi.org/10.1002/gps.3823

Aguirre, E., Spector, A., & Orrell, M. (2014). Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical Interventions in Aging*, *9*, 1003–1007. https://doi.org/10.2147/CIA.S61849

* Aguirre, E., Spector, A., Streater, A., Burnell, K., & Orrell, M. (2011). Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia*, *10*(4), 459–473. https://doi.org/10.1177/1471301211417170

Aguirre, E., Woods, R. T., Spector, A., & Orrell, M. (2013). Cognitive stimulation for dementia: a systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing research reviews, 12*(1), 253-262.

* Bailey, J., Kingston, P., Alford, S., Taylor, L., & Tolhurst, E. (2017). An evaluation of Cognitive Stimulation Therapy sessions for people with dementia and a concomitant support group for their carers. *Dementia*, *16*(8), 985–1003. https://doi.org/10.1177/1471301215626851

Bassuk, S. S., Glass, T. A., & Berkman, L. F. (1999). Social disengagement and incident cognitive decline in community-dwelling elderly persons. *Annals of Internal Medicine*, *131*(3), 165. https://doi.org/10.7326/0003-4819-131-3-199908030-00002

Batsch, N. L. B., & Miller, R. V. P. (2009). An assessment of needs for serving individuals diagnosed with Alzheimer's disease and related dementias in the early stages. *Alzheimer's Care Today July/September 10*(3), 140–155.

Bell, V., & Troxel, D. (2001). Spirituality and the person with dementia – a view from the field. *Alzheimer's Care Today, 2(2),* 31-45.

* Bailey, J., Kingston, P., Alford, S., Taylor, L., & Tolhurst, E. (2017). An evaluation of Cognitive Stimulation Therapy sessions for people with dementia and a concomitant support group for their carers. *Dementia*, *16*(8), 985-1003.

* Bertrand, E., Naylor, R., Laks, J., Marinho, V., Spector, A., & Mograbi, D. C. (2018). Cognitive stimulation therapy for brazilian people with dementia: Examination of implementation' issues and cultural adaptation. *Aging & Mental Health*, No-Specified. https://doi.org/http://dx.doi.org/10.1080/13607863.2018.1488944

Beuscher, L., & Grando, V. T. (2009). Challenges in conducting qualitative research with individuals with dementia. *Research in Gerontological nursing*, *2*(1), 6-11.

Black, B. S., Johnston, D., Rabins, P. V., Morrison, A., Lyketsos, C., & Samus, Q. M. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study.

Journal of the American Geriatrics Society, *61*(12), 2087–2095. https://doi.org/10.1111/jgs.12549

Brandt, J., & Rich, J. B. (1995) Memory disorders in the dementias. In A. D. Baddeley, B. A. Wilson, & F. N. Watts (Eds.), *Handbook of memory disorders* (pp. 243 – 270). Chichester, UK: John Wiley & Sons Ltd.

Clarke, V., & Braun, V. (2014). Thematic Analysis. In *Encyclopedia of Quality of Life and Well-Being Research* (pp. 6626–6628). Dordrecht: Springer Netherlands. https://doi.org/10.1007/978-94-007-0753-5_3470

Clare, L., & Woods, R. T. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer’s disease: A review. *Neuropsychological rehabilitation*, *14*(4), 385-401.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., & Medical Research Council Guidance. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ (Clinical Research Ed.), 337*(September), a1655. https://doi.org/10.1136/bmj.a1655

Critical Appraisal Skills, & Programme. (2018). Critical Appraisal Skills Programme. CASP Qualitative Checklist. Date accessed: 16th October 2018, (2018). https://doi.org/10.1007/978-81-322-2743-4_32

D’Amico, F., Rehill, A., Knapp, M., Aguirre, E., Donovan, H., Hoare, Z., … Orrell, M. (2015). Maintenance Cognitive Stimulation Therapy: An economic evaluation within a randomized controlled trial. *Journal of the American Medical Directors Association*, *16*(1), 63–70. https://doi.org/10.1016/J.JAMDA.2014.10.020

* Dickinson, C., Gibson, G., Gotts, Z., Stobbart, L., & Robinson, L. (2017). Cognitive stimulation therapy in dementia care: Exploring the views and experiences of service providers on the barriers and facilitators to implementation in practice using Normalization Process Theory. *International Psychogeriatrics, 29*(11), 1869–1878. https://doi.org/10.1017/S1041610217001272

Dixon-Woods, M., Sutton, A., Shaw, R., Miller, T., Smith, J., Young, B., … Jones, D. (2007). Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy, 12*(1), 42–47. https://doi.org/10.1258/135581907779497486

Elwood, P. C., Gallacher, J. E., Hopkinson, C. A., Pickering, J., Rabbitt P., Stollery, B., … & Bayer, A. (1999). Smoking, drinking and other lifestyle factors and cognitive function in men in the Caerphilly cohort. *Journal of Epidemiology & Community Health, 53*(1), 9-14.

Gerber, G. J., Prince, P. N., Snider, H. G., Atchison, K., Dubois, L., & Kilgour, J. A. (1991). Group activity and cognitive improvement among patients with Alzheimer’s disease. *Psychiatric Services, 42*(8), 843-845.

Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2004). The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing*, *33*(4), 422–426. https://doi.org/10.1093/ageing/afh136

Grady, C. L., McIntosh, A. R., Beig, S., Keightley, M. L., Burian, H., & Black, S. E. (2003). Evidence from functional neuroimaging of a compensatory prefrontal network in Alzheimer's disease. *Journal of Neuroscience*, *23*(3), 986-993.

Hancock, G. A., Woods, B., Challis, D., & Orell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, *21*(1), 43–49. https://doi.org/10.1002/gps.1421

Hope, K. W., & Waterman, H. A. (2004). Using Multi-Sensory Environments (MSEs) with people with dementia. *Dementia*, *3*(1), 45–68. https://doi.org/10.1177/1471301204039324

Jarrott, S. E., & Gigliotti, C. M. (2011). Layers of influence: Important contextual factors in directing dementia care programs. *Journal of Applied Gerontology*, *30*(1), 113–122. https://doi.org/10.1177/0733464809356775

Jonas-Simpson, C. (2001). From silence to voice: knowledge, values, and beliefs guiding healthcare practices with persons living with dementia. *Nursing Science Quarterly*, *14*(4), 304–310. https://doi.org/10.1177/08943180122108607

* Kelly, M. E., Finan, S., Lawless, M., Scully, N., Fitzpatrick, J., Quigley, M., … Devane, A. (2017). An evaluation of community-based cognitive stimulation therapy: A pilot study with an Irish population of people with dementia. *Irish*

Journal of Psychological Medicine, *34*(3), 157–167. https://doi.org/10.1017/ipm.2016.23

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, *1*(1), 13–22. https://doi.org/10.1080/13607869757344

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Open University Press.

Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry*, *188*(6), 574–580. https://doi.org/10.1192/bjp.bp.105.010561

* Kelly, M. E., Finan S., Lawless, M., Scully N., Fitzpatrick, J., Quigley, M., … & Devane, A. (2017). An evaluation of community-based cognitive stimulation therapy: A pilot study with an Irish population of people with dementia. *Irish Journal of Psychological Medicine*, *34*(3), 157–167. https://doi.org/http://dx.doi.org/10.1017/ipm.2016.23

* Leung, P., Yates, L., Orgeta, V., Hamidi, F., & Orrell, M. (2017). The experiences of people with dementia and their carers participating in individual cognitive stimulation therapy. *International Journal of Geriatric Psychiatry*, *32*(12), e34–e42. https://doi.org/10.1002/gps.4648

Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: Methodological study. *BMJ (Online), 339*(7723), 732-734. https://doi.org/10.1136/bmj.b3496

McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., … Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging & Mental Health*, *23*(4), 393–403. https://doi.org/10.1080/13607863.2017.1423031

Moniz-Cook, E., Agar, S., Gibson, G., Win, T., & Wang, M. (1998). A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Aging & Mental Health, 2*(3), 199-211.

Morris, R. G. (1996). *The Cognitive Neuropsychology of Alzheimer-type dementia*. New York, NY, US: Oxford University Press.

NICE (2018) *Dementia: assessment, management and support for people living with dementia and their carers*. Retrieved from http://www.nice.org.uk/guidnace/ng97

Olzarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., … & Spector, A. (2010). Nonpharmacological therapies in Alzheimer’s disease: A systematic review of efficacy. *Dementia and geriatric cognitive disorders, 30*(2), 161-178.

Onder, G., Zanetti, O., Giacobini, E., Frisoni, G. B., Bartorelli, L., Carbone, G., … & Beranbei, R. (2005). Reality oreitnation therapy combined with cholinesterase inhibitors in Alzheimer’s disease: randomised controlled trial., *The British Journal of Psychiatry, 187*(5), 450-455.

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., … Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *British Journal of Psychiatry, 204*(6), 454–461. https://doi.org/10.1192/bjp.bp.113.137414

Orrell, M., Spector, A., Thorgrimsen, L., & Woods, B. (2005). A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. *International Journal of Geriatric Psychiatry, 20*(5), 446–451. https://doi.org/10.1002/gps.1304

Prince M, Wimo A, Guerchet M, Gemma-Claire A, Wu Y-T, P. M. (2015). World Alzheimer Report 2015: The global impact of dementia - An analysis of prevalence, incidence, cost and trends. *Alzheimer’s Disease International (ADI)*, 88.

Prince, M., Bryce, R., & Ferri, C. (2011). World Alzheimer Report 2011 : The benefits of early diagnosis and intervention.

Pullan, S. (2009). *The Experience Of Care Staff Delivering Reminiscence Sessions To People With Dementia*. (Doctoral dissertation, University of Leicester).

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In *Analyzing qualitative data* (pp. 173-194). Routledge.

Salomon, G. (1993). *Distributed cognitions: psychological and educational considerations*. Cambridge University Press.

Salthouse, T. A. (2006). Mental Exercise and Mental Aging. *Perspectives on Psychological Science*, *1*(1), 68–87. https://doi.org/10.1111/j.1745-6916.2006.00005.x

* Spector, A., Gardner, C., & Orrell, M. (2011). The impact of Cognitive Stimulation Therapy groups on people with dementia: Views from participants, their carers and group facilitators. *Aging and Mental Health*, *15*(8), 945–949. https://doi.org/10.1080/13607863.2011.586622

Spector, A., Thorgrimsen, L., Woods, R. T., & Orrell, M. (2006). *Making a difference: an evidence—based group programme to offer Cognitive Stimulation Therapy (CST) to people with dementia.* Hawker Publications.

Spector, A., Thorgrimsen, L., Woods, B. O. B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *The British Journal of Psychiatry*, *183*(3), 248-254.

* Streater, A. J. (2015). *Implementing maintenance cognitive simulation therapy (CST) in practice: a randomised controlled trial (RCT) of training and monitoring studies.* (Doctoral dissertation, UCL (University College London)).

Swaab, D. F., Dubelaar, E. J. G., Hofman, M. A., Scherder, E. J. A., van Someren, E. J. W., & Verwer, R. W. H. (2002). Brain aging and Alzheimer's disease; use it or lose it (pp. 343–373). https://doi.org/10.1016/S0079-6123(02)38086-5

Taulbee, L. R., & Folsom, J. C. (1966). Reality Orientation for Geriatric Patients. *Psychiatric Services*, *17*(5), 133–135. https://doi.org/10.1176/ps.17.5.133

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 45. https://doi.org/10.1186/1471-2288-8-45

Toh, H. M., Ghazali, S. E., & Subramaniam, P. (2016). The acceptability and usefulness of Cognitive Stimulation Therapy for older adults with Dementia: A narrative review. *International Journal of Alzheimer's Disease, 2016*.Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners. *British Journal of Psychiatry*, *181*(6), 468–472. https://doi.org/10.1192/bjp.181.6.468

van Weert, J. C.., Kerkstra, A., van Dulmen, A. M., Bensing, J. M., Peter, J. G., & Ribbe, M. W. (2004). The implementation of snoezelen in psychogeriatric care: an evaluation through the eyes of caregivers. *International Journal of Nursing Studies*, *41*(4), 397–409. https://doi.org/10.1016/J.IJNURSTU.2003.10.011

Vygotsky, L. S., (1978). *Mind in Society: The Development of Higher Psychological Processes.* Harvard University Press.

* Wong, G. H., Yek, O. P., Zhang, A. Y., Lum, T. Y., & Spector, A. (2018). Cultural adaptation of cognitive stimulation therapy (CST) for Chinese people with

dementia: multicentre pilot study. *International journal of geriatric psychiatry, 33*(6), 841 – 848.

Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & Mental Health*, *10*(3), 219–226. https://doi.org/10.1080/13607860500431652

Woods, B., Aguirre, E., AE, S., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, (2), N.PAG-N.PAG.

* Yates, L. A., Orrell, M., Spector, A., Orgeta, V., L.A., Y., M., O., & A., S. (2015). Service users' involvement in the development of individual Cognitive Stimulation Therapy (iCST) for dementia: a qualitative study. *BMC Geriatrics*, *15*, 4. https://doi.org/http://dx.doi.org/10.1186/s12877-015-0004-5

Yeh, S.-C. J., & Liu, Y.-Y. (2003). Influence of social support on cognitive function in the elderly. *BMC Health Services Research*, *3*(1), 9. https://doi.org/10.1186/1472-6963-3-9

Part Two: Empirical Paper

The impact of individual Cognitive Stimulation Therapy (iCST) on cognition in people with dementia: a pilot randomised control trial

2.1 Abstract

Background: This pilot study aimed to evaluate the feasibility of an adapted 14-session programme of individual Cognitive Stimulation Therapy (iCST) for people with dementia (PWD), addressing potential limitations in the previous literature, and to evaluate its possible impact on cognition and quality of life (QoL).

Methods: The modified iCST programme was developed using existing manuals for group and individual CST and consultation with experts in the field. Twenty-nine people with dementia were recruited from care homes and randomly assigned to iCST (14, 45-min sessions) or treatment as usual (TAU) over 7 weeks. Outcomes evaluating impact on cognition and QoL were assessed at baseline and follow-up. This is a joint project completed with Lycia Forde (LF). Analysis of the effects on cognition are reported here.

Results: The intervention appeared feasible with high attendance to sessions, minimal levels of attrition, and ease of recruitment. Analysis of covariance indicated improvement on the ADAS-Cog for PWD receiving iCST compared to TAU ($p = .01$). There were no significant differences between groups on follow-up scores on the SMMSE.

Conclusion: A shorter programme of iCST was feasible and acceptable to PWD and may provide benefits to cognition. A larger RCT would be necessary to fully evaluate intervention impact on cognition and QoL for PWD.

2.2 Introduction

2.2.1 Background

Currently, there are an estimated 850,000 individuals living with dementia in the UK, with an associated cost of approximately £26.3 billion per year. With a consistently ageing population, this number is set to increase yearly, and with it, costs to the NHS, local authorities and to families providing informal, unpaid care (Alzheimer's Society, 2014). Consequently, there is associated pressure to continue developing effective methods of care for people living with dementia. However, despite extensive research into Alzheimer's disease and other forms of dementia, available biomedical treatments, such as acetylcholinesterase inhibitors (AChEIs), are unable to halt or reverse its progression and do little to improve cognition (Feldman, et al. 2007; Jelic, Kivipelto & Winblad, 2006; Petersen et al. 2005; cited in Lautenschlager et al. 2008). On the other hand, psychosocial interventions such as Reality Orientation (Taulbee & Folsom, 1966), which is based on repeated presentation of orientation information, was designed to improve quality of life in people with dementia and has shown promising associated benefits in cognition (Spector et al., 1998, 2000).

Moreover, interventions that offer cognitive stimulation have been shown to provide significant benefit to people living with dementia. For example, a review by Huntley, Gould, Liu, Smith and Howard (2014) found that cognitive stimulation significantly improved scores on measures of cognition. More recently, a systematic review of reviews supported the efficacy of a range of psychosocial interventions in improving the wellbeing of people living with dementia, with most consistent evidence for the positive impact of cognitive stimulation (McDermott et al., 2018).

