Communication training programmes and virtual cognitive stimulation therapy (vCST) for people living with dementia and their caregivers

Luke Perkins

D. Clin. Psy. Thesis (Volume 1), 2021

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

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

Signature:

Name: Luke Perkins

Date: 18/06/2021

Overview

This thesis was originally intended to focus on the development of a new communication training programme for caregivers of people living with dementia. However, the thesis was changed to focus on developing a protocol for virtual Cognitive Stimulation Therapy (vCST) midway through the project due to restrictions from the global Covid-19 pandemic. Therefore, the systematic review and the empirical paper will address different research areas.

Part I is a systematic literature review investigating the current evidence base for communication training programmes for informal caregivers of people living with dementia. This is explored through analysing the study characteristics, the quality of the studies, the quantitative outcomes measures used, which outcomes were significant and the key components of each training programme. Nine papers are included in this review.

Part II focuses on the development and pilot feasibility study of new vCST protocol for people living with dementia. This is a joint project with Cerne Felstead (CF). This paper discusses the development of the protocol using stakeholder consultation and assessment of the protocol in a feasibility pilot study using feasibility and acceptability outcomes. It will also discuss the impact on mood and quality of life by assessing related outcome measures at baseline and follow-up. The paper by CF will report on outcomes relating to cognition and qualitative feedback of participants' experiences of attending vCST group sessions.

Part III is a critical appraisal of this work, primarily focusing on Part II, which reflects on the strengths and challenges of conducting a virtual project during the global Covid-19 pandemic.

Impact Statement

Dementia is an umbrella term for a group of neurodegenerative conditions that affect approximately 885,000 individuals in the UK and rising. Current evidence suggests that a variety of psychosocial interventions can be beneficial in supporting people living with dementia and their caregivers, including communication training programmes and Cognitive Stimulation Therapy (CST).

The literature review addressed a gap in the research on communication training programmes as it is the only review to specifically synthesise quantitative studies on interventions that primarily focus on communication training for informal caregivers of people living with dementia. The review analysed the quality of the current evidence base and identified the key components that were common across all current communication training programmes, including outcome measures used, which outcomes were significant, dose, method of delivery and content of the sessions. Based on these findings, recommendations were generated for future researchers developing new communication training programmes that state the optimal conditions and components for maximising the effectiveness of these interventions. By analysing the current literature base and providing this foundation for future interventions, this review has lent further support to the need for developing and implementing communication training programmes into dementia services, especially given the potential benefits that have been identified.

The empirical paper outlined a study conducted by Luke Perkins and Cerne Felstead, led by Aimee Spector and Josh Stott, of the development and feasibility pilot study of a new virtual Cognitive Stimulation Therapy (vCST) intervention protocol. The study built on the well-established evidence base for group CST, using stakeholder consultation to inform adaptations that would enable the intervention to be delivered in a virtual setting. This project transpired from the social distancing restrictions implemented during the global Covid-19 pandemic and highlighted the need for virtual dementia interventions during the pandemic and

beyond. The feasibility pilot study found the intervention to be feasible, acceptable and may have benefits in relation to mood, quality of life and cognition. These findings demonstrated the need for further vCST trials to continue to assess these outcomes, alongside testing the effectiveness of the programme, as it was found to be a beneficial and well-regarded intervention. This study identified a current lack of online interventions for people living with dementia who would not normally be able to access services or groups in-person, because of social distancing rules during the global Covid-19 pandemic, physical health problems or transport issues. It is therefore essential that vCST be assessed through larger randomised controlled trials in order to support implementation into dementia care services and increase access for these individuals. These results will be disseminated in relevant journals in order to support this ongoing research.

Table of Contents

List of Tables

List of Figures

Acknowledgements

I would like to extend my biggest thank you to my supervisors Aimee Spector and Joshua Stott for this project would not have been possible without them. Your consistent support and guidance have been valuable throughout this project, especially through the most stressful times such as having to start the project again due to Covid-19 and when I was feeling lost with how to proceed throughout the project. I am also very grateful to my project partner Cerne Felstead, whose enthusiasm, knowledge and skills have been essential in the success of this joint venture. I would like to thank all of the participants who took part in the project, alongside all the professionals who supported the recruitment and design of the project, for giving up your time to contribute to such valuable research. I am also grateful to Claire Rooney, Diyanah Abdul Wahab, Michelle Leung, Carey Fagan and the Hong Kong Facecog team for your assistance and collaborations throughout the project.

I would like to thank all of my family, friends and colleagues for all of their support and encouragement over the last three years. Lastly, I would like to extend the most important thank you to my partner and best friend Aariel. You have been an essential source of support, encouragement and love throughout this process and you have kept me going throughout all of the ups and the downs that I have experienced throughout this journey.

Part 1: Literature Review

Communication training programmes for informal caregivers of people living with dementia: A systematic review.

Abstract

Introduction: Impairments in communication skills occur across dementias and can create difficulties in an individual's relationships with others. Participation in communication training programmes by caregivers of people living with dementia can benefit both parties by improving communication, quality of life and stress. Previous reviews have focused on synthesising evidence of programmes for both formal and informal caregivers jointly. This review aimed to focus specifically on evaluating the current evidence base for communication training programmes for informal caregivers only, the quality of this research and key components of the programmes.

Method: A systematic literature search identified 45 relevant studies in relation to the research questions, 36 of which were excluded based on pre-specified criteria. Nine studies were included in the final synthesis of the literature using a quality appraisal tool.

Results: Overall, the programmes used in the nine identified studies averaged five to six hours in length, were spread over four to five sessions, were mostly face-to-face in both group and individual settings and were developed using a range of communication and psychological theories. Studies demonstrated variable quality and outcomes making it difficult to identify optimal components. However, careful consideration of different factors enabled some recommendations for training dose, delivery method, content and outcomes to measure.

Conclusions: Communication training programmes can benefit people living with dementia and their informal caregivers in outcomes such as communication skills and quality of life. However, the limited pool and variable quality of the evidence means that future research is essential in consolidating these findings.

Introduction

'Dementia' is 'an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain the activities of daily living' (World Health Organization, 2017). It is estimated that there are 885,000 people in the UK living with a diagnosis of dementia and rising (Wittenberg et al, 2019). The impact of living with dementia on the individual and their caregivers is huge (Lindeza et al, 2020) with a risk of increasing caregiver burden and reduction in quality of life (Karg et al, 2018; Alvira et al, 2015). One contributing factor to this impact is the breakdown of communication between people living with dementia and their caregivers (Downs & Collins, 2015). Although language problems are common in most forms of dementia (Banovic et al, 2018), effective communication between people living with dementia and their caregivers can improve quality of life (QoL) and lessen the impact these symptoms have on mental wellbeing (Eggenberger et al, 2013). It is, therefore, important to be able to offer interventions that support the development of effective communication to people living with dementia and their caregivers, as this could improve QoL, reduce caregiver burden and reduce costs to the healthcare system (Eggenberger et al, 2013; Williams et al, 2017).

Communication difficulties in dementia

Both verbal and non-verbal communication is fundamental for two or more people to interact with each other. Being able to communicate effectively is a necessity for people living with dementia to be able to receive high quality care from their caregivers (Nguyen et al, 2018). This relies on all parties involved in an interaction to have the skills to be able to communicate effectively. Although there are a wide range of different types of dementia, including Alzheimer's Disease, Vascular Dementia and Fronto-Temporal Dementia, impairments in language skills are common across the board (Banovic et al, 2018). Common deficits include 'word finding difficulties (anomia), sentence comprehension deficits, and lack of cohesion

in discourse' (Kempler & Goral, 2008). This occurs due to gradual decline in a multitude of cognitive domains. Impairments occur both at the semantic level (i.e., meaning of words), and a pragmatic level; the ability to adapt language to the specific social situation that the person finds themselves in at any particular time (Ferris & Farlow, 2013). The impact of these impairments is such that people living with dementia find it increasingly more difficult to express their needs and can become cognitively overloaded in conversations with others (Ferris & Farlow, 2013). Not only can this lead to increased psychological distress and reduced QoL for people living with dementia but can also reduce the quality of interactions and relationships with others (Potkins et al, 2003; Watson et al, 2012).

One concept that can start to explain the breakdown in relationships and interactions between people living with dementia and their caregivers is that of 'Personhood' (Kitwood, 1997). Although there is no precise definition for this construct, Kitwood (1997) stated that it is 'a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust'. A person's wellbeing or 'illbeing' is therefore influenced by the level of 'recognition, respect and trust' received by those around them (Mitchell & Agnelli, 2015). Kitwood's theory sought to identify different behaviours that would undermine someone's 'personhood' and, therefore, wellbeing. He used the term 'Malignant Social Psychology' to label this range of behaviours. He used this term because he recognised that people living with dementia are often undervalued or depersonalised by society, usually through a lack of understanding, education or training about the effects of dementia. This lack of acknowledgement is usually unintentional, but Kitwood (1997) stated that it can have a negative impact on people living with dementia's wellbeing.

One behaviour that Kitwood (1997) identified as having a negative impact on 'personhood' is 'infantilisation'. This is defined by Kitwood (1997) as 'treating a person like a child' and can contribute to communication breakdown between

people living with dementia and their caregivers through the caregiver's use of 'Elderspeak'. 'Elderspeak' refers to a communication style adopted by a person interacting with an older adult where speech is characterised by a 'simplified speech register', often used with young children and is based on negative stereotypes of older adults being physically frail and cognitively impaired (Kemper, 1994). If a people living with dementia is finding it increasingly difficult to express themselves due to the decline in language ability as described earlier, this can appear to fit with others' negative stereotypes of older people's ability to participate in conversation and lead to an increase in the use of 'Elderspeak'. There is some evidence that suggests 'Elderspeak' can support comprehension and recall in older adults, but studies have shown that 'Elderspeak' is perceived as patronising and inappropriate by its receivers, can reinforce unhelpful, negative stereotypes and can contribute to cognitive decline through limiting communication opportunities (Cohen & Faulkner, 1986; Williams et al, 2018).