2.2.2 Cognitive Stimulation Therapy

Cognitive Stimulation Therapy (CST) is a well-known group intervention for people with mild to moderate dementia. CST was initially developed following results of a Cochrane review of Reality Orientation (Spector et al., 2001) and drawing from other therapies. An initial randomised controlled trial (RCT) indicated that CST improves cognition and quality of life (Spector et al., 2003), and the evidence for these benefits has been consistently shown (Spector et al, 2003; Prince, Bryce & Ferri, 2011; Orrell et al., 2014). In addition, CST was established to be cost-effective with comparable effects to AChEIs (Knapp et al. 2006), which led to its recognition and recommendation by the National Institute for Health and Care Excellence (NICE) to people living with mild to moderate dementia (NICE, 2018). Furthermore, a study of factors affecting outcomes of CST showed that it improves cognition for those already taking dementia medications (Woods et al., 2012).

A pilot extended programme of maintenance CST (MCST) consisting of 16 sessions was also developed, which provided significant benefit to cognitive function (Orrell, Spector, Thorgrimsen & Woods, 2005). This led to development of a 24-week MCST programme which provided longer term cognitive benefits for people also taking AChEIs (Orrell et al., 2014). Alongside the success of CST in the UK, there have been more recent developments of numerous cultural adaptations of CST for implementation across the world (Aguirre, Spector & Orrell, 2014; Bertrand et al. 2018; Mahmood, Ahmed, Orrell, & Kinsler, 2012; Mkenda et al., 2018; Wong, Yek, Zhang, Lum & Spector, 2017; Yamanaka et al. 2013).

One of the key principles of CST is mental stimulation. It is thought to activate neurons and subsequently enhance function and survival, both during aging and in the context of dementia (Salthouse, 2006; Swaab et al., 2002). Stimulation is provided via a range of activities which require the implementation of cognitive skills within a social setting, further enhancing the level of stimulation provided. The effects on cognition may also be a mediator for the improvements to quality of life seen in most CST studies. This is further supported by findings that the greatest improvements in quality of life are associated with impact on memory, energy levels, ability to do chores, and relationships with caregivers (Woods, Thorgrimsen, Spector, Royan & Orrell, 2006).

Hall, Orrell and Spector (2013) explored the neuropsychological mechanisms underpinning these cognitive benefits using a range of neurocognitive tests. Findings indicated that memory, orientation and language comprehension were most impacted for people with mild to moderate dementia. Though this corroborates with previous literature, the domains most affected by CST is contested. Whilst Hall et al.'s (2013) study showed benefits to memory, a study by Spector et al. (2010) indicated benefits to language comprehension and spoken language, without the significant effects on memory. It is hypothesised that this relates to CST's emphasis on implicit stimulation, as opposed to explicit rehearsal of information.

However, despite its increasing popularity worldwide and availability within memory services, charity organisations, and in some residential care settings, many individuals may not have access to CST. For some, current groups may not be available near their home, which contributes to the burden on carers or localities to arrange transport. Other individuals may dislike being part of group activities or have practical barriers, such as sensory impairments, which make it more difficult to participate in a group setting (Yates, Leung, Orgeta, Spector & Orrell, 2015). These issues were indicative of a need for adaptation of CST for to one-to-one delivery.

2.2.3 Individual Cognitive Stimulation Therapy

Over the past few years, individual Cognitive Stimulation Therapy (iCST) has been developed to provide alternative means to receiving the benefits of CST without attending a group (Yates et al. 2015). The iCST intervention was based on the original group CST and MCST programmes (Aguirre et al., 2011; Spector, Thorgrimsen, Woods & Orrell, 2006). The resulting programme consisted of 75-sessions designed to be delivered by family caregivers at home (Yates et al. 2015), both for the benefits to caregiver well-being, but to allow greater accessibility to CST for those unable to attend group settings (Orrell et al. 2012). Prior research had also suggested that cognitive stimulation delivered by carers in a one-to-one setting by a carer was helpful for verbal fluency, problem-solving and immediate memory (Quayhagen & Quayhagen, 2001).

A large randomised controlled trial of the iCST programme indicated no difference between iCST and treatment as usual groups in post-intervention measures of cognition, and self-reported quality of life (Orrell et al. 2017). There was an improvement in the caregiving relationship, and carer quality of life though the effect sizes were small. However, the findings were skewed by poor adherence to the intervention. Furthermore, subsequent exploration of the experiences of both carers and people with dementia highlighted a number of potential limiting factors and feasibility issues.

2.2.4 Barriers to the original iCST program

The RCT reported only 40% of the sample allocated to iCST completed at least two sessions a week, with a further 22% completing no sessions (Orrell et al. 2017). Previous research indicated twice-weekly sessions of group CST leads to cognitive improvements, as compared to once-weekly sessions (Cove et al., 2014). This suggests that more than 50% of participants were potentially receiving a sub-optimum ‘dose’ of iCST. The development phase and follow-up qualitative interviews highlighted several reasons why adherence to the study, and additionally the fidelity of the intervention may have been poor. Firstly, carers in the development phase previously raised concerns about fitting iCST into their weekly schedule (Yates et al. 2015), and this was noted by family carers in follow-up interviews following the RCT (Leung et al., 2017). The qualitative data suggested difficulties for carers engaging with the intervention related to the level of decline associated with dementia, and there was a difficult dynamic within close family relationships that could be difficult when family members became the “therapist”, which felt discordant with their role as a family member. Some carers reported difficulty encouraging the person with dementia to participate in activities (Yates et al., 2015). Furthermore, some carers did not feel skilled enough to deliver the sessions (Orrell et al., 2017).

In addition, the study was carried out in the community, yet 39% of people living with dementia are living in care homes (Prince et al., 2014). Many of those who live in residential care are typically under stimulated due to a lack or absence of appropriate daytime activities, (Knapp et al., 2006; Hancock, Woods, Challis & Orrell., 2006). Research suggests that a lack of mental stimulation is associated with decline in both normal aging and dementia (Salthouse, 2006; Small, 2002). Furthermore, those who might typically find it difficult to engage in group activities may have generally limited social interaction. Of interest, social disengagement has been identified as a risk a factor for cognitive impairment for older adults, whilst social interaction is shown to be a protective factor (Bassuk, Glass, & Berkman, 1999, cited in Yeh, & Liu, 2003; Elwood et al. 1999 cited in Yates et al. 2014). As such, individuals in residential care may be more sensitive to change, and equally may benefit more from additional interaction. Historically, CST research has been conducted in care homes, and a further study in this setting could be suitable to expand our understanding and re-evaluate iCST's potential for people living with dementia.

2.2.5 The current study

In consideration of the barriers and limitations present in the Orrell et al RCT, iCST should still be explored as an intervention for those living with dementia unable to access group CST. Firstly, delivery by professionals may be more beneficial than through family carers, by providing a different dynamic to that felt by a family carer and person with dementia. Professionals should also be less exposed to factors affecting motivation, such as the level of decline associated with dementia, thereby reducing some of the difficulties previously experienced. Secondly, the adherence rates and qualitative data suggest that the original frequency and number of sessions may not be feasible for many. Twice-weekly sessions would allow greater flexibility in the timing and delivery of sessions as compared to thrice-weekly. Moreover, past research has consistently supported the benefits of a 14-session CST programme, suggesting that this dose is sufficient to detect benefits if they exist. In contrast, longer term CST did not yield similar benefits without combination with anti-dementia medications (Aguirre et al. 2011). Lastly, the provision of multi-sensory stimulation will still be central to the intervention, involving cognitive skills in a supportive environment (Hall et al., 2013). Further, it will continue to focus on implicit memory activation, which is both responsive to mental stimulation and generally better preserved than explicit memory (van Tilborg, Kessels, & Hulstjin, 2011).

2.2.5.1 Aims

The current study aims to develop and pilot a revised iCST programme that minimises the barriers identified in the previous iCST trial and subsequent qualitative feedback (Orrell et al., 2017; Leung et al., 2017). It assesses whether a programme of 14, 45-minute iCST sessions, delivered by a professional twice weekly over seven weeks is feasible, and considers its impact on cognition and quality of life in people living with dementia compared to treatment as usual (TAU). This is a joint research project conducted by researchers LG and LF. This study evaluates the impact of the intervention on cognition.

2.3 Method

This is a joint research project conducted with LF. The present study outlines the effectiveness of iCST for people with dementia on outcomes of cognition, whilst LF will report on the effectiveness on outcomes of quality of life. The feasibility of the study is reported in both studies. The contribution of each trainee to the research is outlined in Appendix G.

2.3.1 Ethical Considerations

Ethical approval for the study was received from the University College London Research Ethics Committee (Project ID: 12503/001; Appendix D). All participants gave informed consent prior to inclusion within the study. They were informed that they could withdraw from the study at any time, without giving a reason. Their consent to take part in iCST activities and assessments was reviewed throughout the study.

2.3.2 iCST Development

In preparation for designing the adapted iCST program, researchers reviewed the current literature on CST, including the original group CST manual (Spector et al.

2006), MCST manual (Aguirre et al. 2011) and iCST manual (Yates et al. 2015). In addition, data from the field-testing phase of the development of iCST was reviewed to determine which sessions may be more valued or popular (Yates, Orgeta, Leung, Spector & Orrell, 2016). The resulting iCST materials included a manual with guidance for each session, ideas for activities, and a booklet of paper resources for activities, as well as suggested materials that may benefit each session. The key principles of iCST were taken directly from the iCST manual (Yates et al. 2015). The revised manual was finalised through iterative consultation with Professor Aimee Spector and Dr Lauren Yates.

2.3.2.1 Structure of iCST

The structure of sessions was based on that of the original iCST manual. Sessions started with sensitive discussion of orientation information including date, time and weather, and current affairs (Yates et al. 2015). The manual then presents the themed activity for that session. The sessions have a suggested length of 45-minutes, which allowed for provision of the same dose as the original CST programme in both frequency of sessions and weekly time. However, if the session length was too long for individuals, allowances were made where they wanted to terminate a session early.

2.3.2.2 Content of the Program

The session manual outlines 14 iCST sessions following a similar order and content to the group CST manual with adjusted guidance to reflect the one-to-one nature of the intervention. Provided worksheets and suggested materials were developed accordingly from available manuals, alongside new suggestions where appropriate. The initial session on “Life History” from the iCST manual was retained as it provided a way of getting to know individuals and discover their preferences, which could be helpful in tailoring the remaining sessions. The original CST session on “Current Affairs” was removed to allow for this, as current affairs was incorporated into each session during the warm-up. Moreover, it was rated as less interesting and enjoyable than other sessions within the field-testing phase of iCST (Yates et al. 2016). Where possible, positively rated sessions from the iCST manual were amalgamated as an alternative option for sessions within the revised manual, for example discussing food slogans within the “Food” session. Although the individual quiz developed for iCST is popular, the “Thinking Cards” session was chosen as the final session as a widely enjoyed activity. The final order of sessions was the following (see Appendix F for iCST Manual):

1. Life History
2. Physical Games
3. Sounds
4. Childhood
5. Food
6. Faces
7. Word Association
8. Being Creative
9. Categorising Objects
10. Orientation
11. Using Money
12. Number Games
13. Word Games
14. Thinking Cards

2.3.2.3 iCST Delivery

Sessions were delivered by researchers in the study. Sessions were conducted within a resident's room or a suitably private and quiet location in the care home. All sessions were conducted in the same room each week if possible.

2.3.3 Participants

Participants were recruited from care homes across London. Care homes were initially contacted via email, and then managers of homes introduced us to residents who met the inclusion criteria below and might be interested in taking part. Researchers discussed the study and provided full detail to participants, providing the opportunity for any related questions before proceeding with the consent forms (see Appendix C for information sheets and consent forms).

2.3.3.1 Inclusion Criteria

In order to take part individuals were required to meet the following inclusion criteria (informed by previous CST research):

- required to meet criteria for dementia of the Diagnostic and Statistical Manual of Mental Disorders V (DSM-V, American Psychiatric Association, 2013)
- have the capacity to provide informed consent
- have mild to moderate dementia evidenced by scoring at least 10/30 on the standardised Mini-Mental State Examination (SMMSE) (Molloy, Alemayehu, & Roberts, 1991)
- be able to communicate, understand, see and hear well enough to participate in activities as part of iCST
- have no major health issues which might affect participation.

2.3.4 Procedure

Following provision of informed consent, participants were screened for suitability for the study using the SMMSE as described in the inclusion criteria. Participants passing initial screening completed all remaining measures of cognition and quality of life. The full battery of assessments was estimated to take approximately one hour at each time point.

2.3.4.1 Capacity

During initial meetings with participants, capacity to consent to the study was established in accordance with the Mental Capacity Act (2005). Potential participants were provided with clear written and verbal information about the study. Participants were encouraged to share the information with any family member or carers if they felt it would be helpful. Care home staff were also provided with all relevant information about study participation. The participant information sheet was verbally discussed section by section, with repetition of information as necessary. Ample opportunity for questions were provided and understanding of each section was ensured before moving to the next. Completion of the consent forms was used as a further opportunity to establish participant understanding of the study and answer any further questions, and to re-iterate that they could withdraw from the study at any time. In addition, only those scoring a minimum of 10 on the SMMSE were included in the study.

Capacity to continue taking part was assessed via observation of participants at each visit to ascertain whether there was significant decline in cognition or understanding of their involvement.

2.3.4.2 Blinding

After baseline assessment, participants were randomly allocated by an independent web-based randomiser to allocate them to iCST or treatment as usual groups with a 1:1 ratio. Researchers conducting follow-up assessments were blinded to this allocation, however this was not checked systematically

2.3.4.3 Measures

Participants were asked to complete two measures of cognition alongside measures of quality of life (these are described within report by LF). See Appendix E for cognition measures utilised in this study.

SMMSE

The SMMSE is a standardised version of the Mini-Mental State Examination (Folstein, Folstein & McHugh, 1975; Molloy et al. 1991). It is a tool used for dementia screening, with improved reliability as compared to the original MMSE, though it is important to note it has only modest sensitivity (Sheehan, 2012). The SMMSE provides a total score of 0 – 30, with a higher score indicated better cognitive function. Scores can also be adjusted to account for non-cognitive impairments that may affect items. It was used as both a screening tool of suitability for participation in the study, and a measure of cognitive function including orientation, immediate recall, language, and constructive ability. For the purposes of comparison to previous trials of CST, MMSE and SMMSE scores were considered equivalent.

ADAS-Cog

The Alzheimer’s disease Assessment Scale-Cognitive Subscale (ADAS-Cog) (Rosen, Mohs, and Davis, 1984) is comprised of 11 tasks assessing memory, language, praxis, attention and other cognitive domains. When combined, this provides a total score of 0 – 75, with a lower score indicating better cognitive function. It has good reliability and validity and is a recommended and widely utilised scale for trials in which cognition is a primary outcome (Sheehan, 2012). The ADAS-Cog can be divided into three sub-scales of memory and new learning, language and praxis (Spector et al. 2010). Furthermore, previously published CST research has used the ADAS-Cog as a primary outcome allowing for more direct comparison with the wider literature.

2.3.5 Data analysis

Statistical analysis was conducted using IBM SPSS Statistics 25. Data was assessed for normality and heterogeneity. Where assumptions were not met, non-parametric alternatives were used.

2.3.5.1 Data analysis procedures.

Analysis of covariance (ANCOVA) was used to explore the differences between iCST and TAU groups for people with dementia at follow-up. The baseline score on outcome measures was used as a covariate in the analyses. Non-parametric tests (Mann-Whitney) were used to compare change at follow-up on sub-scales on the ADAS-Cog as the range on these is limited.

2.3.5.2 Power analysis

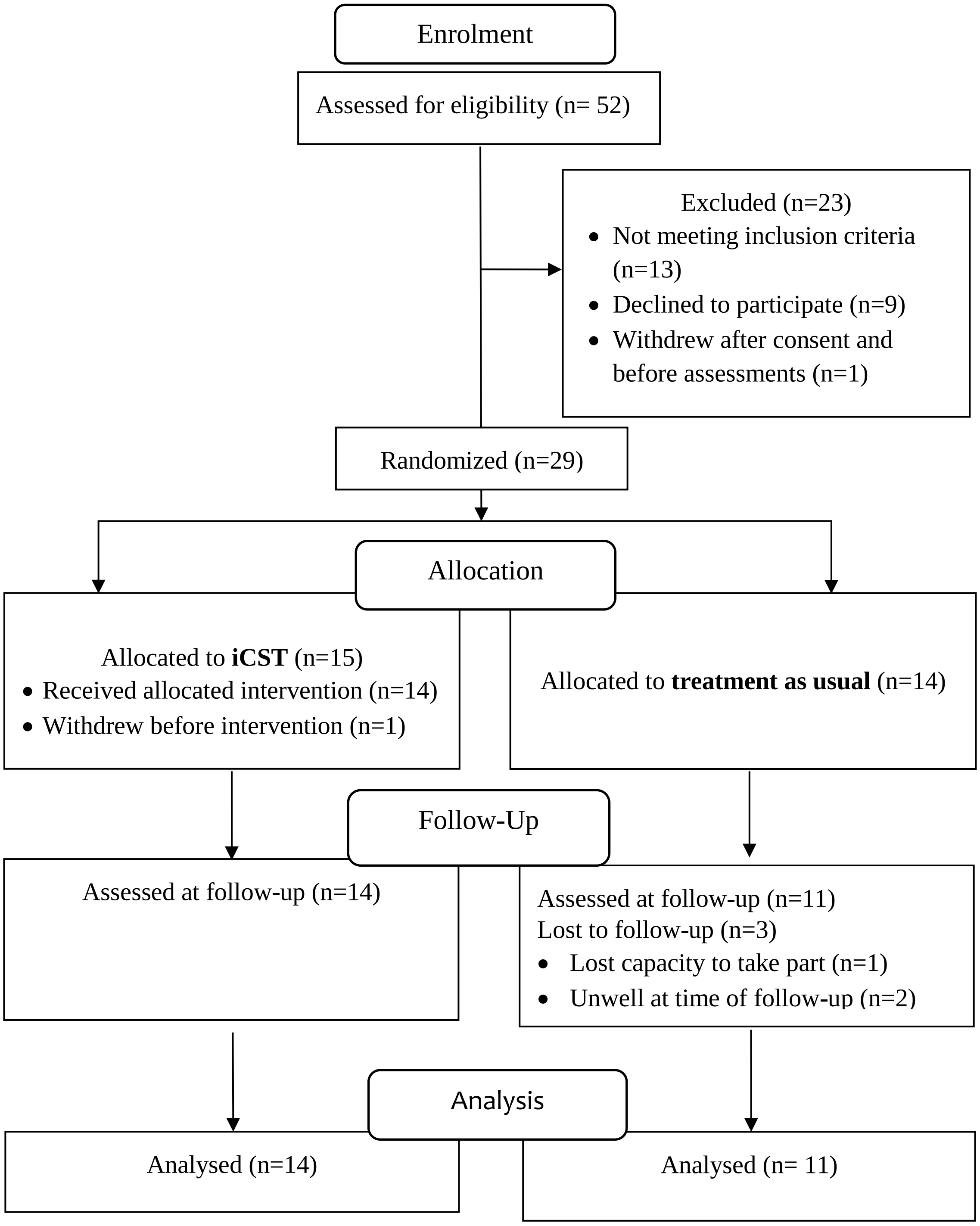
As this is a pilot study, it is not expected that analyses will be sufficiently powered to detect small to medium effects. A sample size of 32 was identified as feasible to recruit, and G*Power (Faul, Erdfelder, Lang & Buchner 2007) was used to determine that based on this number, when alpha is set at .05 and power at 0.80, we could detect a large effect size of 0.51 (Cohen’s *f*) with an ANCOVA with one covariate.

2.4 Results

2.4.1 Participants

Of the 52 people with dementia approached, twenty-nine people with dementia were recruited and completed baseline (BL) assessments (see Figure 1 for flow diagram or recruitment and retention of participants).

Figure 1. Flow diagram of recruitment and retention of participants



Their basic demographics are summarised in table 1. Following randomisation, 15 participants were allocated to receive iCST, and 14 to receive treatment as usual.

Table 1. Participant Demographics at Baseline

Characteristics	**All participants (n=29)**	**iCST (n=15)**	**TAU (n=14)**
Age (years)			
Mean (SD)	81.07 (10.74)	86.20 (1.43)	75.57 (3.30)
Range	56 - 98	75 – 98	56 - 94
Gender			
Male (%)	13 (44.8)	8 (57.1)	5 (33.3)
Female (%)	16 (55.2)	6 (42.9)	10 (66.7)
MMSE Score			
Mean (SD)	21.45 (3.58)	20.73 (2.96)	22.21 (4.12)
Range	14 – 27	14 - 25	14 - 27
ADAS-Cog Score			
Mean (SD)	25.21 (10.03)	24.93 (7.17)	25.50 (12.70)
Range	10 - 45	18 - 39	10 - 45
Ethnicity			
White British (%)	23 (79.3)	12 (80)	11 (78.6)
White Other (%)	2 (6.9)	2 (13.3)	0 (0)
Asian (%)	3 (10.3)	1 (6.7)	2 (14.3)
Black British (%)	1 (3.4)	0 (0)	1 (7.1)

2.4.2 Feasibility and Acceptability

2.4.2.1 Recruitment and Retention

Six out of 26 homes (23%) approached agreed to take part in the study. Within recruited homes, 52 participants were put forward by care home managers and invited to take part. Thirteen (25%) did not fulfil the eligibility criteria. Of those meeting eligibility criteria, 9 of the 39 (23%) were not interested in taking part.

Thirty people initially consented to the study, which was accomplished in approximately six months. However, one participant dropped out prior to baseline assessment. Twenty-nine completed baseline assessments, of which twenty-five (86%) were retained at follow-up. In the iCST group, one withdrew before intervention. In the treatment as usual group, one participant was withdrawn from the study as they had lost capacity, and two were unable to complete follow-ups due to ill health.

2.4.2.2 Attendance and Adherence

Fourteen people received sessions of iCST, eleven of which (79%) completed all 14 sessions, with 97% of sessions attended overall. One participant missed one session, one missed two sessions, and one missed three sessions of iCST**.** Reasons for missing sessions were generally being too tired, not in the mood, or being busy with another activity that day.

2.4.2.3 Feasibility of Outcome Measures

There was no missing data on measures of cognition. The SMMSE accommodates difficulties with items relating to sensory or physical impairment by allowing an adjusted score based on total items completed. For the ADAS-Cog, items made difficult by factors other than cognitive impairment were found similarly difficult at follow-up indicating little impact on scores. It was intended for the same researchers to complete assessments at baseline and follow-up for each resident. This was not the case for 40% of cases due to availability of researchers.

2.4.2.4 Fidelity

No fidelity checklist was used in the current study, however neither researcher reported difficulties with adherence to the manual.

2.4.2.5 Adverse Events

There were no unexpected adverse events for those taking part in the study.

2.4.3 Exploratory Analyses

Analyses were conducted only for participants completing both baseline and follow-up assessments. For the 25 participants, average BL SMMSE scores did not differ significantly between groups (iCST = 20.71, TAU = 22.91), t (23) = 1.723, $p > .05$ (95% confidence intervals (CI): -0.44 to 4.83). Average ADAS-Cog scores did not differ significantly at baseline between groups (iCST =25.07, TAU = 24.36), t (23) = -0.18, $p > .05$ (95% CI: -8.90 to 7.45).

Analysis of Covariance (ANCOVA) was used to compare groups at follow-up whilst adjusting for BL scores. Levene's Test for Equality of Variance was not significant for both comparisons, $p >.05$, indicating equal variances could be assumed between groups at follow-up. Differences at follow-up on the SMMSE were not significant. However, participants receiving iCST scored significantly lower at follow-up on the ADAS-Cog (indicating better cognitive function) compared to TAU. The BL SMMSE scores had a significant effect on follow-up SMMSE scores, F (1,22) = 10.68, $p = .004$, partial $\eta^2 = 0.327$. BL ADAS-Cog scores also had a significant effect on follow-up ADAS-Cog scores, F (1,22) = 48.89, $p <.001$, partial $\eta^2 = 0.69$.

Table 2. ANCOVA comparing group differences at follow-up adjusting for BL scores

Cognition Measure	**Scores at Follow-Up**		**Mean Difference**		**ANCOVA (between-group difference)**
	iCST Mean (SD)	TAU Mean (SD)	Mean (SD)	95% CI	
SMMSE	20.36 (3.86)	22.18 (4.79)	-0.08 (1.58)	-3.32 to 3.08	F (1,22) = 0.006, p = .94

ADAS-Cog	19.71 (3.54)	24.91 (12.05)	-5.67 (2.00)	-9.69 to -1.70	F (1,22) = 8.00, p = .007* partial $\eta^2 = 0.29$

* Denotes a significant difference at alpha = .01

ADAS-Cog = Alzheimer's Disease Assessment Scale-Cognitive Sub-scale; SMMSE = Standardised Mini Mental State Examination; Mean Difference = mean difference adjusting for BL scores

2.4.4 Post-Hoc Analyses

The Bonferroni correction was applied when considering these analyses, and a significance level of .017 was used. Mann-Whitney U tests indicated that participants receiving iCST had significantly greater improvement on the 'memory and new learning' sub-scale (U = 29.50, *p* = .008). There were no significant differences between groups for changes on 'language' or 'praxis' sub-scales (*p* > .05).

2.5 Discussion

The current study aimed to develop and pilot a randomised controlled trial of a 14-session programme of iCST in 29 people with dementia. This study demonstrated that the intervention was feasible and may provide benefits to cognition for people with dementia. These findings are discussed with reference to previous studies in the CST literature.

2.5.1 Feasibility

The revised programme of iCST was feasible to deliver and seemed acceptable to people with dementia. Attendance of sessions was good, with 78.5% of individuals receiving a full dose of 14 sessions of iCST and 97% of sessions being received overall. Additionally, the dropout rate for the study was minimal, with only individuals from TAU withdrawing from the study for reasons unrelated to study participation. Of note, one of the main limitations in the previous trial of iCST was poor treatment adherence (Orrell et al. 2017) and there are several key differences between the current study and the previous RCT that may underlie this. Firstly, the revised manual was based on preferences found within the iCST development phase (Yates et al. 2014) and the original series of session in group CST (Spector et al. 2006). As such, the content of each session may have been more broadly enjoyed, as it incorporated sessions and activities shown to be preferred in previous research. Secondly, the use of professionals could have addressed difficulties experienced by family carers delivering iCST as they are likely to have received more training, for example in the communication skills necessary to facilitate sessions and engage people with dementia. It is possible that professionals also hold more positive perceptions of dementia, whereas perception of dementia as progressive was previously identified as a barrier to facilitation (Leung et al. 2017). Finally, carers delivering iCST had found it difficult fitting sessions into a busy schedule (Orrell et al. 2017; Yates et al. 2016). Use of professionals and reducing the program to 14 sessions appeared to address this barrier, whilst still providing a suitable dose of cognitive stimulation each week (Cove et al. 2014). However, it is important to note that the revised programme would need to be trialled again with caregivers to fully consider this. Also, there were no unexpected negative effects on cognition or adverse events from taking part.

Although fidelity was not assessed as it was beyond the resources of the current study, the intervention was manualised and there were no difficulties reported by researchers in delivering the intervention as planned. It is also important to note that most care homes and participants were recruited for the study within a short period of time. Although 28.84% of people approached did not meet inclusion criteria, this may be a result of care home manager eagerness for individuals to receive intervention and, for example, putting forward several people who did not have a diagnosis of dementia.

2.5.2 Interpretation of Findings

People with dementia receiving iCST had improved scores on the ADAS-Cog at follow-up compared to TAU whilst accounting for scores at baseline. This suggests that iCST may provide benefits to cognition for PWD, in contrast to previous findings for the longer programme of iCST (Orrell et al. 2017). Of note, a change of four points or more on the ADAS-Cog, as found in the iCST group which changed by 5 points, has historically been considered clinically important in drug trials (Rockwood et al. 2007, cited in Sheehan, 2012). In addition, the effect size of the intervention on ADAS-Cog scores is large according to Cohen's guidelines (Cohen, 1992), but it is important to note this may be exaggerated in small sample sizes. People receiving iCST also improved significantly more than TAU on the 'memory and new learning' sub-scale.

There may be several explanations for the difference in these findings compared to past trials of iCST. Firstly, the current study was more closely related to group CST, as the weekly dose and the majority of content have been kept the same (Spector et al. 2006) and the sample was similarly recruited from care homes. Secondly, as mentioned above, professionals may be better equipped to deliver sessions in terms of training and skills. In combination with improved adherence, these differences may have contributed to the contrast in findings to prior trials of iCST.

Conversely, there was no significant differences between groups on the SMMSE. Of interest, this is comparable to Hall et al. (2013), who found benefits to memory and orientation following group CST, but no improvement on the MMSE. However, it is possible that the MMSE, which has a relatively small range, is simply less sensitive to smaller change in cognition. This is reflected in past findings, where change in points on the MMSE was half of that found in the ADAS-Cog (Spector et al., 2010).

2.5.3 Strengths and Limitations

There are several strengths associated with the current study. Firstly, the modification of the intervention was guided by the extensive development of the original iCST program (Yates et al. 2015; Orrell et al. 2018). The advantage of this was the availability of data that could be utilised in refining the intervention, including the perspective and experience of both people with dementia and their carers (Yates et al. 2016). By constraining the intervention to 14 sessions, the program addressed the previous barrier of frequency of sessions and the authors were also able to provide additional options for each session to accommodate the preferences of each participant. Secondly, although the sample size was small, there was a reasonable spread of ages included in the study overall, and a balance of sexes within each group. However, in terms of ethnicity, participants were predominantly White British which makes it more difficult to generalise findings to other ethnic and cultural groups. Lastly, this was a single blind study, which was supported by participants being reminded not to discuss their allocation with researchers prior to follow-up assessments.

Conversely, the main limitation of the current study is the small sample size, although this is expected in the context of a pilot study. Further, our inclusion criteria did not restrict participation to only those unsuitable for group CST, for example those with poorer hearing or indication that they dislike group activity. Future research could consider recruiting based on these reasons, however there may be other reasons iCST is preferable, even if the person is suitable for group CST. For example, iCST may fit more closely within smaller nursing homes with fewer people with dementia, or with individuals with varying levels of cognitive impairment, which could make it difficult to provide group CST appropriate to all those involved. A further limitation was the difficulty in using the same researchers for assessment at baseline and follow-up. Although all efforts were made to standardise the assessment process, there is always a level of interpretation involved with assessments and a total of six researchers, including the authors, were required to administer cognitive measures. In addition, the levels of blinding were not verified at follow-up, though no researchers reported being unblinded to participant allocation. Another possible limitation is how representative the sample was in relation to severity of dementia. There was higher baseline SMMSE compared to previous RCTs of CST and MCST (Orrell et al. 2014; Spector et al. 2003). Few participants were in the moderate range of dementia and several participants scored above 25, which is typically more associated with mild cognitive impairment. When considered alongside the inability to verify diagnosis in medical histories, this contributes a level of uncertainty to whether all participants had a diagnosis of dementia. This may also be associated with a certain level of ambiguity in the inclusion criteria, which specify meeting the criteria for a diagnosis of dementia, and do not require having formal diagnosis. However, this served to accommodate the lack of formal diagnosis in some residents who experience memory problems but may not have attended memory services. Also, no longer-term follow-up data was collected so it was not possible to assess whether benefits might be represented by maintenance of cognition over time. Lastly, different care homes may have also had different standards of ‘treatment as usual’, which would mean control groups could not be considered homogenous. It may be useful to systematically measure this in a full randomised controlled trial. It may also be beneficial to assess fidelity via audio recording of sessions or creating a checklist appropriate to the intervention.