Improving communication between people living with dementia and their caregivers

Informal caregivers of people living with dementia are defined as 'non-professional people (such as a family member, friend or paid caregiver) who provide care…assistance and supervision that are necessary to fulfil the basic needs of people with dementia living in the community' (Chiao et al, 2015). The most up to date figures report that there are 670,000 unpaid, informal caregivers for people living with dementia in the UK, saving the economy £11bilion per year (Alzheimer's Society, 2014). Caregivers of people living with dementia face massive physical and emotional demands to ensure the care needs of the people they care for are met and often find that the various roles and identities they hold, such as friend, family member, worker and caregiver, become less distinguished and more intertwined (Mattock & McIntyre, 2015). This can leave caregivers feeling overwhelmed when trying to juggle the various burdens that these roles and identities entail. This

includes giving up more time and energy to support people living with dementia in their role as a caregiver, whilst managing difficult emotions, such as loss and grief, through their role as a friend or family member. As all of these identities are relational in nature, supporting caregivers and people living with dementia with these relationships is paramount in reducing this stress and burden on both sides.

One way that these relationships can be maintained is through supporting people living with dementia and their caregivers with improving communication. Young et al (2011) suggested that reducing 'Elderspeak' and improving efficient communication between people living with dementia and caregivers can increase wellbeing in people living with dementia through increasing a sense of agency, self and, therefore, 'personhood'. They stated that the aim of seeking to improve communication is to 'initiate and perpetuate a virtuous circle, whereby the recognition of and support for people living with dementia's individuality and agency by caregivers increases both individuals' sense of self and competence, positively changing the nature of the social interaction for all parties. Not only do they suggest that improved communication can increase a sense of wellbeing and personhood in people living with dementia, but it can also have a positive impact on caregivers by reducing stress and increasing QoL. However, Morris et al (2020) stated that focusing solely on person-centred approaches as Young et al (2011) suggests is insufficient as it does not take into account the relational nature of the interactions between people living with dementia and their caregivers. Therefore, they developed the empowered conversations model which states that communication can be improved both through focusing on the pragmatics of communication, alongside working on the relationship between involved parties through increasing the ability to mentalise each other's' needs.

A systematic review by Egan et al (2010) investigated the literature to find the best methods of improving communication in people living with dementia and their caregivers. They found that the interventions demonstrating most improvement

in communication were memory aids and communication training with caregivers. However, Egan et al (2010) noted that these results should be looked at with caution as much of the evidence lacked internal validity or was poorly designed. Much of the evidence in this review favoured memory aids, whereas the evidence for the effectiveness of specific communication training packages was less clear. Despite this, this review demonstrated that communication training packages had the potential to support people living with dementia and their caregivers to improve communication with one another.

A systematic review by Fossey et al (2014) investigated the evidence base of 170 manualised training packages used in UK care homes of people living with dementia. They found that only 30 met their quality criteria and only four had any evidence from clinical trials. Furthermore, a literature review by Kindell et al (2017) found that most of the current advice and training on communication difficulties in dementia has no theoretical basis. These findings suggest that although communication training packages seem to be helpful in improving communication between people living with dementia and their caregivers, there is little on offer that is based on theory and has an evidence base. These reviews also seem to suggest that most of the training that does exist is aimed at care staff of people living with dementia rather than informal caregivers.

A more recent review by Nguyen et al (2018) sought to not only evaluate the communication training packages on offer to caregivers of people living with dementia, but also to investigate the potential benefits of these on caregivers and the people they care for. They looked at the impact that these interventions had on caregiver communication skills, caregiver psycho-physiological states and neuropsychiatric symptoms of people living with dementia. The most significant effects they identified were regarding outcomes relating to communication skills, knowledge and attitudes in caregivers, finding that these effects appeared to be sustained past the end of the intervention period. Through meta-analysis of the

included studies, Nguyen et al (2018) also identified a significant reduction in negative caregiver psycho-physiological states and neuropsychiatric symptoms of people living with dementia at follow up. This is further evidence that communication trainings for caregivers of people living with dementia can lead to a variety of positive outcomes for both caregivers and they people they care for. However, most of the evidence identified in the review was from formal, paid caregivers of people living with dementia and the evidence for informal caregivers was less clear.

Aims of the current review

Although there are a number of published papers that review the evidence base of multi and single component communication training packages for both formal and informal caregivers of people living with dementia (Egan et al 2010; Eggenberger et al, 2013; Fossey et al, 2014; Morris et al, 2018; Nguyen et al, 2018; Piersol et al, 2017), there is currently no systematic review that specifically investigates training that prioritises communication skills over other components and focuses solely on informal, unpaid caregivers. For example, although the review by Morris at al (2018) does include research conducted solely with informal caregivers, many of the interventions in these papers are multi component trainings where communication forms only a small part. The aim of the current review is therefore to synthesise the evidence base for communication training programmes in this specific area. The two research questions that this review will address are:

1. What is the current evidence base for communication training programmes for informal caregivers of dementia? This includes the quality of the evidence, the main outcome measures used to assess change in these trainings and which changes in outcomes are significant.
2. What are the key features of the current evidence-based communication training programmes for informal caregivers of dementia? This includes optimal dose, method of training and content of sessions.

Method

Search strategy

Initial searches were conducted on electronic databases CINAHL, Embase, Medline and PsycInfo to identify relevant studies published from January 2000 until April 2020. Three umbrella search term categories with additional search terms were identified from key words in existing literature (see table 1.) Terms were initially entered separately and then combined. Results were limited to studies written in English that were published in peer-reviewed journals. A further search was conducted by hand on the reference lists of the included studies and in other related review papers to identify any additional studies not picked up in the electronic search.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were guided by the research questions and previous review papers that focused on communication training for caregivers of people living with dementia. A flow diagram is provided to demonstrate how studies were eliminated from the final literature pool (see Figure 1).

Table 1. Electronic search strategy

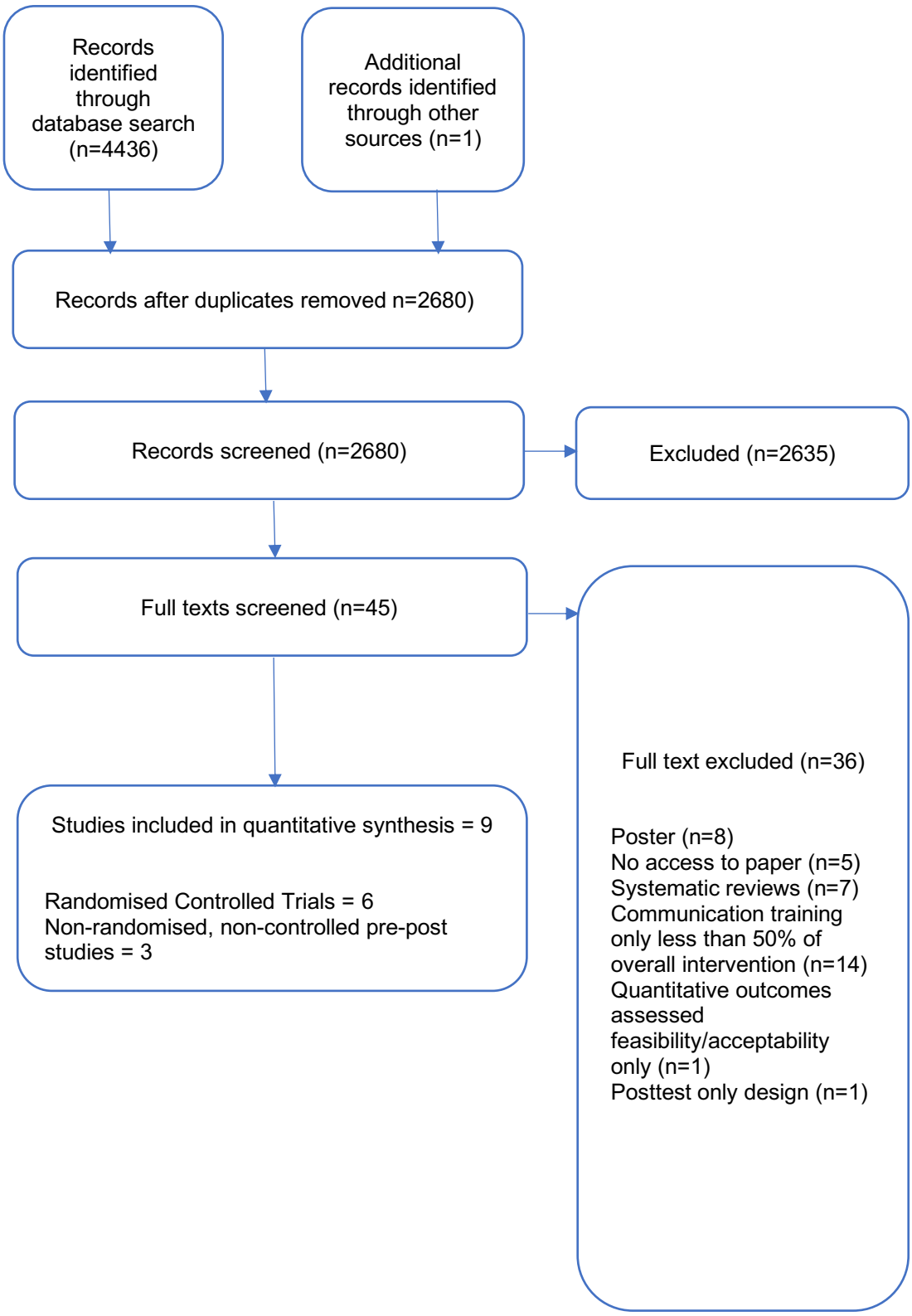
Search Term Category	Terms Applied	Combined with
Informal Caregivers	Informal care* Unpaid care* Carer* Caregiver*	OR
Dementia	Dementia* Alzheimer*	OR
Communication Training	Communication train* Communication interven* Communication skill* Training in Communicat* Communicat*	OR

AND

AND

Notes: *Denotes truncation, looks for variants of words such as carer and carers

Figure 1: Flow diagram illustrating the inclusion of studies in the review



Inclusion and exclusion of studies were based on the following criteria:

- *Study design:* Studies were included if outcome measures were administered both before and after participation in the intervention. This includes randomised controlled trials and non-randomised, non-controlled pre-posttest designs. Studies that only administered measures at one time point were excluded, for example posttest only designs.
- *Participants*: Studies were included if the sample consisted solely of informal caregivers of a person living with a diagnosis of any type of dementia. The definition of 'dementia' was intentionally kept broad to increase the likelihood of including appropriate studies. This included all types of known dementia diagnoses, such as Alzheimer's Disease, Vascular Dementia, Posterior Cortical Atrophy and Frontotemporal Dementia. Studies were excluded if the sample included informal caregivers of people who did not have a dementia diagnosis. Studies were also excluded if the sample included formal caregivers of people living with dementia.
- *Intervention content:* Both group and individual interventions that primarily focused on communication training were included in the review. To be included, at least 50% of the intervention content need to be focused on communication problems and strategies. Studies were excluded if this content formed less than 50% of the overall intervention, for example one session out of four.
- *Measures:* Studies were included if they used any form of quantitative measure as part of the data collection that assessed outcomes relating to potential benefits of communication training programmes for people living with dementia and their caregivers. This includes studies using solely descriptive statistics and those who created outcome measures for the purposes of the study. However, studies that solely reported outcomes relating to feasibility and/or acceptability but no other quantitative outcomes

were excluded. Studies that included both quantitative and qualitative measures were included but only the quantitative data were reviewed. Qualitative measures included any written or verbal data that is non-numerical in nature and, therefore, cannot be subjected to descriptive or inferential statistical analysis. This includes data such as interviews and written feedback. Studies that used only qualitative measures were excluded.