2.5.4 Implications

Despite CST being widely implemented across the NHS, many people cannot access groups for several reasons, for example poor mobility, health problems or difficulty arranging transport. The findings suggest that the revised programme was feasible and potentially beneficial to cognition and could therefore represent a hopeful alternative to group CST. As such, a larger RCT would be appropriate to establish the efficacy of the intervention, which could also utilize more sophisticated analyses exploring which other factors might predict changes in cognition. For example, Aguirre et al. (2013) found that group CST benefitted cognition including for those on dementia medications and found associations with age and gender. Similarly, sessional feedback from participants would lend further understanding of the acceptability of the intervention and the content of sessions. In addition, qualitative input is recommended for complex intervention development (Medical research Council, 2008) and would be insightful for future development, as it would give us greater understanding of responses to the intervention (Lewin, Glenton & Oxman, 2009).

Further, it is recommended that subsequent studies include assessment of fidelity to the intervention and should aim to recruit a more representative sample of mild to moderate dementia. As some participants scored above 25 on the SMMSE, an upper bound on the inclusion criteria as used in Spector et al. (2003) may ensure that those taking part are more sensitive to change and would benefit most from intervention. It would also be recommended that the baseline and follow-up assessors are kept consistent where possible. In addition, it is suggested that research in iCST continues to be conducted in residential care allowing better comparison to previous research. Most importantly, it is these individuals who are most in need and may benefit substantially from intervention (Hancock et al., 2006; Knapp et al., 2006). Should a larger RCT support the efficacy of iCST, the intervention may then also be amenable to re-evaluation for delivery by familial caregivers. Orrell et al. (2017) highlighted benefits of involving family and carers in intervention for dementia, and the positive impacts to caregiver relationships and QOL were evident in their study. Past research in group CST suggests this programme could equally be developed for other cultural backgrounds (Aguirre et al. 2014).

2.5.5 Conclusions

Overall, a 14-session programme of iCST for people with dementia was feasible in consideration of adherence and retention in the current study. Further, findings suggest that it may offer improvements to cognition for people with dementia and may offer real hope as a treatment to care home populations. This is especially important for those currently unable to access treatment, who are at potential risk of greater cognitive decline.

2.6 References

Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell, M. (2013). Cognitive stimulation therapy (CST) for people with dementia-who benefits most? *International Journal of Geriatric Psychiatry*, *28*(3), 284–290. https://doi.org/10.1002/gps.3823

Aguirre, E., Spector, A., & Orrell, M. (2014). Guidelines for adapting cognitive stimulation therapy to other cultures. *Clinical Interventions in Aging*, *9*, 1003–1007. https://doi.org/10.2147/CIA.S61849

Aguirre, E., Spector, A., Streater, A., Hoe, J., Woods, B., & Orrell, M. (2011). Making a Difference 2: Volume Two: An evidence-based group programme to offer Maintenance Cognitive Stimulation Therapy (CST) to people with dementia. *London: Hawker*.

Aguirre, E., Spector, A., Streater, A., Burnell, K., & Orrell, M. (2011). Service users' involvement in the development of a maintenance cognitive stimulation therapy (CST) programme: A comparison of the views of people with dementia, staff and family carers. *Dementia*, *10*(4), 459–473. https://doi.org/10.1177/1471301211417170

Aguirre, E., Woods, R. T., Spector, A., & Orrell, M. (2013). Cognitive stimulation for dementia: a systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing research reviews*, *12*(1), 253-262.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Balsis, S., Benge, J. F., Lowe, D. A., Geraci, L., & Doody, R. S. (2015). How do scores on the ADAS-Cog, MMSE, and CDR-SOB correspond? *Clinical Neuropsychologist*, *29*(7), 1002–1009. https://doi.org/10.1080/13854046.2015.1119312

Bassuk, S. S., Glass, T. A., & Berkman, L. F. (1999). Social disengagement and incident cognitive decline in community-dwelling elderly persons. *Annals of Internal Medicine*, *131*(3), 165. https://doi.org/10.7326/0003-4819-131-3-199908030-00002

Bertrand, E., Naylor, R., Laks, J., Marinho, V., Spector, A., & Mograbi, D. C. (2018). Cognitive stimulation therapy for brazilian people with dementia: Examination of implementation' issues and cultural adaptation. *Aging & Mental Health*, No-Specified. https://doi.org/http://dx.doi.org/10.1080/13607863.2018.1488944

Clare, L., & Woods, R. T. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation*, *14*(4), 385–401. https://doi.org/10.1080/09602010443000074

Cove, J., Jacobi, N., Donovan, H., Orrell, M., Stott, J., & Spector, A. (2014). E E ffectiveness of weekly cognitive stimulation therapy for people with dementia and the additional impact of enhancing cognitive stimulation therapy with a carer training program. *CLINICAL INTERVENTIONS IN AGING*, *9*, 2143–2150. https://doi.org/10.2147/CIA.S66232

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., & Medical Research Council Guidance. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ (Clinical Research Ed.), 337, a1655. https://doi.org/10.1136/bmj.a1655

Dementia, U. K. (2014). Dementia UK: update. Alzheimer’s Society, London, UK.

Day, J. R., Anderson, R. A., Davis, L. L., & Carolina, N. (2015). with Dementia, 35(10), 796–804. https://doi.org/10.3109/01612840.2014.917133.Compassion

Dugmore, O., Orrell, M., & Spector, A. (2015). Qualitative studies of psychosocial interventions for dementia: A systematic review. *Aging and Mental Health*, *19*(11), 955–967. https://doi.org/10.1080/13607863.2015.1011079

Elwood, P. C., Gallacher, J. E., Hopkinson, C. A., Pickering, J., Rabbitt P., Stollery, B., … & Bayer, A. (1999). Smoking, drinking and other lifestyle factors and cognitive function in men in the Caerphilly cohort. *Journal of Epidemiology & Community Health, 53*(1), 9-14.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175-191

Feldman, H. H., Ferris, S., Winblad, B., Sfi, N., Mancione, L., He, Y., … Herrmann, N. (2007). Articles Effect of rivastigmine on delay to diagnosis of Alzheimer's disease from mild cognitive impairment: the InDDEx study. https://doi.org/10.1016/S1474-4422(07)70109-6

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. Journal of psychiatric research, 12(3), 189-198. Hall, L., Stott, J., Hall, L., Orrell, M., Stott, J., & Spector, A. (2012). Cognitive stimulation therapy (CST): Neuropsychological mechanisms of change Cognitive stimulation therapy (CST): neuropsychological, (November). https://doi.org/10.1017/S1041610212001822

Hancock, G. A., Woods, B., Challis, D., & Orell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, *21*(1), 43–49. https://doi.org/10.1002/gps.1421

Huntley, J. D., Gould, R. L., Liu, K., Smith, M., & Howard, R. J. (2015). Do cognitive interventions improve general cognition in dementia? A meta-analysis and meta-regression. *BMJ Open*, *5*(4), 1–12. https://doi.org/10.1136/bmjopen-2014-005247

Jelic, V., Kivipelto, M., & Winblad, B. (2006). Clinical trials in mild cognitive impairment: lessons for the future. *Journal of Neurology, Neurosurgery, and Psychiatry*, *77*(4), 429. https://doi.org/10.1136/JNNP.2005.072926

Lautenschlager, N. T., Almeida, O. P., van Bockxmeer, F. M., Greenop, K. R., Cox, K. L., Xiao, J., … Foster, J. K. (2008). Effect of Physical Activity on Cognitive

Function in Older Adults at Risk for Alzheimer Disease. *Jama*, *300*(9), 1027. https://doi.org/10.1001/jama.300.9.1027

Leung, P., Yates, L., Orgeta, V., Hamidi, F., & Orrell, M. (2017). The experiences of people with dementia and their carers participating in individual cognitive stimulation therapy. *International Journal of Geriatric Psychiatry*, *32*(12), e34–e42. https://doi.org/10.1002/gps.4648

Lewin, S., Glenton, C., & Oxman, A. D. (2009). Use of qualitative methods alongside randomised controlled trials of complex healthcare interventions: Methodological study. *BMJ (Online)*, *339*(7723), 732–734. https://doi.org/10.1136/bmj.b3496

Lobbia, A., Carbone, E., Faggian, S., Gardini, S., Piras, F., Spector, A., & Borella, E. (2018). The efficacy of cognitive stimulation therapy (CST) for people with mild-to-moderate dementia: A review. *European Psychologist*, No-Specified. https://doi.org/http://dx.doi.org/10.1027/1016-9040/a000342

Mahmood, S., Ahmed, S., Orrell, M., & Kinsler, H. (2012, January). Developing cognitive stimulation therapy (CST) for dementia with South Asian ethnic groups. In *27th International conference of Alzheimer's disease* (pp. 57-60). MEDIMOND SRL.

McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., … Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging & Mental Health*, *23*(4), 393–403. https://doi.org/10.1080/13607863.2017.1423031

Mkenda, S., Olakehinde, O., Mbowe, G., Siwoku, A., Kisoli, A., Paddick, S.-M., … Ogunniyi, A. (2018). Cognitive stimulation therapy as a low-resource intervention for dementia in sub-Saharan Africa (CST-SSA): Adaptation for rural Tanzania and Nigeria. *Dementia*, *17*(4), 515–530. https://doi.org/10.1177/1471301216649272

Molloy, D. W., Alemayehu, E., & Roberts, R. (1991). Reliability of a standardized mini-mental state examination compared with the traditional mini-mental state examination. *Am J Psychiatry*, *148*(1), 102-105.

National Institute for Health Research. (2017). Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis, 574–581.

NICE (2018) *Dementia: assessment, management and support for people living with dementia and their carers*. Retrieved from http://www.nice.org.uk/guidnace/ng97

Olzarán, J., Reisberg, B., Clare, L., Cruz, I., Peña-Casanova, J., Del Ser, T., … Muñiz, R. (2010). Nonpharmacological therapies in alzheimer’s disease: A systematic review of efficacy. *Dementia and Geriatric Cognitive Disorders*, *30*(2), 161–178. https://doi.org/10.1159/000316119

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., … Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: Single-blind, multicentre, pragmatic randomised controlled trial. *British Journal of Psychiatry*, *204*(6), 454–461. https://doi.org/10.1192/bjp.bp.113.137414

Orrell, M., Aguirre, E., Woods, R. T., & Spector, A. (2013). Cognitive stimulation for dementia: A systematic review of the evidence of effectiveness from randomised controlled trials. *Ageing Research Reviews*, *12*, 253–262.

Orrell, M., Spector, A., Thorgrimsen, L., & Woods, B. (2005). A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. *International Journal of Geriatric Psychiatry*, *20*(5), 446–451. https://doi.org/10.1002/gps.1304

Orrell, M., Yates, L. A., Burns, A., Russell, I., Woods, R. T., Hoare, Z., … Orgeta, V. (2012). Individual Cognitive Stimulation Therapy for dementia (iCST): study protocol for a randomized controlled trial. *TRIALS*, *13*. https://doi.org/10.1186/1745-6215-13-172

Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., … Orgeta, V. (2017). The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial. *PLoS Medicine*, *14*(3), 1–22. https://doi.org/10.1371/journal.pmed.1002269

Petersen, R. C., Thomas, R. G., Grundman, M., Bennett, D., Doody, R., Ferris, S., … Thal, L. J. (2005). Vitamin E and Donepezil for the treatment of mild cognitive impairment. *New England Journal of Medicine*, *352*(23), 2379–2388. https://doi.org/10.1056/NEJMoa050151

Prince, M., Bryce, R., & Ferri, C. (2011). World Alzheimer Report 2011: The benefits of early diagnosis and intervention.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., ... & Rehill, A. (2014). Dementia UK: Update. Alzheimer's Society.

Quayhagen, M. P., & Quayhagen, M. (2001). Testing of a cognitive stimulation intervention for dementia caregiving dyads. *Neuropsychological Rehabilitation*, *11*(3–4), 319–332. https://doi.org/10.1080/09602010042000024

Rockwood, K., Fay, S., Gorman, M., Carver, D., & Graham, J. E. (2007). The clinical meaningfulness of ADAS-Cog changes in Alzheimer's disease patients treated with donepezil in an open-label trial, *8*, 1–8. https://doi.org/10.1186/1471-2377-7-26

Rosen, W. G., Mohs, R. C., & Davis, K. L. (1984). A new rating scale for Alzheimer's disease. *The American journal of psychiatry*.

Salthouse, T. A. (2006). Mental exercise and mental aging: evaluating the validity of the "Use It or Lose It" hypothesis. *Perspectives on Psychological Science*, *1*(1), 68–87. https://doi.org/10.1111/j.1745-6916.2006.00005.x

Sheehan, B. (2012). Assessment scales in dementia. *Therapeutic Advances in Neurological Disorders*, *5*(6), 349–358. https://doi.org/10.1177/1756285612455733

Small, G. W. (2002). What we need to know about age related memory loss. *BMJ (Clinical Research Ed.), 324*(7352), 1502–1505.

Spector, A., Davies, S., Woods, B., & Orrell, M. (2000). Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist, 40*(2), 206-212.

Spector, A., Orrell, M., Davies, S., & Woods, R. T. (1998). Reality Orientation for dementia: A review of the evidence of effectiveness. *The Cochrane Database for Systematic Reviews*, *40*(2), 206–212.

Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia. *Neuropsychological Rehabilitation*, *11*(3–4), 377–397. https://doi.org/10.1080/09602010143000068

Spector, A., Thorgrimsen, L., Woods, R. T., & Orrell, M. (2006). *Making a difference: an evidence-based group programme to offer Cognitive Stimulation therapy (CST) to people with dementia*. Hawker Publications.

Spector, A., Orrell, M., & Woods, B. (2010). Cognitive Stimulation Therapy (CST): Effects on different areas of cognitive function for people with dementia. International Journal of Geriatric Psychiatry, 25(12), 1253–1258. https://doi.org/10.1002/gps.2464

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of a cognitive stimulation therapy programme for people with dementia. The British Journal of Psychiatry, 183, 248–254. https://doi.org/10.1192/03-23

Orrell, M., Spector, A., Thorgrimsen, L., & Woods, B. (2005). A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. International Journal of Geriatric Psychiatry: A journal of the psychiatry of late life and allied sciences, 20(5), 446-451.

Swaab, D. F., Dubelaar, E. J. G., Hofman, M. A., Scherder, E. J. A., van Someren, E. J. W., & Verwer, R. W. H. (2002). Brain aging and Alzheimer's disease; use it or lose it (pp. 343–373). https://doi.org/10.1016/S0079-6123(02)38086-5

Taulbee, L. R., & Folsom, J. C. (1966). Reality Orientation for geriatric patients. *Psychiatric Services*, *17*(5), 133–135. https://doi.org/10.1176/ps.17.5.133

van Tilborg, I. A., Kessels, R. P., & Hulstijn, W. (2011). How should we teach everyday skills in dementia? A controlled study comparing implicit and explicit training methods. *Clinical Rehabilitation*, *25*(7), 638–648. https://doi.org/10.1177/0269215510396738

Wang, H., Karp, A., Winblad, B., & Fratiglioni, L. (2002). Decreased risk of dementia: A longitudinal study from the Kungsholmen Project. *American Journal of Epidemiology*, *155*(12), 1081–1087. https://doi.org/doi: 10.1093/aje/155.12.1081

Wey, S. (2006). 'Working in the zone'–a social-ecological framework for dementia rehabilitation. *Assistive Technology in Dementia Care, Hawker, London,* 85-103.

Wong, G. H. Y., Yek, O. P. L., Zhang, A. Y., Lum, T. Y. S., & Spector, A. (2018). Cultural adaptation of cognitive stimulation therapy (CST) for Chinese people with dementia: multicentre pilot study. *International Journal of Geriatric Psychiatry*, *33*(6), 841–848. https://doi.org/10.1002/gps.4663

Woods, B., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation therapy in dementia. *Aging & Mental Health*, *10*(3), 219–226. https://doi.org/10.1080/13607860500431652

Woods, B., Aguirre, E., Spector, A. E., & Orrell, M. (2012). Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, (2). https://doi.org/10.1002/14651858.CD005562.pub2

Yamanaka, K., Kawano, Y., Noguchi, D., Nakaaki, S., Watanabe, N., Amano, T., & Spector, A. (2013). Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial. *Aging & mental health*, *17*(5), 579–586. https://doi.org/10.1080/13607863.2013.777395

Yates, L. A., Leung, P., Orgeta, V., Spector, A., & Orrell, M. (2015). The development of individual cognitive stimulation therapy (iCST) for dementia. *Clinical interventions in aging, 10,* 95–104. https://doi.org/10.2147/CIA.S73844

Yates, L., Orrell, M., Leung, P., Spector, A. E., Woods, B., & Orgeta, V. (2014). Making a Difference 3: Individualised CST–A manual for carers.

Yates, L. A., Orgeta, V., Leung, P., Spector, A., & Orrell, M. (2016). Field-testing phase of the development of individual cognitive stimulation therapy (iCST) for dementia. *BMC Health Services Research, 16*. https://doi.org/10.1186/s12913-016-1499-y

Yates, L. A. (2016). *The development and evaluation of individual Cognitive Stimulation Therapy (iCST) for people with dementia* (Doctoral dissertation, UCL (University College London)).

Yeh, S. C. J., & Liu, Y.-Y. (2003). Influence of social support on cognitive function in the elderly. *BMC Health Services Research*, *3*(1), 9. https://doi.org/10.1186/1472-6963-3-9

Part Three: Critical Appraisal

3.1 Introduction

This appraisal describes the professional and personal experiences that led to my decision to research dementia and Cognitive Stimulation Therapy (Spector et al., 2003). It will also discuss the challenges encountered when conducting research in care homes, thoughts and recommendations generated whilst facilitating the intervention, and my own observations and feedback from staff and participants during the study.

3.2 My Background in Dementia Research

Prior to starting the Doctorate in Clinical Psychology, I worked as a Research Assistant in the North East London Foundation Trust. During this time, I visited many care homes across London conducting interviews with staff and people with dementia. I was struck by how often people with dementia could be found sitting in front of TV sets, or with music playing in otherwise empty rooms, with little apparent sense of enjoyment or interest in their surroundings. This was reinforced by personal experiences of visiting my relatives with dementia in care homes and finding them alone in front of TV sets watching shows they would find very difficult to understand. Though not true of all homes, this is in keeping with research that suggests people in care homes are under stimulated or not provided with appropriate activities (Knapp et al., 2006; Hancock, Woods, Challis & Orrell., 2006) and a study by Popham and Orrell (2012) which identified that people with dementia in care homes often felt bored, with families agreeing that people with dementia were under stimulated. In addition, I've often felt struck by vast differences in care homes, where some had daily activity and events, with efforts made to include and support those in more difficult tasks, whilst others appeared under-staffed with little to do each day other than watch television.

I had also previously worked with Aimee Spector during my undergraduate degree in Psychology. As part of my research, I familiarised myself with the Biopsychosocial model of dementia, for which a key feature is the idea of excess disability, defined as the difference between “possible” and “actual” functioning for people with dementia (Spector and Orrell, 2010). Importantly, the model describes fixed and tractable factors (those that can change), where attention to the tractable factors might work to reduce the level of excess disability. As such, it offers a perspective that is often not understood in dementia, which is the changeability and possibility for improvement in an otherwise progressive condition (Spector and Orrell, 2010). Within the psychosocial factors described in the model, mental stimulation plays a key role, and is similarly important in CST. Although findings in the original iCST study (Orrell et al. 2017) did not identify specific benefits to cognition or quality of life for people with dementia, this project appealed to me as the need for an intervention for people in care homes has been clear through my personal and academic experience. In addition, this project provided not only the opportunity to further develop an intervention that could provide a real sense of hope and enjoyment to people in care homes, but also to deliver that intervention as part of the research process.

3.3 Challenges in Care Home Research

Although recruitment was accomplished across a relatively short time, there were various difficulties we encountered, of which several have been raised in previous research within care home populations. For example, although recruitment was substantially benefitted by not requiring NHS ethical approval as most care homes are within the private sector, this also meant we were unable to collect additional demographics data including diagnosis and use of anticholinesterase inhibitors which has often been included in CST research (Aguirre et al. 2013; D'Amico et al. 2015; Orrell et al. 2014; Orrell et al. 2017). In future I would be keen to collect this information to better understand the factors affecting outcomes.

3.3.1 Identifying Care Homes

A recent review of research in long-term care facilities identified that administrators held mixed views about the value of research, for example some managers could be suspicious of the motives of researchers (Lam et al., 2018). During our recruitment phase, I experienced this with homes who quickly asked what the cost would be for us to deliver the intervention. Other homes simply reported they are not allowed to have research studies other than those conducted by their own organisation. As such, I found it helpful to speak with other researchers in this field as they were able to signpost me to care homes more open to research. Further, recruitment is shown to benefit from using existing relationships with care home staff, and further establishing trust between yourself and the home (Tzouvara, Papadopoulos & Randhawa, 2016, cited in, Wyld 2017). For example, the first home I recruited was one I had worked with as part of my undergraduate dissertation. However, once care homes were identified, the second difficulty encountered was whether they had enough suitable candidates for the study.

This was made more challenging by the typical number of residents in care homes across London. When I search for relevant care homes (e.g. carehome.co.uk), only approximately 50% of homes could be identified with more than 40 residents in London who had also identified dementia as one of their registered care categories. Further, only 28 homes were found with more than 100 residents. In addition, whilst the prevalence of people with dementia living in care homes has risen over the years (Matthews et al. 2013), it was also necessary for participants to have capacity to consent. This represented a much smaller percentage of residents, and some care homes found it difficult to identify any candidates they felt were suitable in this regard. These numbers were even more restricted by the locality of researchers and those delivering intervention. In hindsight, I would have better clarified inclusion criteria with managers prior to visiting homes. Past experience in care home research had also informed a need to over recruit, as the rate of attrition with older adults can be high due to ill health, other commitments, and sometimes mortality (Lam et al. 2018; Maas, Kelley, Park & Specht, 2002; Murfield, Cooke, Moyle, Shum & Harrison, 2011). For example, the three participants lost to follow-up in the current study related to ill health or a loss of capacity, and over recruiting may be helpful in future. Unfortunately, as this was a feasibility study as part of a doctoral thesis, we were more restricted in the number we could realistically consent to the study.

These barriers also suggest the need to sample from several care homes when conducting research. Whilst acceptable and necessary, this can create greater diversity in age, culture, and ethnicity across sites, which could lead to groups being more heterogeneous at baseline (Maas et al. 2002). Furthermore, different care homes offer vastly different schedules of activity and quality of care, for example measured by the Care Quality Commission, which is problematic in terms of defining TAU. As mentioned in the empirical study, it could be useful to systematically measure treatment as usual in care homes to ensure that this is not having a significant impact on findings. From a logistical perspective, sampling from several care homes can also be problematic and time-consuming for researchers in terms of travel and organisation of study visits.

3.3.2 Involvement of Staff

During the study it was important to thoroughly discuss the needs of the study in terms of managerial and staff involvement. In the first instance, I organised several meetings with managers to talk about aspects of the research. However, due to the demands on managers' time, they did not always disseminate this information to their teams. As a result, care home staff could misunderstand our inclusion criteria. For example, I was asked to speak with several participants with no diagnosis of dementia or history of memory complaints. Secondly, staff can be highly influential during recruitment, although it was important to ensure staff were not pressuring individuals to consent (Rapp, Topps-Uriri, & Beck. 1994, cited in Tripp-Reimer & Mentes, 2002). Whenever possible, the manager or a senior staff member introduced me to potential participants on my first visit to the home, which is common in studies but does require staff to do so in addition to their other responsibilities (Lam et al. 2018). This was helpful as when I subsequently returned to discuss the study, many individuals recognised me, even if they were unable to recall my role or name at the time. Once the intervention started, staff were also supportive in locating residents when it was time for their sessions. However, some participants were less physically able and therefore needed assistance from staff, in some instances use of a hoist. This meant I sometimes had to wait for appropriately trained staff, or relevant equipment, before I could meet with a participant.

Of note, care home staff are typically very busy, and often under high emotional and physical demands (Albers, Block & Stichele, 2014). As such, Tripp-Reimer and Mentes (2002) suggest building a good rapport and effective communication with staff is invaluable in research, and so it was helpful to get to know as many staff in the home as possible. This not only alleviated any suspicion of my role at the home but meant that I became familiar with the workings of the home and staff including their weekly schedules. It is also not unusual to reimburse care homes for their time and resources in supporting research and has been recommended by past research (Maas et al. 2002). In the current study, care homes were offered small monetary rewards relating to the number of participants taking part. This was well received, however a further incentive that was preferred by several homes was the offer of training after the end of the study. The World Alzheimer Report (2013) found that staff in care homes often desire further training, and this was reflected in both managers and carers expressing interest in CST during my time there. Further, carers in one home had approached me to ask how they might facilitate sessions themselves in future. In addition, the offer for professionals to provide potentially beneficial intervention to residents without cost to the care home was well received by managers.

One of the other difficulties encountered in care home research is concerns about staff practice. Hall, Longhurst and Higginson (2009) also recognised the benefits of staff involvement, but simultaneously found that staff could attempt to support research in ways that are less helpful. For example, they noticed that staff could introduce researchers in a way that emphasises the institution. I noticed this at one home, where a member of staff referred to me as the “UCL Psychiatrist” despite attempts to address this. This could confuse residents as to my role and required clarity on my part when meeting with residents to reassure them that my role was research oriented, and not a medical assessment or anything that would affect their day to day care.

3.3.4 Working with people with dementia

There were several factors I would keep in mind following this project. Firstly, the amount of time necessary for consenting people with dementia is often increased as compared to healthy participants in care. This was further increased by the length of the consent form, which may have been tiring or fatiguing for some participants. This meant that breaks were often needed to ensure participants could provide their full attention to the consent process and was still a potentially tiring process. Lam et al. (2018) identified several studies which reported that consenting individuals to research, including those with cognitive impairment, is challenging and time-consuming. This was often the case, especially with poorer cognitive function. In addition, Maas et al. (2002) identified that older adults can be sceptical of research, and not want to participate and this is potentially increased in dementia. Secondly, on a couple of occasions, I had to discuss with my supervisor about the appropriateness of a participant, and for one it was deemed that she would not be able to take part as she lacked capacity to consent. Hall et al. (2009) noted the difficulty of informed consent in a care home population and suggest having a set protocol for researchers on how to manage situations where participants appear unable to provide informed consent, or lack capacity to consent. In hindsight, this could be useful, for example if a larger study involves other researchers, especially if they are less familiar with dementia. Another helpful recommendation was to leave a card with details of your next research visit, alongside a photograph of the researcher to ensure recognition and clear information is available to participants, and to the care homes, especially for those receiving the intervention.

3.3.5 Challenges during the intervention

Both I and LF delivered the intervention as part of the study, and we had received training as part of the Doctorate in Clinical Psychology. Further, I had the opportunity to facilitate group CST as part of my placement in a memory service. In addition, the use of the iCST DVD (Yates et al. 2014) as a training tool provided a useful resource, especially for parts of the intervention such as orientation, which carers in the pilot of iCST had initially struggled with (Yates, Orgeta, Leung, Spector & Orrell, 2016). As such, the ideas and topics in sessions felt familiar, but facilitating it individually was a new experience. However, there were several challenges that arose during the course of the study.

Firstly, it could sometimes be a challenge finding a quiet space to conduct sessions. For most participants, sessions were conducted in their rooms, however, one care home initially insisted I keep residents' doors open. This created a potential issue of confidentiality during the sessions. This was addressed via discussion with the manager, and we established that residents taking part in the study also had capacity to decide on whether the door should be open or closed whilst I was there. Secondly, some participants did not want to move from a communal space to have their sessions which created a similar issue of privacy. For example, I made a compromise with one participant to move to a quieter corner of the room, but ensured she understood we would not have as much privacy. Another challenge was interruptions from care home staff, both during sessions and assessment. This is especially problematic for assessment, as they may sometimes interrupt list learning tasks, or other elements of memory tests. This was better managed where the managers had been more present in recruitment and made efforts to introduce me to all staff as we went through the home.

Other times, staff could interrupt to ask if a resident wanted to attend another activity. Though this only occurred a few times prior to my starting a session, it meant I sometimes had to be very flexible with when I delivered sessions.

At times, some participants could also feel concerned about their memory or their ability to complete activities as part of a session. When this occurred, reassurance was offered, and attempts made to re-direct to that sessions activity or asking whether they would prefer to try a different activity for that session. However, it may have been more helpful to enquire empathically and be more curious about their concerns. This may have helped us to establish if something could be done to better address these concerns as a potential barrier to willingness to engage and benefit from intervention.

3.4 Responses to the Study

3.4.1 Response to Measures

An essential part of the study process was assessments at the beginning and end of the study. Throughout, efforts were made to ensure participants felt comfortable, and it was reiterated at appropriate intervals that they could take a break. Hall et al. (2009) had observed that some residents enjoyed interviews and assessments in research. This was mirrored in our study, with several participants remarking at the questionnaires being interesting or ‘fun’. Conversely, others spoke about their ‘performance’ or hoping they did not ‘do too badly’. It was important to reassure participants that we want them to do the best they can, and that there was no ‘good or bad’. Additionally, assessments took longer than expected with several participants. This was sometimes due to tangents in conversations in between measures, and other times related to interruptions from carers. In addition, those more cognitively impaired seemed to take longer, particularly on measures of quality of life, for which answers are more subjective and involved more decision making.

There were also some difficulties relating to staff availability. The rates of staff turnover in care homes settings has been shown to complicate research processes (Tripp-Reimer & Mentes, 2002). Estimates suggest that staff turnover in adult social care is approximately 30.7 percent with rates increasing steadily over the past 6 years (Griffiths et al. 2017). It was necessary for staff to complete one proxy measure of quality of life (the outcome of which was assessed in LF's report). However, carers previously interviewed for outcome measures are sometimes no longer present at follow-up, although this can be due to changing work schedules. In shorter term research, changing work schedules is more of a concern, and it was not unusual that a different carer was the only available source for completing proxy measures at follow-up which could have impacted on outcomes.

3.4.2 Response to Sessions

Although we did not collect qualitative feedback on sessions in the current study, I made notes of some of the feedback from participants and care staff, that provided me with a sense of which sessions were most well received and how carers and managers felt about the intervention. Overall, the adherence to the study with no withdrawals from the iCST group suggests that the intervention was acceptable, but at times there was a sense that some sessions were more 'unusual' or less interesting for some participants. One participant fed back about a session "This is weird", but when I asked if we should do a different activity said that it was also interesting. Something I found particularly encouraging, was when staff in two of the care homes observed that individuals receiving iCST, who had previously stayed in their rooms most days, had started to socialise more with other residents and attend other activities. In particular, one man who tended to sit alone at dinners had started to sit next to another resident, speaking with her on a daily basis. Of interest, this is in keeping with findings from my literature review which identified that people with dementia sought further stimulation and engaged more with others following CST. This may be further supported by individuals having better recognition of abilities retained, rather than a focus on what is lost. More generally, several participants expressed sadness that the sessions were coming to an end.