Data collection and extraction

All studies were downloaded to the reference management software Endnote and duplicates were removed using the 'remove duplicates' function. The titles and abstracts of all remaining studies were screened for relevance to the review question. Studies that referenced communication training for informal caregivers of people living with dementia and appeared to use quantitative measures were subject to a full text review to assess whether they met the inclusion criteria. The remaining articles were then subject to data extraction based on the questions of the current review and a full quality appraisal. A data extraction form was created based on the research questions and the key characteristics that were being analysed, such as the type of study, the intervention content and the quantitative outcome measures used. Once the data from each study was extracted in this way, this was amalgamated and synthesised into the table shown in the results (see Table 2.). The information was then synthesised by comparing similarities and differences of the key characteristics of the studies, taking into account the quality of the research, in order to weight the strengths and weakness in the evidence and make recommendations based on this.

Quality appraisal

Katrak et al (2004) reviewed a vast number of quality assessment tools used in systematic reviews but did not find any that were superior. Therefore, the

'Qualsyst' critical appraisal tool (Kmet at al, 2004) was chosen to screen for quality in the final study pool as it had been used in literature on similar topics (i.e., Scerri et al, 2017). The tool helps to compare studies with diverse designs in a 'systematic, reproducible and quantitative' manner'.

The 'Qualsyst' tool comprises of a checklist of 14 criteria for which papers received a score based on the degree to which each quality criterion is met (see Appendix A). These are scored as zero (criterion not met), one (criterion partially met), two (criterion fully met) or 'N/A' if the criterion was not relevant. Quality scores are then calculated by adding up these scores and dividing by the maximum score that can be achieved by that particular paper, removing any criteria that were not relevant. This allows direct comparison on papers that may have different relevant criteria. All papers were quality appraised by the main reviewer. A second reviewer (CF) quality appraised a third of the included papers to check for reliability of the final quality ratings. All initial disagreements between reviewers in relation to quality ratings were resolved through discussions until an agreement was reached.

Results

Included Studies

A total of 2680 studies were initially identified by database and manual searches. A total of nine papers were included in the final review based on the inclusion criteria. Six of these were randomised controlled trials (RCTS) and three were non-randomised, non-controlled pre-posttest studies.

Research question 1: What is the current evidence base for communication training programmes for informal caregivers of dementia?

Study characteristics

Table 2. outlines the full details of each study. All studies demonstrated some benefits of communication training but varied greatly in dose, method of delivery, content and outcome measures used. These are examined below.

Quality of studies

Overall, study ratings ranged from 0.43 to 1.00 indicating a wide variation in quality (see Table 3.). To facilitate comparison, the studies were divided into three categories depending on the score they achieved using Kmet et al's (2004) Qualsyst tool; high quality (0.8-1.0), medium quality (0.6-0.79) or low quality (0.0-0.59). These categories were created to reflect how the study ratings clustered together following analysis. Barnes and Markham (2018) scored the highest quality rating (1.00) as they managed to fully meet each of the criteria that applied to their study, including a full description of their randomisation procedure, use of robust outcome measures and an outline of their power analysis. Two other studies fell within the high-quality category, scoring 0.92 (Klodnicka Kouri et al, 2011) and 0.88 (Liddle et al, 2012). These generally showed strengths in study design, use of control groups, descriptions of sample characteristics and confounds and blinding were appropriate. Chesneau et al (2019) scored the lowest quality rating (0.43) as the sample size was very small, the participant characteristics were not sufficiently described and the objectives were not clearly stated. One other study fell into the low-quality category for scoring 0.50 (Silvestri et al, 2004) for similar reasons. The remaining four studies were of medium quality, scoring between 0.64 - 0.69 (Haberstroh et al 2011; Williams et al, 2018; Done & Thomas, 2001; Troche et al, 2019). Although generally demonstrating clear objectives, robust designs and appropriate outcomes, these studies tended to use small sample sizes, have insufficient use of a control group and not consider or control for confounds.

Table 2: Summary of studies included in the review

Authors	*Design, setting and intervention*	*N*	*Training Duration*	*Content of sessions*	*Outcome, domains measures and time points*	*Results (follow-up results)*	*Qual. rating*	*Comments*
Barnes & Markham 2018 (UK)	*RCT – face to face, individual sessions* *Intervention – CBT based communication training* *Control – 1 hour individual generic information giving session* *Study – 8 weeks* *Supervision - none*	*Total – 55* *Treatment – 28* *Control - 27*	*3 x 1-hour individual sessions* *Total Duration – 3 hours*	*CBT based intervention following 9 steps –* *1. Knowledge (of dementia & communication difficulties), 2. Insight (into communication difficulties) 3. Thoughts & feelings, 4. Environment, 5. The person 6. How to be the carer 7. Reminders & encouraging conversation, 8. Communication & activities, 9. Challenging behaviours*	*<u>Caregiver</u>* *Depression & Anxiety – HADS* *Quality of Life – ACQOL* *Communication Self-Efficacy – CSES* *General Self-efficacy – GSES* *Experience/belief in people living with dementia's communication skills – CCS* *Therapy engagement and readiness – TEI* *HADS, ACQOL, CSES, GCES & CCS completed as pre/post measures within 12 weeks following consent and within 2 weeks of intervention completion. TEI completed after every session*	*<u>Caregiver</u>* *No significant differences except for specific domains in ACQOL, CSES and TEI, suggesting significantly higher sense of value and less difficulties from the people living with dementia perceived by the caregiver in treatment group. Significantly more readiness for therapy in the control group. Near significant improvement in belief/experience of people living with dementia's communication skills in treatment group*	*1.00*	*Pos: Randomisation method described, Robust outcome measures, power analysis* *Neg: No follow up*
Chesneau et al, 2019 (Canada)	*Non-randomised, non-controlled pre-posttest designs – face to face group sessions* *Intervention- AID-COM programme communication training* *Control - none* *Study – 6 weeks* *Supervision – none*	*Total - 5*	*3 sessions* *Total Duration – Not stated*	*Sessions divided into psychoeducation, practical application and discussion. Psychoeducation – stages of Alzheimer's Disease, impact on communication and strategies. Focus on memory, lexical access, discourse comprehension, and expression.* *Practical component – video scenarios encouraging discussion to identify problems and solutions*	*<u>Caregiver</u>* *Use and effectiveness of strategies questionnaire (developed for the purposes of the study)* *Impact of communication strategies questionnaire (developed for the purposes of the study)* *Both questionnaires were given pre/post intervention*	*<u>Caregiver</u>* *No formal statistical analysis conducted, only descriptive statistics. All participants reported increase in frequency and effectiveness of communication strategies and greater impact on the people living with dementia.*	*0.43*	*Pos: Qualitative interviews conducted* *Neg: Small sample size, no follow up, no control group*

Done & Thomas, 2001 (UK)	*CRCT - face to face group sessions* *Intervention – Speech and language video and discussion-based communication training* *Control – information booklet to read* *Study – 2 weeks* *Supervision - none*	*Total – 45* *Treatment – 30* *Control - 15*	*2 x 1-hour sessions* *Total Duration – 2 hours*	*Video of communication breakdown presented to participants to support discussion of communication difficulties and solutions, followed by video of same scenario using successful communication strategies* *Control group booklet contained cartoon drawings similar to the videos in intervention group and advice on how to manage communication problems*	*<u>Caregiver</u>* *Caregiver Stress - RSS* *Frequency of communication problems – TACI* *Awareness of communication strategies – AACS (developed for the purposes of the study)* *Consumer evaluation – Likert Scales* *All measures were given pre/post intervention*	*<u>Caregiver</u>* *Both groups' awareness of strategies significantly increased but significantly higher for treatment group.* *No significant differences in caregiver stress between or within groups or in frequency of communication problems between groups but both groups reported significant reduction in frequency of communication problems post intervention.*	*0.68*	*Pos: Randomisation method described, controlled for confounds, blinding of researchers* *Neg: No blinding of participants, no power analysis, outcome measure not standardised*
Haberstroh et al, 2011 (Germany)	*RCT - face to face group sessions* *Intervention – TANDEM programme communication training* *Control – no treatment, waiting list to receive group after post measures* *Study – 5 weeks* *Supervision – none*	*Total – 22* *Treatment – 9* *Control - 13*	*5 x 2.5-hour sessions* *Total Duration – 12.5 hours*	*Psychoeducation on concepts and skills of TANDEM model: sender presentation, receiver attention, receiver comprehension and receiver remembering. Session format: 1. Review previous session, 2. Exchange experiences from the week, 3. Intro to topic with case studies, 4. Relate to individual experiences, 5. Use to highlight strengths and weaknesses of topic, 6. Case studies and experiences used to find communication strategies, 7. New skills role played, 8. Set objectives for the week*	*<u>Caregiver</u>* *Mood – Likert scale every day using diaries during intervention* *Frequency of strategy use – Number recorded every day using diaries* *Caregiver Burden - HPS* *<u>People living with dementia</u>* QoL – QoL-AD (completed by caregivers pre/post intervention) Mood and frequency of strategy use was measured each session. QoL and burden were measures pre/post	*<u>Caregiver</u>* *Frequency of strategy use increased significantly throughout training and caregiver mood was significantly improved on training days.* *No significant change in burden between groups* *<u>people living with dementia</u>* *QoL significantly improved in intervention group*	*0.69*	*Pos: Use of observational measures, robust outcome measures, attrition described* *Neg: Small sample size, no power analysis, true randomisation not possible*