My systematic review also raised several other benefits that are not typically picked up by quantitative outcomes. Future research would benefit from more qualitative perspectives both from the people with dementia, and from care home staff to capture these responses. For example, one carer was surprised when she asked a participant what the session had been about, and they recounted that we had been playing cards. This led to a suggestion that the carer could visit that person to play cards in future. This is in keeping with one of the key principles of CST, which is to maximise potential via stimulation and providing opportunities (Spector et al. 2006). As such, it may be that we were discovering the potential of individuals through the use of different activities, however it is also possible that the additional stimulation reduced level of excess disability (Spector & Orrell, 2010).

3.5 Recommendations for Sessions

Although the intervention is manualised, there is also an inherent level of flexibility and adjustment to each session for the individual. The literature review in Part I of the thesis highlighted how adaptability may be a key feature of CST, especially how it allows us to adjust content to match an individual's abilities and interest. As such, there were different ideas and suggestions that arose during course of the study. For example, there is a current affairs discussion at the start of every session and for several participants, articles in a daily newspaper may be too difficult or not of interest. For some, I found it helpful to have prepared simple articles beforehand, for example taking something from online news and tailoring the language to be more accessible. However, this does increase the time necessary to prepare for sessions.

For each session, I recognised the importance of bringing options and choice. Providing this choice may give an added sense of agency to your interactions and meant that it was possible to address issues of interest, or difficulty. For example, the physical capabilities of people with dementia varies significantly. Although there is a session called "Physical games", this can be anything from a game of Boule, to trying to keep a balloon in the air which can be done seated. We are also in an age where technology can provide us with so many options and ideas that can be added to sessions. The session on sounds and music is often a favourite and can really be heightened with the use of video which contributes to the multisensory approach. Research has shown that environments providing multisensory stimulation produce positive impact on behaviour and mood of people with dementia, and the use of multisensory stimuli in sessions may also be helpful in heightening the effects of the intervention (Sánchez, Millán-Calenti, Lorenzo-Lopéz & Maseda, 2013). Similarly, having childhood toys, images of better known celebrities when they were younger, and examples of old coins, seemed to really generate a sense of sense of reminiscence, which has been shown to be beneficial as it taps into what is most preserved in people with dementia (Morris, 1996).

3.6 Conclusions

This project has been very enjoyable but has also provided several lessons as a researcher. Firstly, it has highlighted the necessity of having a clear and practical protocol for the study. It has also re-affirmed some of the difficulties of care home research and emphasised the importance of getting care home staff engaged alongside your research. Secondly, I found it helpful to have developed the intervention ourselves, as it gave a better understanding of why each session was chosen and the thought process behind the content of those sessions. In addition, it has reinvigorated my sense of enjoyment and pleasure from working with people with dementia. Lastly, the verbal feedback we received alongside the findings of my systematic review have consolidated the need for qualitative research with people with dementia, as there is a wealth of information there that is missed if we only use quantitative outcomes in studying interventions.

3.7 References

Aguirre, E., Hoare, Z., Streater, A., Spector, A., Woods, B., Hoe, J., & Orrell, M. (2013). Cognitive stimulation therapy (CST) for people with dementia-who benefits most? *International Journal of Geriatric Psychiatry*, *28*(3), 284–290. https://doi.org/10.1002/gps.3823

Albers, G., Van den Block, L., & Vander Stichele, R. (2014). The burden of caring for people with dementia at the end of life in nursing homes: A postdeath study among nursing staff. *International Journal of Older People Nursing*, *9*(2), 106–117. https://doi.org/10.1111/opn.12050

D'Amico, F., Rehill, A., Knapp, M., Aguirre, E., Donovan, H., Hoare, Z., … Orrell, M. (2015). Maintenance Cognitive Stimulation Therapy: An Economic Evaluation Within a Randomized Controlled Trial. *Journal of the American Medical Directors Association*, *16*(1), 63–70. https://doi.org/10.1016/J.JAMDA.2014.10.020

Griffiths, D, Fenton, W, Polzin, G, Price, R, Arkesden, J, McCaffrey, R. (2018). Skills for Care, The state of the adult social care workforce in England, 2018, (September).

Hall, S., Longhurst, S., & Higginson, I. J. (2009). Challenges to conducting research with older people living in nursing homes. *BMC Geriatrics*, *9*(1), 1–6. https://doi.org/10.1186/1471-2318-9-38

Hancock, G. A., Woods, B., Challis, D., & Orell, M. (2006). The needs of older people with dementia in residential care. *International Journal of Geriatric Psychiatry*, *21*(1), 43–49. https://doi.org/10.1002/gps.1421

Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry*, *188*(6), 574–580. https://doi.org/10.1192/bjp.bp.105.010561

Lam, H. R., Chow, S., Taylor, K., Chow, R., Lam, H., Bonin, K., ... & Herrmann, N. (2018). Challenges of conducting research in long-term care facilities: a systematic review. *BMC geriatrics*, *18*(1), 242.

Lawrence, V., Fossey, J., Ballard, C., Moniz-Cook, E., & Murray, J. (2012). Improving quality of life for people with dementia in care homes: Making psychosocial interventions work. *British Journal of Psychiatry*, *201*(5), 344–351. https://doi.org/10.1192/bjp.bp.111.101402

Maas, M. L., Kelley, L. S., Park, M., & Specht, J. P. (2002). Issues in conducting research in nursing homes. *Western Journal of Nursing Research*, *24*(4), 373–389. https://doi.org/10.1177/01945902024004006

Mentes, J. C., & Tripp-Reimer, T. (2002). Barriers and facilitators in nursing home intervention research. *Western Journal of Nursing Research*, *24*(8), 918–936. https://doi.org/10.1177/019394502237702

Matthews, F. E., Arthur, A., Barnes, L. E., Bond, J., Jagger, C., Robinson, L., ... & Medical Research Council Cognitive Function and Ageing Collaboration. (2013). A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *The Lancet*, *382*(9902), 1405-1412.

Morris, R. G. (1996). *The Cognitive Neuropsychology of Alzheimer-type dementia*. New York, NY, US: Oxford University Press.

Murfield, J., Cooke, M., Moyle, W., Shum, D., & Harrison, S. (2011). Conducting randomized controlled trials with older people with dementia in long-term care: Challenges and lessons learnt. *International Journal of Nursing Practice*, *17*(1), 52–59. https://doi.org/10.1111/j.1440-172X.2010.01906.x

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., … Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: Single-blind, multicentre, pragmatic randomised controlled trial. *British Journal of Psychiatry, 204*(6), 454–461. https://doi.org/10.1192/bjp.bp.113.137414

Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., ... & Pearson, S. (2017). The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial. *PLoS medicine*, *14*(3), e1002269.

Popham, C., & Orrell, M. (2012). What matters for people with dementia in care homes? *Aging and Mental Health*, *16*(2), 181–188. https://doi.org/10.1080/13607863.2011.628972

Prince, M. J., Prina, M., & Guerchet, M. (2013). *World Alzheimer report 2013: Journey of caring: an analysis of long-term care for dementia*. Alzheimer's Disease International.

Rapp, C. G., Topps-Uriri, J., & Beck, C. (1994). Obtaining and maintaining a research sample with cognitively impaired nursing home residents. *Geriatric Nursing, 15,* 193-196.

Sánchez, A., Millán-Calenti, J. C., Lorenzo-López, L., Maseda, A. (2013). Multisensory stimulation for people with dementia: A review of the literature. *American Journal of Alzheimer's Disease & Other Dementias, 28*(1), 7-14.

Spector, A., Thorgrimsen, L., Woods, R. T., & Orrell, M. (2006). *Making a difference: an evidence-based group programme to offer Cognitive Stimulation therapy (CST) to people with dementia*. Hawker Publications.

Spector, A., Thorgrimsen, L., Woods, B. O. B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *The British Journal of Psychiatry*, *183*(3), 248-254.

Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. *International Psychogeriatrics*, *22*(6), 957–965. https://doi.org/10.1017/s1041610210000840

Tzouvara, V., Papadopoulos, C., & Randhawa, G. (2016). Lessons learned from recruiting nursing homes to a quantitative cross-sectional pilot study. *Nurse researcher*, *23*(4).

Wyld, J. (2017). The experiences of participants in care home research.

Yates, L. A., Orgeta, V., Leung, P., Spector, A., & Orrell, M. (2016). Field-testing phase of the development of individual cognitive stimulation therapy (iCST) for dementia. *BMC Health Services Research*, *16*(1), 1–11. https://doi.org/10.1186/s12913-016-1499-y

Yates, L., Orrell, M., Leung, P., Spector, A. E., Woods, B., & Orgeta, V. (2014). Making a Difference 3: Individualised CST–A manual for carers.

Appendices

Appendix A – Search Terms: January 2019

Source	Search Strategy	Articles retrieved
PsychINFO	1. exp VASCULAR DEMENTIA/ or exp DEMENTIA/ or exp SEMANTIC DEMENTIA/ or exp PRESENILE DEMENTIA/ or exp DEMENTIA WITH LEWY BODIES/ or exp SENILE DEMENTIA/ 2. exp Delirium/ 3. exp alzheimer's disease/ 4. exp cognitive impairment/ 5. dement*.mp 6. Alzheimer*.mp 7. Cognitive stimulation therapy.mp 8. CST.mp 9. 7 or 8 10. or/1-6 11. 9 and 10	106
MEDLINE	1. Exp Dementia/ 2. Alcoholic Korsakoff syndrome/ or huntington disease/ or cognitive dysfunction/ 3. Dement*.mp 4. Alzheimer*.mp 5. Exp Parkinsonian Disorders/ 6. Parkinson*.mp 7. Cognitive Stimulation Therapy.mp 8. CST.mp 9. 7 or 8 10. Or/1-6 11. 9 and 10	496
EMBASE	1. Exp HIV associated dementia/ or exp multiinfarct dementia/ or exp semantic dementia/ or exp Pick presenile dementia/ or exp presenile dementia/ or exp dementia/ or exp frontotermporal dementia/ 2. Cognitive defect/	157

	3. Dement*.mp 4. Alzheimer*.mp 5. Vascular.mp 6. Parkinson disease/ 7. “supranuclear palsy”.mp 8. Parkinson*.mp 9. Cognitive stimulation therapy.mp 10. CST 11. Or/1-8 12. 9 or 10 13. 11 and 12	
CINAHL	1. MH “Dementia +” 2. TX dement* 3. TX Alzheimer* 4. (MH “Delirium”) OR (MH “Delirium, Dementia, Amnestic, Cognitive Disorders”) 5. TX cognitive impairment 6. TX lewy* N2 bod* 7. TX deliri* 8. TX Parkinson* 9. “cognitive stimulation therapy” 10. TX cognitive stimulation therapy 11. “CST”	126
WebOfScience	TOPIC:((dement* OR alzheimer* OR "lew* bod*" OR deliri* OR parkinson*)) ANDTOPIC: ((CST OR "cognitive stimulation therapy")) Timespan: All years. Indexes: SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC.	221

Appendix B. Quality appraisal tool based on Critical Appraisal Skills Programme Qualitative Checklist (CASP-QC) (2018)

Criterion	Guiding questions
1. Was there a clear statement of the aims of the research?	• What was the goal of the research • Why it was thought important • It's relevance
2. Is a qualitative methodology appropriate	• If the research seeks to interpret or illuminate actions or subjective experience of research participants • Is qualitative research the right methodology for addressing the research goal
3. Was the research design appropriate to address the aims of research	• If the researcher has justified the research design • Have they discussed how they decided on the method
4. Was the recruitment strategy appropriate to the aims of the research?	• If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part)
5. Was the data collected in a way that addressed the research issue?	• If the setting for the data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) • If methods were modified during the study. If so, has the researcher explained how and why

	• If the form of data is clear (e.g. tape recordings, video material, notes etc.) • If the researcher has discussed saturation of data
6. Has the relationship between researcher and participants been adequately considered?	• If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
7. Have ethical issues been taken into consideration?	• If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee
8. Was the data analysis sufficiently rigorous?	• If there is an in-depth description of the analysis process • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • If sufficient data are presented to support the findings • To what extent contradictory data are taken into account • Whether the researcher critically examined their own role, potential bias and influence

	during analysis and selection of data for presentation
9. Is there a clear statement of findings?	• If the findings are explicit • If there is adequate discussion of the evidence both for and against the researcher’s arguments • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question
10. How valuable is the research?	• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C. Participant Information Sheets and Consent Forms

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	Lycia Forde
Trainee Clinical Psychologist	Trainee Clinical Psychologist
[redacted]	[redacted]
[redacted]	[redacted]

Name and Contact Details of the Principal Researcher:

Dr Aimee Spector
[redacted]
[redacted]

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@ucl.ac.uk.

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

14. Contact for further information

For more information about this research, please contact:

Luke Gibbor
[redacted]

Lycia Forde
[redacted]

Or the principal investigator:

Dr Aimee Spector
1-19 Torrington Place
London
WC1E 7HB
[redacted]

If you agree to take part in the study, you will be given a copy of the information sheet and signed consent form to keep.

Thank you for reading this information sheet and for considering to take part in this research study.

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	Lycia Forde
Trainee Clinical Psychologist	Trainee Clinical Psychologist
[redacted]	[redacted]
[redacted]	[redacted]

Name and Contact Details of the Principal Researcher:

Dr Aimee Spector
[redacted]
[redacted]

Name and Contact Details of the UCL Data Protection Officer:

Lee Shailer
[redacted]

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 mean 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*)* - 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.	**Use of the information for this project only** 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. 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.	
5.	I understand that my anonymised information may be subject to review by responsible individuals from the University or monitoring and audit purposes.	

6.	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. 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.	
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 be 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.	I hereby confirm that: (a) I understand the exclusion criteria as detailed in the Information Sheet and explained to me by the researcher; and (b) I do not fall under the exclusion criteria.	
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.	**Use of information for this project and beyond**	

	I would be happy for the data I provide to be archived at University College London for a period of up to 5 years. I understand that other authenticated researchers will have access to my anonymised data.	

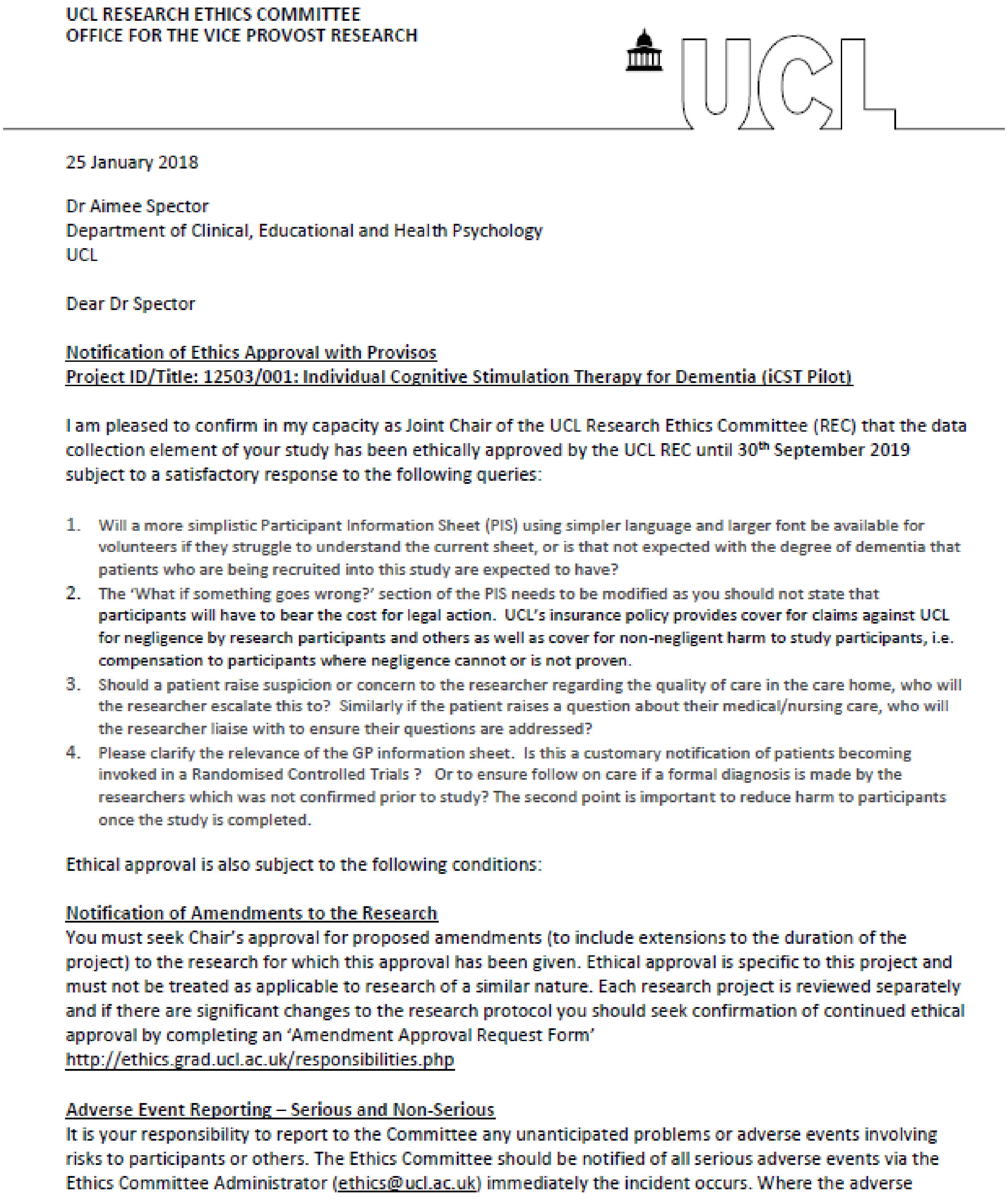
Name of Participant Date Signature

____________________ _____________ ___________________

Researcher Date Signature

____________________ _____________ ___________________

Appendix D. Ethics Approval Letter



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.