Klodnicka Kouri et al, 2011 (Canada)	*RCT – face to face individual sessions* *Intervention – Social Cognitive theory-based communication training* *Control – Booklet on memory and communication problems* *Study – 5 weeks* *Supervision - none*	*Total – 50* *Treatment – 25* *Control - 25*	*5 x 90-120-minute sessions* *Total Duration – 7.5 - 10 hours*	*Psychoeducational approach consisting of five modules related to specific communication related subjects. Four self-efficacy strengthening skills incorporated – 1. Learner given opportunity to master communication skills, 2. Effective models shared with learner, 3. Learner persuaded to perform skills, 4. Diverse action-approaches used to reduce learner's anxieties.*	*<u>Caregiver</u>* *Self-efficacy – CSS* *Perceived communication-related behavioural problems – RMPBC* *Communication knowledge – The Knowledge Measure (developed for the purposes of the study)* *Communication Skills – The Communication Skills Measure (developed for the purposes of the study)* *All measures were conducted pre/post intervention*	*<u>Caregiver</u>* *Significant increase in communication knowledge, skills and self-efficacy and significant decrease in perceived communication-related behavioural problems in treatment group compared to control. However, there was no significant difference for perceived communication difficulties.*	*0.92*	*Pos: 6 week follow up, robust measures, blinding of assessors* *Neg: small sample size, randomisation method not described*
Liddle et al, 2012 (Australia)	*RCT – DVD training* *Intervention – RECAPS and MESSAGE communication and memory training programme* *Control – TAU* *Study – 1 weeks* *Supervision – None*	*Total – 29* *Treatment – 13* *Control - 16*	*2 x 45-minute sessions* *Total Duration – 1.5 hours*	*Psychoeducational strategies for communication and memory delivered in a didactic approach. Each letter of RECAPS and MESSAGE representing a different strategy. RECAPS = Reminders, Environment, Consistent routines, Attention, Practice, Simple steps. MESSAGE = Maximise attention, Expression and body language, keep it Simple, Support conversations, Assist with visual aids, Get their message, Encourage and engage in conversation.*	*<u>Caregiver</u>* *Knowledge of support strategies – Communication and Memory Support in Dementia (developed for the purposes of the study)* *Caregiver Burden – Short ZBI* *Positive aspects of caring – PAC* *Perceived communication-related behavioural problems – RMPBC* *<u>People living with dementia</u>* *Depression – CSDD (completed by caregiver)* *General mood – Faces scale for wellbeing (developed for the purposes of the study)* *All measures were complete pre/post except the MMSE which was complete pre intervention and the Faces scale which was completed post*	*<u>Caregiver</u>* *Significant improvement in knowledge of strategies and near significant improvement in positive aspects of caring and perceived communication-related behavioural problems in treatment group. No significant difference found in caregiver burden* *<u>people living with dementia</u>* *No significant differences found for depression or general mood*	*0.88*	*Pos: Power analysis, 3 month follow up* *Neg: Outcome measures vulnerable to bias, small sample size*

Silvestri et al, 2004 (Italy)	*RCT – Individual and group face to face sessions* *Treatment – Communication strategies in Alzheimer's disease* *Control – No training* *Study - 6 weeks* *Supervision - none*	*Total – 35* *Treatment – 18* *Control - 17*	*4 x group sessions* *2 x individual sessions* *Total Duration – Not stated*	*Psychoeducation on different communication problems at different stages of disease progression and verbal and non-verbal strategies to support communication at each stage. Strategies included speaking in familiar places, using present tense, use more concrete ideas and use of non-verbal communication.*	*<u>People living with dementia</u>* *Cognition – MMSE* *Activities of Daily Living – ADL & IADL (rated by researchers)* *Alzheimer's Disease related behaviours - E-Behave-AD (rated by researchers)* *AI measures were completed pre/post intervention*	*<u>people living with dementia</u>* *Significant improvement in Cognition and AD related behaviours in treatment group compared to control group.* *No significant change in ADLs in treatment group but control group significantly worse.*	*0.50*	*Pos: Robust and appropriate outcome measures* *Neg: No power analysis, randomisation not described, no follow up, small sample size*
Troche et al, 2019 (USA)	*Non-randomised, non-controlled pre-posttest designs – Group face to face sessions* *Treatment – Supported conversations for Adults (SCA) with dementia communication* *Control – none* *Study – 6 weeks*	*Total – 4*	*4 x 1-hour sessions* *Total Duration – 4 hours*	*Psychoeducational didactic training. Session 1. Dementia education and acknowledging competence, i.e., speaking in a natural voice and avoiding quizzing. Session 2. 'Getting the message in', i.e., writing keywords, using yes/no questions. Session 3. 'Getting the message out', i.e., ask one question at a time, give time to answer. Session 4. 'Getting verification of message', i.e., summarising.*	*<u>Caregiver</u>* *Skills in engaging people living with dementia using SCA principles – MSC (rated by researchers)* *Caregiver Burden – Short ZBI* *<u>people living with dementia</u>* *Skills in participating in conversation – MPC (rated by researchers)* *All measures completed pre/post intervention*	*Descriptive statistics only due to small sample size.* *<u>Caregiver</u>* *Skills in engaging people living with dementia using SCA principles increased and burden decreased post intervention* *<u>people living with dementia</u>* *Skills in participating increased post intervention*	*0.64*	*Pos: blinding of assessors, robust outcome measures, observational outcome measures used* *Neg: no control group, small sample size. No follow up*

Williams et al, 2018 (USA)	*Non-randomised, non-controlled pre-posttest designs - Individual face to face sessions at home* *Treatment – CARE communication training programme* *Control – none* *Study – 12 weeks* *Supervision - Yes*	*Total – 15 dyads*	*10 x 50-minute sessions* *Total Duration – 8 hours*	*Observations and role play to tailor 10 modules including psychoeducation on dementia and communication difficulties, empathy, simplifying communication, using questions, responding to conflict, nonverbals, adaptation, challenges, compassion and strengthening relationships. Session format: assess people living with dementia's needs, discuss and role play new strategies with the caregiver, caregiver and people living with dementia coached together, caregiver and people living with dementia observed.*	*<u>Caregiver</u>* *Effective communication – VNVIS-CG* *<u>People living with dementia</u>* *Effective communication – VNVIS – CR* *Cognition - MMSE* *All measures were taken pre/post intervention except for the MMSE which was complete pre intervention only.*	*<u>Caregiver</u>* *Significant improvement in effective communication* *<u>people living with dementia</u>* *No significant improvement in effective communication post intervention, however a significant improvement was found post intervention when controlled for cognition (using MMSE scores).*	*0.68*	*Pos: robust and appropriate outcome measures, observational outcome measures used* *Neg: no control group, small sample size, no follow up*

**Questionnaire Acronyms – AACS = Assessment of Awareness about Communication Strategies, ACQOL = Adult Carers Quality of Life questionnaire, CSDD = Cornell Scale of Depression in Dementia, CCS = Communication Competence Scale, CSES = Communication Self-Efficacy Scale, CSS = Carer Self-efficacy Scale, GSES = General Self-Efficacy Scale, HADS = Hospital Anxiety and Depression Scale, HPS - Häusliche-Pflege-Skala (Home Care Scale), MMSE – Mini Mental State Examination, MPC – Measure of Participation in Conversation, MSC – Measure of Skill in Supported Conversation, PAC = Positive Aspects of Caregiving questionnaire, QoL-AD = Quality of Life Alzheimer's Dementia, RSS = Relative Stress Scale, RMBPC – Revised Memory and Behaviour Problems Checklist TACI = Thomas Assessment of Communication Inadequacy, VNVIS-CG = The Verbal and Non-verbal Interaction Scale for Caregivers, VNVIS- CR = The Verbal and Non-verbal Interaction Scale for Care Receivers, ZBI = Zarit Burden Inventory*

Table 3: Results of quality appraisal

** = criteria fulfilled; * = criteria partially fulfilled; 'blank' = criteria not fulfilled; - = not applicable for study type.

Quality rating criteria and scores (Kmet et al, 2004)															
	Question/Objective sufficiently described?	Study design evident and appropriate?	Method of subject/comparison group selection described and appropriate?	Subject and comparison group characteristics sufficiently described?	Was random allocation described?	Was blinding of investigators reported?	Was blinding of subjects reported?	Outcome measures well defined and robust?	Sample size appropriate?	Analytic methods described and appropriate?	Some estimate of variance reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Quality rating (total sum/total possible sum)
Barnes & Markham (2018)	**	**	**	**	**	-	-	**	**	**	**	**	**	**	1.00
Klodnicka Kouri et al (2011)	**	**	**	**	*	**		**	*	**	**	**	**	**	0.92
Liddle et al (2012)	**	**	**	**	*	**	-	*	*	**	**	**	**	**	0.88
Haberstroh et al (2011)	**	**	**	**	*		-	**	*	**	*	*	*	*	0.69
Williams et al (2018)	**	**	*	**	-	-	-	**		*	*	*	*	**	0.68
Done & Thomas (2001)	**	**	*		**	*		*	*	*	**	**	**	**	0.68
Troche et al (2019)	**	*	*	*	-	**	-	**		**	**	-	**	**	0.64
Silvestri et al (2004)	*	**	*	*			-	*	*	**		*	*	**	0.50
Chesneau et al (2019)	*	**	-		-	-	-	*		-	-	-	*	*	0.43

Outcome measures used

A total of 32 different quantitative measures were used across the studies, assessing a variety of different domains. Of these, ten were created for the purposes of the study as researchers were unable to find pre-existing measures for the constructs under investigation. The only two measures used more than once across the nine studies were the Revised Memory and Behaviour Problems Checklist (RMBPC) (Teri et al, 1992) and the short version of the Zarit Burden Inventory (ZBI) (Bédard et al, 2001), both of which were used in higher quality studies. No other measure was used more than once across the nine studies. The most common construct that was assessed with outcome measures was communication skills and knowledge, assessed in every study except one. Other common constructs that were assessed with outcome measures in three to four of the studies were dementia related communication or behavioural problems, caregiver stress and burden and depression and anxiety. Less common constructs that were assessed with outcome measures in only one or two studies were QoL, self-efficacy, activities of daily living (ADLs) and therapeutic engagement.

Significant outcomes for caregivers

There was evidence of improvements in caregivers' knowledge, skills and self-efficacy in communication strategies in all eight of the studies that assessed this. This was evident in both higher quality studies that demonstrated significant or near significant outcomes in these constructs and in the lower quality studies that relied solely on descriptive statistics. However, this finding should be taken with caution as the outcome measures that demonstrated the strongest evidence were developed as part of the study and had therefore not been subject to the rigours of validity testing that well established measures have foregone. This is because the authors of these studies state that they were unable to find validated measures for the constructs that they wished to assess. When taking study quality and significance into account, the most established and validated communication

outcome measure that demonstrated the most change was the Verbal and Non-verbal Interaction Scale for Caregivers (VNVIS- CG) (Williams & Parker, 2012). Future research should consider using this measure to assess changes in communication in caregivers, subject newly developed measures to validity testing or to search for other established communication measures.

There was some evidence in one high quality study that communication training could improve QoL in caregivers as Barnes & Markham (2018) found a significant improvement in the 'values' subsection of the Adult Carers Quality of Life questionnaire (ACQOL) (Joseph et al, 2012) from caregivers in the treatment groups compared to controls. However, caregiver QoL was only measured in one study where significant changes were only observed within some of the QoL sub-categories and, therefore, requires further investigation. The evidence for self-efficacy being improved through communication training was mixed. Klodnicka Kouri et al (2011) reported a significant improvement in caregivers' communication specific self-efficacy using the Carer Self-efficacy Scale (CSS) (Bandura, 1997), whereas Barnes & Markham (2018) reported no significant improvement in either general or communication specific self-efficacy using the General Self-Efficacy Scale (GSES) (Schwarzer, & Jerusalem, 1995) and a measure developed and validated during the study called the Communication Self-Efficacy Scale (CSES). However, Barnes & Markham (2018) did find a significant result in the 'happens' subsection of the CSES. This suggests that further research is needed to investigate the impact of communication training on both general and communication specific self-efficacy using the CSS and GSES scales.

None of studies reported a significant change in caregiver burden or stress, although Liddle et al (2012) reported a near significant improvement in the positive aspects of the caregiving experience in the treatment group using used the Positive Aspects of Caregiving scale (PAC) (Tarlow et al, 2004). Troche et al (2019) reported a reduction in caregiver burden using the short version of the Zarit Burden Inventory

(ZBI) (Bédard et al, 2001), however the study only used descriptive statistics due to a very low sample size so these results are not reliable. No significant improvements in mood or anxiety were found in caregivers. However, Haberstroh et al (2011) found that caregivers reporting a significantly higher mood rating on training days compared to non-training days using a subjective Likert scale mood rating. Although little to no evidence was found to suggest that communication training can lead to improvements in caregiver stress, burden, mood or anxiety, these should be investigated through higher quality research as the current evidence suggests that there could still be some potential benefits.

Significant outcomes for people living with dementia

There was some evidence that caregivers' participation in communication training could support improvement in the communication skills of people they care for, although this is tentative due to the quality and sample sizes of the two studies that it was assessed in (Troche et al, 2019; Williams et al, 2018). Although these initial findings are promising, further investigation of these outcomes in higher quality research is needed to establish the extent of these benefits. The Verbal and Non-verbal Interaction Scale for Care Receivers (VNVIS- CR) (Williams et al, 2017) is the most recommended scale to use in future research, as it was the only validated measure used that demonstrated evidence of change in the reviewed literature. However, it should be noted that significant change was only detected using this measure when cognition was controlled for using the Mini Mental State Examination (MMSE) (Folstein et al, 1975) as the communication skills of people living with dementia are less likely to improve as their dementia grows more severe.

There was stronger evidence for an improvement in communication and behavioural difficulties presenting in people living with dementia following training. All four studies that measured this demonstrated significant or near significant improvements in the treatment group when compared to controls. Based on the reviewed literature, the Revised Memory and Behaviour Problems Checklist

(RMBPC) (Teri et al, 1992) is the most recommended outcome measure to use to measure this construct as it is well established as a measure and showed significant or near significant change in two high quality studies.

There was some evidence that the people living with dementia's QoL can improve following communication training. However, this finding should be taken with caution as it was found in one study of medium quality and was measured using the Quality of Life Alzheimer's Dementia (QoL-AD) (Logsdon et al, 1999) which was completed by the caregiver rather than by the people living with dementia themselves. Further investigation of this finding is required through high quality research using scales that can be completed directly by people living with dementia rather than by the people who care for them. There was some weak evidence to suggest that caregivers' participation in communication training can slow down decline in the people they care, when compared to a control group. This was measured using the Activities of Daily Living (ADL) (Katz et al, 1963) and Instrumental Activities of Daily Living (IADL) (Lawton & Brody, 1969) measures. However, this finding was from one low quality study and requires further investigation through high quality research. There was no evidence that communication training can support improvements in mood or anxiety in people living with dementia.

Research Question 2: What are the key features of the programmes?

Dose

For the purposes of the review, treatment dose includes the number of sessions offered to participants, the length of each session and the total duration of the training. The number of sessions ranged from two to ten, with the mean number of sessions being 4.44. The duration of each session ranged from 45 to 150 minutes, with the mean duration being 77.86 minutes. The total duration of the intervention ranged from 1.5 hours to 12.5 hours, with the mean duration being 5.86

hours. Two low quality studies did not include information on session length so were not included in the data for session duration and total duration (Chesnau et al, 2019; Silvestri et al 2004). There was no clear suggestion for what the optimal dose of the training should be. However, the intervention used in Klodnicka Kouri et al's (2011) study demonstrated the strongest evidence when taking quality of research and the significance of the data into account. Their intervention offered five sessions lasting 90 – 120 minutes each, totalling 7.5 – 10 hours across the whole intervention. The other high quality studies (Barnes & Markahm, 2018; Liddle et al, 2012) offered lower doses at around two to three hours for the whole intervention, however the change in outcomes measured in these studies was not as evident.

Method of Delivery

All studies delivered training face to face except for one high quality study which used a training DVD for participants to watch at home by themselves (Liddle et al, 2012). Three medium quality studies (Done & Thomas, 2001; Haberstroh et al 2011; Troche et al, 2019) and one low quality study (Chesnau et al, 2019) delivered training in a group format, three high quality studies (Barnes & Markham, 2018; Klodnicka Kouri et al, 2011; Liddle et al, 2012) and one medium quality study (Williams et al, 2018) delivered training in an individual format and one low quality study (Silvestri et al, 2004) used a mix of individual and group sessions. There was no clear recommended method of delivery, however the higher quality studies tended to offer individual sessions rather than group.

Content of Sessions

Each of the studies developed their training programme using a wide variety of theoretical frameworks. Most were based on basic models of dyadic communication and interactions, however two high quality studies (Barnes & Markham, 2018; Klodnicka Kouri et al, 2011) used the psychological models of Cognitive Behavioural Therapy and Social Cognitive Theory on which to base their trainings. The key elements of the trainings that were present across all studies

were providing psychoeducation into the nature of dementia, its impact on communication and strategies to reduce the impact of these difficulties. Strategies included simplifying communication, using yes/no questions, giving time to answer, encouraging engagement in conversation, speaking in a natural voice and using non-verbal communication. One medium quality study (Done & Thomas, 2001) and one low quality study (Chesnau et al, 2019) additionally used videos depicting caregiver and people living with dementia dyads demonstrating helpful and unhelpful interactions to encourage discussion about communication between group participants. One medium quality study (Williams et al, 2018) used role play and observations of interactions between dyads to practice new strategies.

Given this information, communication trainings that use psychological theories such as Cognitive Behavioural therapy and Social Cognitive theory demonstrated stronger evidence than those using only pure communication theory. There is also more evidence for didactic methods of training over use of role play or video, the key elements of which should be psychoeducation into the nature of dementia and communication related difficulties and specific communication strategies based on cognitive and communication theory. Although using role play or video may be beneficial in training, there is a lack of evidence to suggest that it is superior, therefore further research of these methods is required.

Discussion

Summary of findings

Overall, the findings of the current literature suggest that informal caregivers' participation in communication training programmes can benefit both the caregivers themselves and the people living with dementia that they care for. However, research in this particular area was found to be very limited and of variable quality so these findings should be looked at with extreme caution. An extensive literature search found only nine papers that met the inclusion criteria for the review and out

of these nine papers only three were high quality studies, whilst five were of medium quality and two were of low quality. Given that these papers demonstrate evidence that improving communication between caregivers and people living with dementia could lead to positive outcomes for both parties (i.e., Barnes & Markham, 2018; Haberstroh et al, 2011; Klodnicka Kouri et al, 2011), there is a clear need for further, high quality research in this area.

Although a large number of different outcome measures of different constructs were used across the studies with variable degrees of significance in findings, there were clearly some benefits of communication training to both caregivers and people living with dementia. For caregivers there was strong evidence that training can improve communication skills and knowledge and some slightly weaker evidence that it can improve self-efficacy and QoL. The most recommended measures to use for these outcomes were the VNVIS- CG to measure communication skills and knowledge, the ACQOL to measure caregiver QoL and the CSS and GSES to measure self-efficacy. Little to no evidence was found that training could improve caregivers' stress, burden, mood or anxiety.