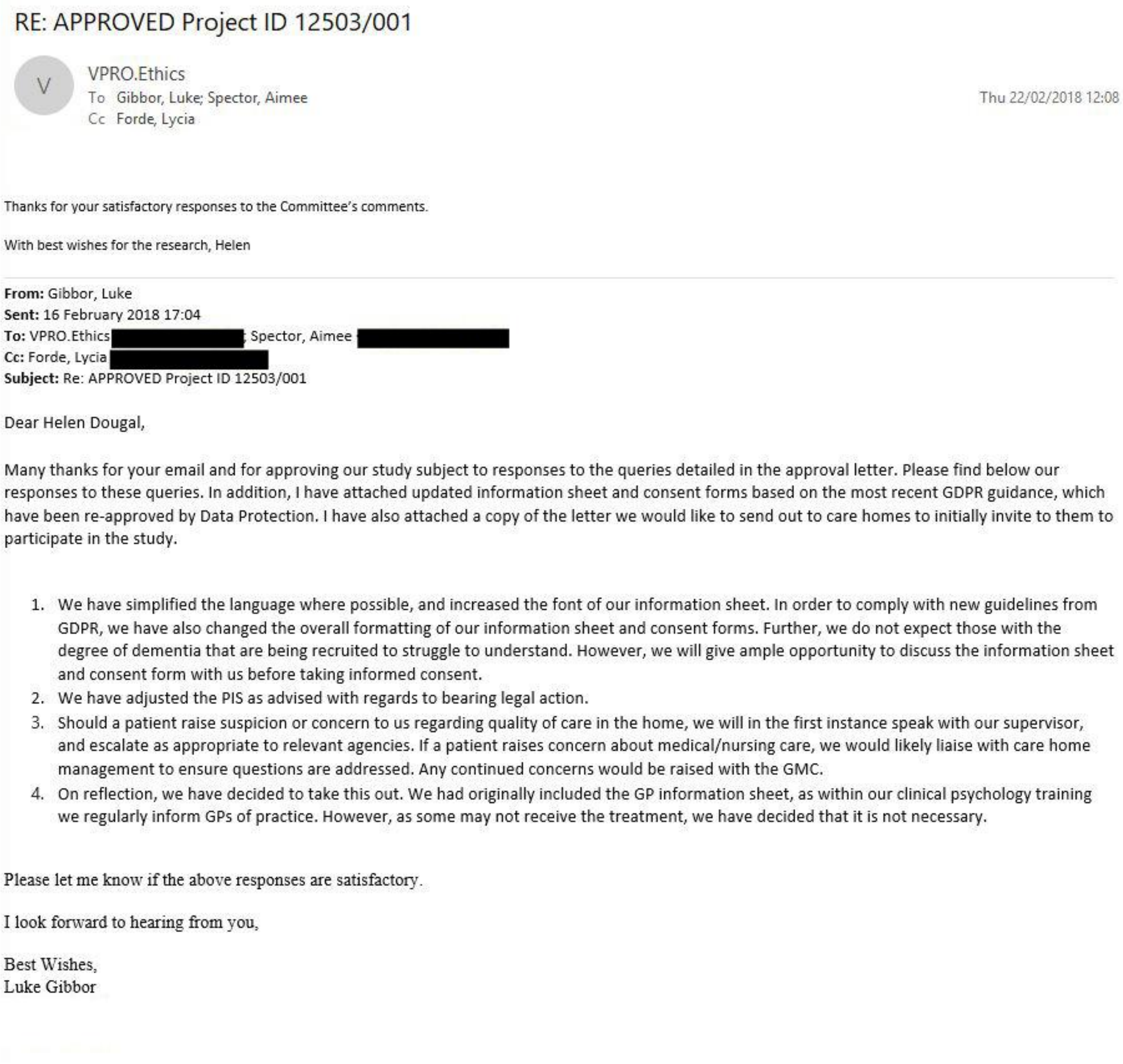
With best wishes for the research.

Yours sincerely

[redacted]

Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Luke Gibbor and Lycia Forde



RE: APPROVED Project ID 12503/001

V

VPRO.Ethics
To Gibbor, Luke; Spector, Aimee
Cc Forde, Lycia

Thu 22/02/2018 12:08

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

With best wishes for the research, Helen

From: Gibbor, Luke
Sent: 16 February 2018 17:04
To: VPRO.Ethics [redacted]; Spector, Aimee [redacted]
Cc: Forde, Lycia [redacted]
Subject: Re: APPROVED Project ID 12503/001

Dear Helen Dougal,

Many thanks for your email and for approving our study subject to responses to the queries detailed in the approval letter. Please find below our responses to these queries. In addition, I have attached updated information sheet and consent forms based on the most recent GDPR guidance, which have been re-approved by Data Protection. I have also attached a copy of the letter we would like to send out to care homes to initially invite to them to participate in the study.

1. We have simplified the language where possible, and increased the font of our information sheet. In order to comply with new guidelines from GDPR, we have also changed the overall formatting of our information sheet and consent forms. Further, we do not expect those with the degree of dementia that are being recruited to struggle to understand. However, we will give ample opportunity to discuss the information sheet and consent form with us before taking informed consent.
2. We have adjusted the PIS as advised with regards to bearing legal action.
3. Should a patient raise suspicion or concern to us regarding quality of care in the home, we will in the first instance speak with our supervisor, and escalate as appropriate to relevant agencies. If a patient raises concern about medical/nursing care, we would likely liaise with care home management to ensure questions are addressed. Any continued concerns would be raised with the GMC.
4. On reflection, we have decided to take this out. We had originally included the GP information sheet, as within our clinical psychology training we regularly inform GPs of practice. However, as some may not receive the treatment, we have decided that it is not necessary.

Please let me know if the above responses are satisfactory.

I look forward to hearing from you,

Best Wishes,
Luke Gibbor

Appendix E. Cognition measures used at baseline and follow-up
Standardised MMSE

Time to administer this test is approximately 10 minutes. The total possible score is 30 points. If participant scores below 10 at **baseline assessment**, the individual is not suitable for participation in this study. Please stop testing at this point.

Say: **"I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can."**

1. Allow ten seconds for each reply (each question is one mark). Say:
   - **a) What year is this?** (accept exact answer only)
   - **b) What season is this?** (during last week of old season or first week of new season, accept either)
   - **c) What month is this?** (on first day of a new month or last day of previous, accept either)
   - **d) What is today's date?** (accept previous or next date)
   - **e) What day of the week is this?** (accept exact answer only)

Score 0-5 ☐

2. Allow ten seconds for each reply (each question is one mark). Say:
   - **a) What country are we in?** (accept exact answer only)
   - **b) What state/county are we in?** (accept exact answer only)
   - **c) What city/town are we in?** (accept exact answer only)
   - **d) <At home> What is the street address of this house?** (accept street name and house number or equivalent in rural areas)
     <In facility> What is the name of this building? (accept exact name of institution only)
   - **e) <At home> What room are we in?** (accept exact answer only)
     <In facility> What floor of the building are we on? (accept exact answer only)

Score 0-5 ☐

3. "I am going to name three objects. When I am finished, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes (say slowly at approximately one-second intervals)."

Ball Car Man
For repeated use: Bell, Jar, Fan; Bill, Tar, Can; Bull, Bar, Pan

Please repeat the three items for me (score one point for each correct ply on first attempt)
Allow 20 seconds for reply; if the person did not repeat all three, repeat until they are learned or up to a maximum of five times (but only score the first attempt).

______________ ______________ ______________

Score 0-3 ☐

4. "Spell the word WORLD" (you may help the person to spell the word correctly). Then say, **"Now spell it backwards please."** Allow 30 seconds. If the person cannot spell world even with assistance, score zero. Refer to accompanying guide for scoring instructions.

Score 0-5 ☐

5. "Now what were the three objects I asked you to remember?" (score one point for each correct response regardless of order; allow ten seconds)

_____________ ______________ ______________

Score 0-3 ☐

6. Show wristwatch (**not on your wrist**) and ask, **"What is this called?"**
(Score one for correct response; accept 'wristwatch' or 'watch'; do not accept 'clock' or 'time'. Allow ten seconds.)
Show a pencil, and ask **"What is this called?"**
(Score one point for correct response; accept 'pencil' only; score zero for pen; Allow ten seconds for reply)

Score 0-2 ☐

7. "I would like you to repeat a phrase after me. Ready?" Say, **"No ifs, ands, or buts."** (Make sure you pronounce this clearly. Score one point for a correct repetition, which must be exact).

Score 0-1 ☐

8. “Read the words on this page and then do what it says”
Then, **hand** the person the sheet with **CLOSE YOUR EYES** (see page 5).If the subject just reads and does not close their eyes, you **may repeat**: **“Read the words on this page and then do what it says,”** a maximum of **three times**. (Allow ten seconds, score one point if person closes eyes. They do not need to read aloud.)

Score 0-1 ☐

9. Hand the person a pencil and paper. Say, **“Write any complete sentence on that piece of paper.”** (Allow 30 seconds. Score one point, and sentence must make sense. Ignore spelling errors).

Score 0-1 ☐

10. Place design (see page 5), pencil, eraser and paper in front of person. Say **“Copy this design please.”** Allow multiple tries.
Wait until finished and hands it back. One point for a correct diagram (See manual). Person must have drawn four-sided figure between two five-sided figures. Maximum time: One minute.

Score 0-1 ☐

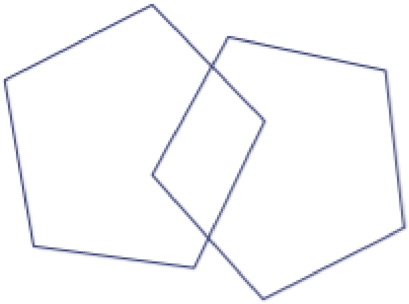
11. Ask the person if they are right or lefthanded. Take a piece of paper, hold it up in front of them and say, **“Take this paper in your right/left hand (non-dominant), fold the paper in half once with both hands, and put the paper down on the floor**.”

Took paper in correct hand _____________
Folds it in half ____________
Puts it on the floor ____________

Score 0-3 ☐

``

TOTAL SCORE ☐☐
s(out of 30)



Time:

D	L	R	O	W

= ☐

CLOSE YOUR EYES

ADAS-COG

1. WORD RECALL. The subject is given 3 trials to learn a list of 10 words. The patient reads the 10 words exposed for 2 seconds each. The patient then recalls the words aloud. A total of **3 trials** of reading and recall are given. At the start of the first trial, give the following instructions: **"I am going to show you some words, printed on these white cards one at a time. Please read each word out loud and try to remember it, because later I will ask you to try to remember all of the words I have shown you. Ready, read the word and try to remember it".** After the presentation, ask the subject to try to recall as many of the words as possible by saying: **"Good, now tell me all the words you remember that were on the list".** For trials 2 and 3, say: **"Now I'm going to show you that same list again. Read each word out loud and try to remember it".**

Trial 1			**Trial 2**			**Trial 3**		
	Recalled	**Not Recalle**		**Recalled**	**Not Recalled**		**Recalled**	**Not Recalled**
Home	☐	☐	Skin	☐	☐	Railroad	☐	☐
Coin	☐	☐	Child	☐	☐	Ocean	☐	☐
Railroad	☐	☐	Wheat	☐	☐	Flag	☐	☐
Child	☐	☐	Library	☐	☐	Army	☐	☐
Army	☐	☐	Home	☐	☐	Wheat	☐	☐
Flag	☐	☐	Ocean	☐	☐	Child	☐	☐
Skin	☐	☐	Railroad	☐	☐	Coin	☐	☐
Library	☐	☐	Flag	☐	☐	Skin	☐	☐
Wheat	☐	☐	Coin	☐	☐	Home	☐	☐
Ocean	☐	☐	Army	☐	☐	Library	☐	☐

TOTAL NOT RECALLED ☐☐ **TOTAL NOT RECALLED** ☐☐ **TOTAL NOT RECALLED** ☐☐

Score = mean number of words <u>not</u> recalled on three trials (maximum score = 10)

☐☐

2. NAMING OBJECTS AND FINGERS

The subject is asked to name 12 randomly presented real objects. Give the subject the following instructions: **"Now I am going to show you some objects. I want you to tell me what their names are. What is this called? or What is the name of this thing?"**. If the subject does not respond, the examiner should give the clue for that item provided below. If the subject still does not respond or makes an error, go on to the next object.

ITEM CLUES	**Correct**	**Incorrect (or not named)**
Flower – (grows in a garden)	☐	☐
Bed – (used for sleeping in)	☐	☐
Whistle – (makes a sound when you blow on it)	☐	☐
Pencil – (used for writing)	☐	☐
Rattle – (a baby's toy)	☐	☐
Mask – (hides your face)	☐	☐
Scissors – (cuts paper)	☐	☐
Comb – (used on hair)	☐	☐

Wallet – (holds your money)	☐	☐
Harmonica – (a musical instrument)	☐	☐
Stethoscope – (doctor uses it to listen to your heart)	☐	☐
Tweezers – (used to pick up things)	☐	☐

Total Incorrect (maximum 12) ☐☐

The subject is also asked to name the fingers of his/her dominant hand (e.g. thumb, index [pointer/forefinger], middle, ring finger, and little finger/pinky). Give the subject the following instructions: **"Now I am going to point to a part of your hand and I want you to tell me what it's called. What is this? or What is another name for this finger?".**

Item	**Correct**	**Incorrect (or not named)**
Thumb	☐	☐
Index/forefinger/pointer	☐	☐

Middle	☐ ☐
Ring	☐ ☐
Little finger/Pinky	☐ ☐

Total Incorrect
(maximum 5) ☐☐

Score

- **0 0-2 items (objects and fingers) named incorrectly**
- **1 3-5 items (objects and fingers) named incorrectly**
- **2 6-8 items (objects and fingers) named incorrectly**
- **3 9-11 items (objects and fingers) named incorrectly**
- **4 12-14 items (objects and fingers) named incorrectly**
- **5 15-17 items (objects and fingers) named incorrectly**

Score ☐
(maximum 5)

3. COMMANDS

The subject is asked to carry out 5 separate commands with 1 to 5 steps per command. Each command should be read once. If the subject does not respond or makes an error, give the ENTIRE command one more time. Give the following instructions**: "Now I am going to ask you to do a few things. First, … "Make a *FIST*", "Point to the *CEILING* and then to the *FLOOR*".** Line up a Pencil, Watch, and Card on the table. Say: **"Put the *PENCIL ON TOP OF THE CARD* and then *PUT IT BACK*". "Put the *WATCH* on the *OTHER SIDE OF THE PENCIL* and then *TURN OVER THE CARD*".** Remove items and say: **"*TAP EACH SHOULDER TWICE* with *TWO FINGERS* keeping your *EYES SHUT*".** All components must be correct for the response to be scored as correct.