For people living with dementia, there was strong evidence that their caregivers' participation in communication training can support improvement in their dementia related communication and behavioural difficulties and weaker evidence for improvement in communication skills, QoL and slower decline in ADLs. The most recommended measures to use for these outcomes were the RMBPC for dementia related communication and behavioural difficulties, the VNVIS-CR for communication skills, the QoL-AD for QoL and the ADL or IADL to measure ADLs. There was little to no evidence that it can improve mood and anxiety in people living with dementia. Although this review was able to identify some optimal features and clear benefits of communication trainings with informal caregivers, significantly more higher quality research is needed to support this due to limited pool and poor quality of the current evidence base.

There was a vast range of differences in key features between the nine studies, making it difficult to assess which features were optimal. However, this review was able to preliminarily identify optimal features when considering factors such as study quality and significance of findings. In relation to optimal dose, the intervention used in Klodnicka Kouri et al's (2011) study demonstrated the strongest evidence and consisted of five sessions lasting 90 – 120 minutes each, totalling 7.5 – 10 hours across the whole intervention. Other high quality studies used much shorter interventions but demonstrated weaker outcomes. There was no clear indication whether individual or group sessions were superior, however higher quality studies opted for individual making this method more recommended. In terms of session content, interventions that used psychological models such as Cognitive Behavioural therapy or Social Cognitive theory demonstrated the strongest evidence and thus interventions should, at a minimum, consist of psychoeducation into the nature of dementia, communication related difficulties and specific communication strategies based these theories. These interventions can be didactic in nature as there was no evidence that use of role plays or videos were superior. However, this may be due to the lack of use as evidence from learning theory suggests that role plays are one of the best methods of enhancing learning (Petracchi, 1999; Berkhof et al, 2011).

Methodological limitations of the literature

Through the quality appraisal process, a number of different methodological issues were found within the studies included in this review. There was an array of limitations that could be identified in each study, however this review will focus only on limitations that were most common across the literature. One of the most common issues identified was a small sample size. Sample sizes from the included studies ranged from four to 55 participants. There is no general consensus as to what the 'rule of thumb' should be for sample sizes in pilot studies, with the literature suggesting a minimum of anywhere between 12 per treatment group to 70 in total

(Julious, 2005; Teare et al, 2014). Even with this variability in minimum samples, three of the nine included studies failed to reach any of these estimates, meaning that the validity of the data is questionable. Although the remaining six studies meet some of the suggested sample size requirements in pilot or feasibility pilot studies, they are all unlikely to be sufficiently powered to be able to detect small to medium effect sizes and therefore increase the risk of type II errors (Leon, 2008; Biau et al, 2008).

Another common issue across many of the studies is that little to no follow up was conducted following the end of the intervention. Conducting follow up in research is important as it can highlight long term benefits of interventions and strengthen the validity of the data (Llewellyn-Bennett et al, 2016). Even though the included studies all showed some benefits of communication training immediately post-intervention, the lack of follow up means that it is impossible to assess whether there are any long-term benefits of the intervention and whether participants are able to maintain use of the learnt strategies. As the review conducted by Nguyen et al (2018) demonstrated, potential benefits for both formal and informal caregivers that were not identified immediately post-intervention only became apparent when assessed at follow up. This could mean that some of the non-significant results identified in the current review may actually be different if assessed through follow up studies.

There also appear to be limitations in relation to the outcomes used across the studies. Not only was the number of different outcome measures used across the nine studies high, making cross comparisons difficult, nearly a third of all the measures used were newly developed as part of the study as authors stated that they were unable to find suitable measures in the literature. It is important to try to use outcome measures that are well established and have faced rigorous testing in order to ensure reproducibility and to be certain that they are able to validly measure the constructs and populations that they claim to measure (Jerosch-Herold, 2005).

As many of the outcome measures used across the nine studies were newly developed, it is unlikely that they would have faced these rigorous tests and means that the validity and reliability of the data is relatively unknown.

One final, common issue identified across the literature was in relation to blinding. Blinding occurs when participants or assessors do not know which groups participants are allocated to and is important in research as it helps to reduce performance bias, ascertainment bias and can improve the validity of the data (Renjith, 2007). Although it would have been very difficult for participants and researchers to remain blind to group allocation in the studies included in the current review, it is still worth highlighting that the data is likely to been subject to the biases described.

Strengths and limitations of the review

Despite the lack of high-quality studies found within this subject area, this review was able to identify clear benefits and recommendations through rigorous analysis. The results were limited to studies written in English that were published in peer-reviewed journals in order to increase the likelihood of only including high quality data. However, it should be acknowledged that this may have introduced publication bias. Despite these strengths, there were some limitations to this review that have been identified.

The review makes inferences on significance of outcome data based on the information in the included papers, however no further statistical analysis was conducted on these data as they were not amenable to meta-analysis. As the studies used a plethora of methods, design and outcome measures, this makes it difficult to infer direct comparisons between the data. The review conducted by Nguyen et al (2018) demonstrated that effects not identified in initial analyses, could become apparent if data were further subjected to meta-analysis. Also, it is recognised that the use of Kmet et al's (2004) Quality Appraisal tool has its own limitations. For example, quality appraisal tools are designed subjectively as there is

always variability in the criteria chosen to define what dictates quality in research design. The tool does not include guidance on what scores should be considered 'high, medium and low' quality, so it is inevitable that different authors conducting similar reviews using this tool will define these cut offs differently. The authors of the tool also state that it has limited assessment of inter-rater reliability and small sample size on which is it has been tested. Despite this, it was felt to be an appropriate tool in which to assess quality in the current review.

Implications for clinical settings and future research

As the findings from this review demonstrate that participating in communication training programmes can benefit informal caregivers of people living with dementia and the people they care for, there is a clear need for these interventions to be offered in clinical contexts. This is especially important given previous evidence for links between communication, QoL and financial costs (Eggenberger et al, 2013; Zhu & Sano, 2006). However, given the very limited pool of evidence found in this review, it is unlikely that dementia services are currently offering evidence-based training programmes that have a sole or majority focus on communication. This is further compounded by the lack of availability of manuals and protocols from existing evidence-based interventions. Although some of the programmes in this review state that manuals are available, an online search for these by the primary reviewer found that they were either not easily accessible or not published. This makes it difficult for dementia services to train their staff to offer these interventions to their clients.

However, it is worth noting that there may be more systemic reasons that these interventions may not be on offer in clinical contexts. One such reason could be that dementia services maybe be delivering other interventions, such as the STrAtegies for RelaTives (START) programme (Livingston et al, 2013), where communication training is one component. In this instance, there would be less of a need for services to offer interventions that focus solely or majorly on

communication. Despite this, it is important for communication training programmes to be on offer in clinical contexts given the benefits that have been demonstrated. This means that not only is there a need for further research to expand on the current evidence found in this review, there is also a need to ensure that manuals and protocols for these evidence-based interventions are more readily available to increase the likelihood of these programmes being offered in a clinical setting.

It is clear that further research in this area has the potential to develop a strong pool of evidence to support the use of communication trainings with this population. Future research should build on these initial findings by attempting larger scale randomised controlled trials using the training models developed in the current evidence. This will enable more rigorous investigation of the efficacy and efficiency of these interventions. Given the wide variety of outcomes used, it is important for this research to initially focus on further investigation of the outcomes that demonstrated the most benefits for participants. There should also be a focus on trying to narrow down the specific outcome measures used so that closer comparisons can be made across the literature. Doing this will enable more comparison between the interventions to investigate which training models are more efficacious and demonstrate the greatest benefits to participants and the people they cared for, using larger sample sizes that can detect smaller effects. It is also important for future research to routinely incorporate post intervention follow up to allow investigation on the longer-term effects of these training packages.

Conclusions

Although the current evidence base is small, there are clear benefits of offering communication training programmes to informal caregivers of people living with dementia. This review has looked at individual elements of current evidence-based programmes and used this to make recommendations on the key components that trainings should comprise of, the ways in which these trainings can benefit caregivers and the people they care for and which outcome measures

should be used to demonstrate these benefits. However, given the limited pool and varying quality of the current evidence base, recommendations have also been given as to the direction that further research should take in order to build on the existing literature and continue to demonstrate the need for offering communication training programmes to this population.

References

Alvira, M. C., Risco, E., Cabrera, E., Farre´, M., Rahm Hallberg, I., Bleijlevens, M. H., Meyer, G., Koskenniemi, J., Soto, M.E., Zabalegui, A., & RightTimePlaceCare Consortium. (2015). The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: A cross-sectional study. *Journal of Advanced Nursing*, 71(6), 1417–1434.

Alzheimer's Society (2014), Dementia UK: 2014 edition. Alzheimer's Society, Carer Information and Support Programme.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York: W.H. Freeman & Co.

Barnes, C. J., & Markham. C. (2018). A pilot study to evaluate the effectiveness of an individualized and cognitive behavioural communication intervention for informal carers of people with dementia: The Talking Sense programme. *International Journal of Language & Communication Disorders,* 53(3), 615 - 627.

Banovic, S., Zunic, L. J., & Sinanovic, S. (2018). Communication difficulties as a result of Dementia. *Materia Socio Medica,* 30(3), 221 - 224.

Bédard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *Gerontologist,* 41(5), 652–657.

Berkhof, M., Rijssen, H. J., Schellart, A. J. M., Anema, J. R., & van der Beek, A. J. (2011). Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews. *Patient Education and Counselling,* 84(2), 152 – 162.

Biau, D.J., Kernéis, S., & Porcher, R. (2008). Statistics in brief: The importance of sample size in the planning and interpretation of medical research. *Clinical Orthopaedics and Related Research,* 466(9), 2282 – 2288.

Cohen, G., & Faulkner, D. (1986). Does “elderspeak” work? The effect of intonation and stress on comprehension and recall of spoken discourse in old age. *Language and Communication,* 6(9), 1 – 98.

Chesneau, S., Faucher, C., Morin, G., & Le Dorze, G. (2019). Evaluation of AID-COM, a communication-focused program for family carers of people with early-stage Alzheimer's disease: A pilot study (innovative practice). *Dementia.* (London, England).

Chiao, C. Y., Wu H. S., & Hsiao, C. Y. (2015). Caregiver burden for informal caregivers of patients with dementia: A systematic review*. International Nursing Review,* 62, 340 – 350.

Done, D. J., & Thomas, J. A. (2001). Training in communication skills for informal carers of people suffering from dementia: a cluster randomized clinical trial comparing a therapist led workshop and a booklet. *International Journal of Geriatric Psychiatry,* 16(8), 816 - 821.

Downs, M. & Collins, L. (2015). Person-centred communication in dementia care. *Nursing Standard,* 30(11), 37 - 41.

Egan, M., Bérubé,. D., Racine, G., Leonard, C. & Rochon, E. (2010). Methods to enhance verbal communication between individuals with Alzheimer’s disease and their formal and informal caregivers: A systematic review. *International Journal of Alzheimer’s Disease*, 1 – 12.

Eggenberger, E., Heimerl, K., & Bennett, M. (2013). Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics,* 25(3), 345 – 358.

Ferris, S. H., & Farlow, M. (2013). Language impairment in Alzheimer's disease and benefits of acetylcholinesterase inhibitors. *Clinical Interventions in Aging,* 8, 1007 – 1014.

Fossey. J., Masson. S., Stafford., J., Lawrence, V., Corbett, A. & Ballard, C. (2014). The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia. *International Journal of Geriatric Psychiatry,* 29(8), 797 – 807.

Haberstroh, J., Neumeyer, K., Krause, K., Franzmann, J., & Pantel, J. (2011). TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental Health,* 15(3), 405 - 413.

Jerosch-Herold, C. (2005). An evidence-based approach to choosing outcome measures: A checklist for the critical appraisal validity, reliability and responsiveness studies. *British Journal of Occupational Therapy,* 68(8), 347 – 353.

Joseph, S., Becker, S., Elwick, H., & Silburn, R. (2012). Adult carers quality of life questionnaire (AC-QoL): development of an evidence-based tool. *Mental Health Review Journal,* 17(2), 57 - 69.

Julious, S. A. (2005). Sample size of 12 per group rule of thumb for a pilot study. *The Journal of Applied Statistics in the Pharmaceutical Industry,* 4(4), 287 – 291.

Karg, N., Graessel, E., Randzio, O., Pendergrass, A. (2018). Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BioMed Central Geriatrics,* 18(1), 189.

Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Kumar, V. S., & Grimmer, K. A. (2004). A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology*, 4(1), 1.

Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A., & Jaffe, M.W. (1963). Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychosocial function. *Journal of the American Medical Association,* 185, 914 – 919.

Kemper, S. (1994). Elderspeak: Speech accommodation to older adults. *Aging and Cognition,* 1(1), 17 – 28.

Kempler, D., & Goral, M. (2008). Language and dementia: Neuropsychological aspects. *Annual Review of Applied Linguistics,* 1(28), 73 – 90.

Kindell, J., Keady, J., Sage, K. & Wilkinson, R. (2017). Everyday conversation in dementia: a review of the literature to inform research and practice. *International Journal of Language & Communication Disorders,* 52(4), 392 – 406.

Kitwood, T (1997). *Dementia Reconsidered: The Person Comes First.* Open University Press, Buckingham.

Klodnicka Kouri, K., Ducharme, F. C., & Giroux, F. (2011). A psycho-educational intervention focused on communication for caregivers of a family member in the early stage of Alzheimer's disease: Results of an experimental study. *Dementia,* 10(3), 435 – 453.

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. *Alberta Heritage Foundation for Medical Research.* Downloaded on 28/04/2020 from: http://www.ihe.ca/documents/HTA-FR13.pdf

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. *Journal of the American Geriatrics Society,* 9: 179 – 186.

Leon, A. C. (2008). Implications of clinical trial design on sample size requirements. *Schizophrenia Bulletin,* 34(4), 664 – 669.

Liddle, J., Smith-Conway, E.R., Baker, R., Angwin, A. J., Gallois, C., Copland, D. A., Pachana, N. A., Humphreys, M. S., Byrne, G. J., & Chenery, H. J. (2012). Memory and communication support strategies in dementia: effect of a training program for informal caregivers. *International Psychogeriatrics,* 24(9), 1927 - 1942.

Lindeza, P., Rodrigues, M., Costa, J., Guerreiro, M., & Rosa, M. M. (2020). Impact of dementia on informal care: A systematic review of family caregivers' perceptions. *British Medical Journal Supportive & Palliative Care,* 14: Online ahead of print.

Livingston. G., Barber, J., Rapaport, P., Griffin, M., King, D., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Sampson, E. L., & Cooper, C. (2013). Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *British Medical Journal,* 47

Llewellyn-Bennett, R., Bowman, L., & Bulbulia, R. (2016). Post-trial follow-up methodology in large randomized control trials: A systematic review protocol. *Systematic Reviews,* 5(214).

Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Agin,* 5(1), 21 – 3.

Mattock, S., & McIntyre, A. (2015). Exploring the role of occupation for spouse-carers before and after the death of a spouse with dementia. *British Journal of Occupational Psychology,* 79(2).

Mitchell, G., & Agnelli, J. (2015). Person-Centred care for people with dementia: Kitwood reconsidered. *Nursing Standard,* 30(7), 46 – 50.

Morris, L., Horne, M., McEvoy, P., & Williamson, T. (2018). Communication training interventions for family and professional carers of people living with dementia:

a systematic review of effectiveness, acceptability and conceptual basis. *Aging & Mental Health,* 22(7), 863 - 880.

Morris, L., Mansell, W., Williamson, T., Wray, A., & McEvoy, P. (2020) Communication Empowerment Framework: An integrative framework to support effective communication and interaction between carers and people living with dementia. *Dementia,* 19(6), 1739-1757.

Nguyen, H., Terry, D., Phan, H., Vickers, J., & McInerney, F. (2018). Communication training and its effects on carer and care-receiver outcomes in dementia settings: A systematic review. *Journal of Clinical Nursing,* 28(7-8), 1050 - 1069.

Petracchi, H. E. (1999). Using professionally trained actors in social work role-play simulations. *Journal of Sociology and Social Welfare,* 26(4), 61 – 69.

Piersol, C. V., Canton, K., Connor, S. E., Giller, I., Lipman, S., & Sagar, S. (2017). Effectiveness of interventions for caregivers of people with Alzheimer's disease and related major neurocognitive disorders: A systematic review. *The American Journal of Occupational Therapy,* 71(5), 1 - 10.

Potkins, D., Myint, P., Bannister, C., Tadros, G., Chithramohan, R., Swann, A., O'Brien, J., Fossey, J., George, E., Ballard, C., & Margallo-Lana, M. (2003). Language impairment in dementia: Impact on symptoms and care needs in residential homes. *International Journal of Geriatric Psychiatr,* 18(11), 1002 – 1006.

Renjith, V. (2017). Blinding in randomized controlled trials: What researcher's need to know? *Manipal Journal of Nursing and Health Sciences*, 3(1), 45 – 50.

Scerri, A., Innes, A., & Scerri, C. (2017). Dementia training programmes for staff working in general hospital settings – a systematic review of the literature, *Aging & Mental Health*, 21(8), 783 – 796.

Schwarzer, R., & Jerusalem, M. (1995). Generalised self-efficacy scale. In J. Weinman, S. Wright and M. Johnston (eds), *Measures in Health Psychology: A Users' Portfolio. Causal and Control Beliefs.* Windsor: NFER-Nelson.

Silvestri, A., Rosano, G., Zannino, G., Ricca, F., Marigliano, V., & Fini, M. (2004). Behavioral disturbances in Alzheimer's disease: A non-pharmacological therapeutic approach. *Archives of Gerontology and Geriatrics,* 38(SUPPL.), 379 - 386.

Tarlow, B. J., Wisniewski, S. R., Belle, S. H., Rubert,M., Ory, M. G., & Gallagher-Thompson, D. (2004). Positive aspects of caregiving: contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging,* 26, 429 – 453.

Teare, M. D., Dimairo, M., & Shephard, M. (2014). Sample size requirements to estimate key design parameters from external pilot randomised control trials: A simulation study. *Trials,* 15, 264 – 264.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: the revised memory and behaviour problems checklist. *Psychology and Aging,* 7, 622 – 631.

Troche, J., Willis, A., & Whiteside, J. (2019). Exploring supported conversation with familial caregivers of persons with dementia: A pilot study. *Pilot & Feasibility Studies,* 5, 10.

Watson, B., Aizawa, L. D., Savundranayagam, M. Y., & Orange, J. B. (2012). Links among communication, dementia and caregiver burden. *Canadian Journal of Speech-Language Pathology and Audiology,* 36(4), 276 – 283.

Williams, C. L., Newman, D., & Hammar, L. M. (2017). Preliminary psychometric properties of the verbal and nonverbal interaction scale: an observational measure for communication in persons with dementia. *Issues in Mental Health Nursing*, 38(5), 381 - 390.

Williams, C. L., Newman, D., & Hammar, L. M. (2018). Preliminary study of a communication intervention for family caregivers and spouses with dementia. *International Journal of Geriatric Psychiatry,* 33(2), e343 - e349.

Williams, C., & Parker, C. (2012). Development of an observer rating scale for care-giver communication in persons with Alzheimer's disease. *Issues in Mental Health Nursing,* 33, 244 - 250.

Williams, K. N., Ayyagari, P., Perkhounkova, Y., Bott, M. J., Herman, R., & Bossen, A. (2017). Costs of a staff communication intervention to reduce dementia behaviours in nursing home care. *Journal of Nursing Home Research,* 3, 22 – 27.

Williams, K., Shaw, C., Lee, A., Kim, S., Dinneen, E., Turk, M., Jao, Y. L., & Liu, W. (2017). Voicing ageism in nursing home dementia care. *Journal of Gerontological Nursing,* 43(9), 16 – 20.

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. *Care Policy and Evaluation Centre, London School of Economics and Political Science.* Downloaded on 24/01/2021 from: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

World Health Organization (2017). Global action plan on the public health response to dementia: 2017 – 2025. Downloaded on 08/02/2021 at https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=512E904F42B330C3350385892F5733E0?sequence=1

Young, T. J., Manthorp, C., Howells, D., & Tullo, E. (2011). Developing a carer communication intervention to support personhood and quality of life in dementia. *Ageing & Society,* 31, 1003 – 1025.