	Correct	**Incorrect (or not performed)**
Make a fist	☐	☐
Point to the ceiling and then to the floor	☐	☐
Line up a pencil, watch, and card, on the table		
Put the pencil on top of the card and then put it back	☐	☐
Put the watch on the other side of the pencil and then turn over the card	☐	☐
Tap each shoulder twice, with two fingers, keeping your eyes shut	☐	☐

Score

0 All commands correct
1 1 command incorrect, 4 commands correct
2 2 commands incorrect, 3 commands correct
3 3 commands incorrect, 2 commands correct
4 4 commands incorrect, 1 command correct
5 All 5 commands incorrect

SCORE (maximum 5) ☐

4. CONSTRUCTIONAL PRAXIS

Give the subject the following instructions: **"On this piece of paper is a shape. Try to draw another one that looks just like this, somewhere on the page"** and (if required) **"Take your time and try to draw it just like this one"".** The subject should be allowed <u>two attempts</u> for each shape.

	Correct	**Incorrect**
Circle	☐	☐
Two Overlapping Rectangles	☐	☐
Diamond (Rhombus)	☐	☐
Cube	☐	☐

<u>Score</u>

0	**All 4 drawings correct**
1	**1 form drawn incorrectly**
2	**2 forms drawn incorrectly**
3	**3 forms drawn incorrectly**
4	**4 forms drawn incorrectly**
5	**No figures drawn, scribbles; parts of forms; words instead of forms**

SCORE
(maximum 5) ☐

5. IDEATIONAL PRAXIS

Give the subject the following instructions: **"I want you to pretend you have written yourself a letter. Take this piece of paper, <u>fold it</u> so that it will fit into the envelope, and then <u>put it into the envelope.</u> Then, <u>seal the envelope, address the envelope to yourself,</u> and <u>show me where the stamp goes"</u>.** There are 5 components to this task and each one is underlined in the instructions.

After the first complete instruction only one additional reminder should be given for each component, if the subject forgets or is having difficulty.

	Correct	**Incorrect (or not done)**
Fold the letter	☐	☐
Put the letter in envelope	☐	☐
Seal the envelope	☐	☐
Address the envelope (make note of if there is a name, street, city) (**KEEP ENVELOPE** if uncertain)	☐	☐
Indicate where the stamp goes (put stamp on envelope)	☐	☐

<u>Score</u>

0 All components performed correctly
1 Failure to perform 1 component
2 Failure to perform 2 components
3 Failure to perform 3 components
4 Failure to perform 4 components
5 Failure to perform 5 components

SCORE (maximum 5) ☐

6. ORIENTATION

The components of orientation are **person, day of the week, date, month, year, season, time of day, place**. Make sure no watches, clocks, calendars, etc. are visible to the subject. One restatement of question is allowed (*e.g.* if subject confuses day and date).

Item	**Correct**	**Incorrect (or not given)**
Full name	☐	☐
Day of the Week	☐	☐
Date	☐	☐
Month	☐	☐
Year	☐	☐
Season	☐	☐
Time of Day	☐	☐
Place	☐	☐

SCORE (maximum 8) ☐

Score = 1 point is given for each incorrect response

Acceptable answers include: Date: +/- one day, Time: +/- one hour, Place: Partial name acceptable (e.g., name of hospital, clinic, or professional building), Season: Within one week prior to onset or within two weeks of termination. Month, Year, Day of the Week, and the subject's first and last name must be exact.

7. WORD RECOGNITION

Give the subject the following instructions: **“I am going to show you some words printed on these white cards. I want you to read each word out loud and try to remember it”.** Continue with the following instructions: **“Now I’m going to show you another set of words. Some of the words were on the list I just showed you, and others are new. For each word, I want you to tell me whether it is one of the words I just showed you”.**

Then say: **“Is this one of the words I showed you before, yes or no?”** or **“Did I show you this word before?”** or **“How about this one?”**

If the subject does not remember the task (e.g., reads the word rather than responding “Yes” or “No”), then repeat or rephrase the entire question and make a note that the subject had to be reminded of the task instructions. The score equals the mean number of incorrect responses for the **3 trials** (maximum = 12).

Go through recognition stimuli (pack of 12) before each recognition trial.

Trial 1: score		**Reminders**	
Trial 2: score		**Reminders**	
Trial 3: score		**Reminders**	
Score (mean number of incorrect responses for three trials) (max =		**Total Reminders (for scoring item 8)**	

WORD RECOGNITION

Bold words are the words shown before. Italicized words are the words that the subject has not seen. Tick the subject’s responses; circles = incorrect responses.

TRIAL 1				TRIAL 2				TRIAL 3			
	Yes	No	Rem		Yes	No	Rem		Yes	No	Rem
Corn	○	☐	☐	**River**	☐	○	☐	*Plant*	○	☐	☐
Effort	○	☐	☐	*Officer*	○	☐	☐	**River**	☐	○	☐
Party	○	☐	☐	*Thought*	○	☐	☐	*Amount*	○	☐	☐
River	☐	○	☐	**Event**	☐	○	☐	**Event**	☐	○	☐
Folly	○	☐	☐	**Queen**	☐	○	☐	**Queen**	☐	○	☐
Locker	○	☐	☐	**Position**	☐	○	☐	*Industry*	○	☐	☐
Event	☐	○	☐	*Camp*	○	☐	☐	**Position**	☐	○	☐
Queen	☐	○	☐	*Fate*	○	☐	☐	*Occasion*	○	☐	☐
Position	☐	○	☐	*Golf*	○	☐	☐	**Dove**	☐	○	☐
Quality	○	☐	☐	**Dove**	☐	○	☐	*Cradle*	○	☐	☐
Sunset	○	☐	☐	**Belief**	☐	○	☐	*Banality*	○	☐	☐
Dove	☐	○	☐	*Permission*	○	☐	☐	*Singer*	○	☐	☐
Belief	☐	○	☐	**Umbrella**	☐	○	☐	**Belief**	☐	○	☐
Umbrella	☐	○	☐	**Hint**	☐	○	☐	**Umbrella**	☐	○	☐
Allegory	○	☐	☐	**Missile**	☐	○	☐	*Hypothesis*	○	☐	☐
Hound	○	☐	☐	*Blister*	○	☐	☐	**Hint**	☐	○	☐
Idiom	○	☐	☐	*Concept*	○	☐	☐	**Missile**	☐	○	☐
Hint	☐	○	☐	**Proxy**	☐	○	☐	**Proxy**	☐	○	☐
Missile	☐	○	☐	*Pianist*	○	☐	☐	*Noose*	○	☐	☐
Gem	○	☐	☐	**Lobster**	☐	○	☐	*Distinction*	○	☐	☐
Proxy	☐	○	☐	*Gender*	○	☐	☐	**Lobster**	☐	○	☐
Lobster	☐	○	☐	**Criterion**	☐	○	☐	*Tank*	○	☐	☐
Criterion	☐	○	☐	*Bullet*	○	☐	☐	**Criterion**	☐	○	☐
Deceit	○	☐	☐	*Intellect*	○	☐	☐	*Decree*	○	☐	☐
Total circles ticked (incorrect responses)				Total circles ticked (incorrect responses)				Total circles ticked (incorrect responses)			

8. REMEMBERING TEST INSTRUCTIONS

On each recognition trial, the subject is asked prior to presentation of the first two words**: “Did I show you this word before or is this a new word?”**. For the third word, the subject is asked: **“How about this one?”.** The procedure used for the third word is repeated for words 4-24. Each instance of memory failure for the test instructions is noted.

Score: 0 = Subject never needs extra reminders of instructions

1 = Very mild – forgets once

2 = Mild – must be reminded 2 times

3 = Moderate – must be reminded 3 or 4 times

4 = Moderately severe – must be reminded 5 or 6 times

5 = Severe – must be reminded 7 or more times

SCORE (maximum 5) ☐

9. SPOKEN LANGUAGE ABILITY

This item is a global rating of the quality of speech, *i.e.*, clarity, difficulty in making oneself understood. In rating this item the tester should consider all of the speech produced by the subject during the test session. Quantity of speech and word finding difficulty are not rated on this item.

Score: 0 = No instances where it is difficult to understand the subject

1 = Very mild – one instance of lack of understandability

2 = Mild – subject has difficulty less than 25% of the time

3 = Moderate – subject has difficulty 25-50% of the time

4 = Moderately severe – subject has difficulty more than 50% of the time

5 = Severe – one or two word utterance; fluent, but empty speech; mute

SCORE (maximum 5) ☐

10. WORD-FINDING DIFFICULTY IN SPONTAENEOUS SPEECH

Along with Spoken Language Ability, this item rates impairment in expressive speech, but it rates ***only word finding difficulty***. To rate this item, the tester must determine whether the subject has difficulty in finding the desired word in spontaneous speech. The problem may be overcome by circumlocution, *i.e.* giving explanatory phrases or nearly satisfactory synonyms. Do not include finger and object naming in this rating.

Score: 0 = No evidence of word finding difficulty in spontaneous speech

1 = Very mild – 1 or 2 instances, not clinically significant

2 = Mild – noticeable circumlocution or synonym substitution

3 = Moderate – loss of words without compensation on occasion

4 = Moderately severe – frequent loss of words without compensation

5 = Severe – near total loss of content of words; speech sounds empty;

1-2 word utterances

SCORE(maximum 5) ☐

11. COMPREHENSION

This item rates the subject's ability to understand speech. To rate this item, the tester considers how well the subject was able to understand the tester's speech during the opening discussion and during the test session. Do not include responses to commands.

Score: 0 = No evidence of poor comprehension

1 = Very mild – 1 or 2 instances of misunderstanding

2 = Mild – 3-5 instances of misunderstanding

3 = Moderate – requires several repetitions and rephrasing

4 = Moderately severe – subject only occasionally responds correctly, *i.e.*, yes/no questions

5 = Severe – subject rarely responds to questions appropriately, not due to poverty of speech

SCORE (maximum 5) ☐

12. CONCENTRATION/DISTRACTABILITY

This item rates the frequency with which the patient is distracted by irrelevant stimuli and/or must be reoriented to the ongoing task because of loss of train of thought or the frequency with which the patient appears to be caught up in his or her own thoughts.

Score:

0 = No evidence of poor concentration or distractibility

1 = Very mild; one instance of poor concentration

2 = Mild; 2-3 instances of poor concentration/distractibility; signs of restlessness and inattentiveness

3 = Moderate; 4-5 instances during interview

4 = Moderately severe; poor concentration/distractibility throughout much of interview

5 = Severe; extreme difficulty in concentration and extremely distractible, unable to complete tasks

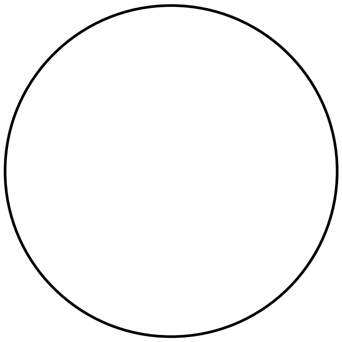
SCORE(maximum 5) ☐

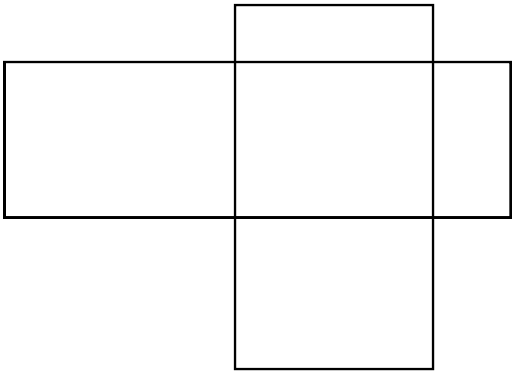
ADAS-COG SCORE SUMMARY SHEET

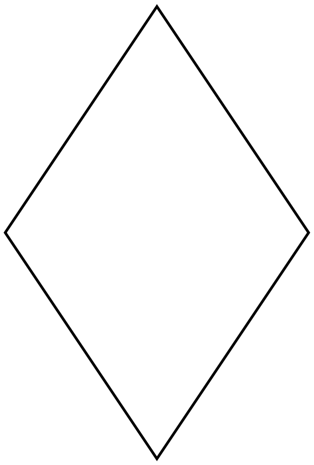
1. WORD RECALL (maximum 10)	☐☐
2. NAMING OBJECTS AND FINGERS (maximum 5)	☐☐
3. COMMANDS (maximum 5)	☐☐
4. CONSTRUCTIONAL PRAXIS (maximum 5)	☐☐
5. IDEATIONAL PRAXIS (maximum 5)	☐☐
6. ORIENTATION (maximum 8)	☐☐
7. WORD RECOGNITION TASK (maximum 12)	☐☐
8. REMEMBERING TEST INSTRUCTIONS (maximum 5)	☐☐
9. SPOKEN LANGUAGE ABILITY (maximum 5)	☐☐
10. WORD FINDING DIFFICULTY (maximum 5)	☐☐
11. COMPREHENSION (maximum 5)	☐☐
12. CONCENTRATION/DISTRACTABILITY (maximum 5)	☐☐

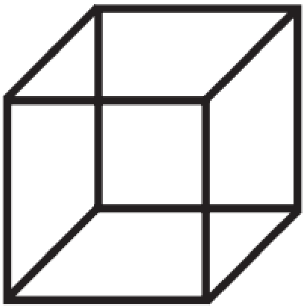
TOTAL SCORE (maximum 75) ☐☐

Constructional Praxis Stimuli









Appendix F. Individual Cognitive Stimulation Therapy for Dementia 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 of iCST (as per Making a Difference 3: Individual CST – A Manual for Carers (Yates et al. 2014).

1. Mental Stimulation

2. Developing new ideas, thoughts and associations

3. Using orientation in a sensitive manner

4. Focusing on opinions rather than facts

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

6. Providing triggers to support memory

7. Stimulate language and communication

8. Stimulate everyday planning ability

9. Using a 'Person-centred' approach

10. Offering a choice of activities

11. Enjoyment and fun

12. Maximising potential

13. Strengthening the relationship by spending quality time together

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?

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 the 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 their 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 below.

- 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 is 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

<u>LEVEL A</u>

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.

<u>LEVEL B</u>

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 categorises 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

<u>LEVEL A</u>

- 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 picket 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?

<u>LEVEL B</u>

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.

<u>LEVEL A & B</u>

- 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 G. Statement of contributions from trainees involved in the project

Luke Gibbor (LG) and Lycia Forde (LF) were jointly and individually responsible for different aspects of the thesis. Additionally, other researchers were involved during this work and their contributions summarised below.

Task	Contributor
Design of the empirical study	LG and LF
Ethics application	LG and LF
Design of the intervention	LG and LF, with consultation with Professor Aimee Spector (internal supervisor) and Dr Lauren Yates (external supervisor)
Recruitment	LG recruited 18 participants LF recruited 11 participants
Delivery of iCST	LG and LF each delivered iCST to seven participants
Creation of assessment packs	LG created document for assessment LG and LF assembled packs and assessment tools
Assessments	LG and LF jointly responsible Assisted by research assistants including Stavros Orfanos (Trainee Clinical Psychologist)
Data entry	LG
Analysis	LG completed analysis of cognitive measures LF completed analysis of quality of life and psychological wellbeing measures
Literature review quality checklist	LG and Anna Volkmer (Speech and Language Therapist)