Zhu, C. W. & Sano, M. (2006). Economic Considerations in the management of Alzheimer's disease. *Clinical Interventions in Aging,* 1(2), 143 – 154.

Part 2: Empirical Paper

vCST - A pilot feasibility study of a newly developed virtual CST protocol for people living with dementia and its impact on mood and quality of life

Abstract

Background: This feasibility pilot study aimed to develop and evaluate a 14-session virtual Cognitive Stimulation Therapy (vCST) programme for people living with dementia. The study investigated the feasibility and acceptability of delivering vCST, the feasibility of investigating vCST in a larger trial and impact of vCST on mood and quality of life.

Method: The vCST protocol was developed using the existing group CST manual, through collaboration with the University of Hong Kong and stakeholder consultation with people living with dementia, caregivers, CST group facilitators and dementia service managers. The vCST protocol was then piloted with 22 people living with dementia recruited from various health services, third sector services and research websites across the UK and Ireland. Twelve participants were allocated to receive vCST and ten to receive treatment as usual. Outcomes relating to feasibility, mood, quality of life and cognition were investigated. This is a joint project with Cerne Felstead. Analysis of feasibility, mood and QoL are reported here.

Results: The intervention appeared both feasible and acceptable, with high recruitment rates, high levels of attendance and low attrition. ANOVAs indicated no significant differences between groups on either the QoL-AD or the Geriatric Depression Scale.

Conclusion: vCST is a feasible and acceptable online intervention for people living with dementia. We recommend that vCST is offered to people living with dementia who cannot access in-person CST for health reasons, travel restrictions or during the Covid-19 pandemic. A larger trial is necessary to further investigate the impact on mood, QoL and other outcomes.

Introduction

Given that there are 50 million people living with dementia across the globe and rising, there is a significant need to develop interventions that tackle the physical, mental, social and financial impacts from this illness (Mauricio et al, 2019). There are currently no known treatments that can halt or reverse the progressive neurological deterioration resulting from dementia, making the need for supportive interventions ever more pressing. Cognitive Stimulation Therapy (CST) is currently the most well-established psychological intervention for people living with dementia and has demonstrated benefits in relation to cognition, quality of life (QoL) and overall cost effectiveness (Spector et al, 2020). It was developed by Spector et al (2003) to be a brief, 14 session intervention for people living with dementia that is delivered in a face-to-face, group-based format. However, CST and other dementia interventions and treatments have been largely inaccessible during the recent Covid-19 pandemic due to the need for social distancing, leading services to cease face to face contact with their clients (Cuffaro et al, 2020). Not only has this created a need to rapidly adapt interventions and treatments so that they can be delivered without face-to-face contact during the current pandemic, but has also highlighted the lack of access to treatments that certain groups face outside of the pandemic context, such as those living with physical disabilities.

Cognitive Stimulation Therapy

CST was developed as a result of a 1998 Cochrane review on Reality Orientation interventions that had been popular to use with people living with dementia for several decades (Spector et al, 2003). Reality orientation interventions are designed to repetitively present orientation-based information to individuals or groups and have been found to be associated with significant benefits in terms of QoL, cognition and behaviour (Spector et al, 2001). However, reality orientation interventions fell out of popular use towards the end of the 21st century as they were criticised for being too rigid and insensitive in their application. Other psychological

interventions, such as Reminiscence therapy and Validation therapy, were also in use with dementia populations, however there was a distinct lack of clear evidence that these interventions were beneficial and the quality of their research base was largely poor. Spector et al (2001) reviewed all the evidence for the different psychological interventions for people living with dementia to develop the CST programme using the various beneficial elements from each therapy that were identified through this evaluation.

CST was designed to provide mental stimulation in a sociable and enjoyable context and is based on a number of principles, including 'using opinions rather than facts, making new associations, giving choice, being multisensory and being person centred' (Spector et al, 2020). It is hypothesised that this mental stimulation activates neurons in the brain, leading to enhanced neuron function and survival (Swaab et al., 2002). This hypothesis was supported through a study by Hall et al (2013) who administered neuropsychological testing to CST participants post-group to investigate its impact on a variety of specific cognitive domains. They found significant improvements in comprehension of syntax and orientation which are the cognitive domains thought to be most activated through CST. However, they also found significant improvements in memory which was surprising as CST relies on implicit learning rather than explicit rehearsal of material or other mechanisms used in memory. Therefore, they also proposed an alternative hypothesis that the positive, yet challenging, learning environment presented by CST activates not only existing memory related pathways, but also creates alternative pathways that ultimately enhance neuronal function.

An initial randomised controlled trial demonstrated that CST can benefit people living with dementia in relation to cognition and QoL (Spector et al, 2003) and, since its development, this evidence base has continued to grow significantly (Woods et al, 2006; Spector et al, 2010; Aguirre et al, 2013; Lobbia et al, 2018). CST has also been shown to be cost-effective (Knapp et al, 2013) and can benefit

people living with dementia independent of any pharmacological treatments they may be using (Aguirre et al, 2013). This has not only resulted in CST being recommended as a key psychosocial intervention for dementia in the UK (NICE, 2018) but for culturally adapted versions of CST to be successfully implemented across the globe (Wong et al, 2018; Mkenda et al, 2018; Marinho et al, 2021). More recently it has culminated in additional versions of CST that bolster its cognitive and QoL benefits, as demonstrated through the 16 to 24 week-long Maintenance CST programme (Orrell et al, 2014), and improve access to those who are unable to make face to face group sessions, as demonstrated through the Individual CST programme (Orrell et al, 2017).

Although CST is now a well-established dementia intervention used globally in both research and clinical contexts, access to face-to-face interventions such as this was immediately and unexpectedly restricted when the Covid-19 pandemic spread throughout the world in early 2020 (Giebel et al, 2020). Not only did this result in people living with dementia who were previously able to access services, treatments and interventions no longer being able to do so, but also highlighted the gap in service provision for people who were not able to access services outside of the pandemic context (Cuffaro et al, 2020). This includes people living with dementia who live in rural communities who cannot readily access transport or those with reduced mobility. In response to the pandemic, many services have had to adapt rapidly in order to keep services accessible whilst maintaining the need for social distancing. This has seen services turn to developing treatments and interventions that can be delivered using digital technology (Cuffaro et al, 2020).

Digital technology in psychological interventions

The use of digital technology or ‘e-Health’ was already becoming widespread in non-dementia populations (such as adults with anxiety and depression), even before its mass adoption that occurred as a response to the pandemic and the need for social distancing (Dores et al, 2020). ‘E-Health’ is defined by the World Health

Organization (2005) as 'the cost-effective and secure use of information and communications technologies in support of health and health-related fields'. Leading up to the pandemic, most of the digital psychological interventions on offer were Cognitive Behavioural Therapy (CBT) based (Fairburn & Patel, 2017), although other psychological therapies have been demonstrated to be beneficial when delivered virtually (Donker et al, 2013; Pots et al, 2016). Overall evidence suggests that using E-health technologies in order to continue to deliver psychological interventions during the pandemic and beyond can still be feasible and effective (Di Carlo et al, 2021).

Despite this evidence surrounding the use of digital technologies in psychological interventions, there is a clear underrepresentation of use of e-health with older adults in the literature despite being an effective treatment option for this population (Crabb et al, 2012; Staples et al, 2016). Although it can still be effective, evidence suggests that older adults can find it more difficult than working age adults to access e-health interventions due to a number of barriers. These include reduced computer self-efficacy, lack of trust in digital interventions and beliefs that symptoms they are experiencing are a normal part of aging and so are less likely to seek support (Pywell et al, 2020; Wuthrich & Frei, 2015). This is further compounded in people living with dementia who face declining cognitive ability and independent day-to-day functioning, making engagement in e-health interventions even less feasible (Charness & Boot, 2009; Peel et al, 2011). However, not only has research shown that there is increasing interest in accessing e-health interventions within the dementia population but there is also evidence that people living with dementia can still benefit from e-health interventions in a variety of psychological, social and cognitive domains (LaMonica et al, 2017; Lazar et al, 2014).

As the use of e-health in dementia care is still a relatively new area of interest, especially in relation to the Covid-19 pandemic, the current literature pool is still relatively small. However, the research in this area that does currently exist is

very promising. For example, Burton & O'Connell (2018) investigated the use of delivering goal-orientated cognitive rehabilitation to people living with dementia and found that it was feasible and comparable to face-to-face sessions in relation to goal achievement, albeit with the need for modifications such as more input from caregivers to manipulate materials. Another study investigated the impact of delivering a weekly psycho-social support and psychoeducational intervention to people living with dementia and their caregivers via video conferencing applications during the Covid-19 pandemic and found an improvement in resilience and wellbeing when compared to telephone sessions (Ho-yin Lai et al, 2020). This suggests that despite the barriers that people living with dementia face when accessing e-health interventions, it is both feasible and beneficial to offer these to this population. This is further supported through a review of online cognitive training for people living with dementia (García-Casal et al, 2017) who found that 'computer-based cognitive interventions were associated with significant improvements in cognition, depression and anxiety'.

Aims of the current study

The findings demonstrated in these early stages of research on e-health interventions for people living with dementia pave the way for further expansion of e-health application to a wide variety of currently used programmes. CST is one such programme that could benefit from an adaptation for online use, especially in the context of the Covid-19 pandemic where services are still adhering to social distancing measures. Although there have been trials for testing the feasibility of using technology for individual CST (Rai et al, 2021), no current literature exists for using technology for the group-based CST.

The current study aims to develop and pilot a new virtual CST (vCST) protocol. The main aims of this feasibility pilot study are:

1. To assess whether this vCST protocol is feasible and acceptable to deliver to people living with dementia

2. To assess the feasibility of testing the vCST as part of a larger research trial
3. To consider the impact of vCST on mood and QoL

Method

This is a joint research study conducted with CF. The present study reports on outcomes relating to the development of vCST, outcomes of feasibility and acceptability and outcome measures of mood and QoL. CF will report on outcomes of cognition and qualitative feedback post-group. The contributions of each trainee to the research are outlined in Appendix B.

Ethical considerations

Ethical approval for the study was received from the University College London Research Ethics Committee (Project ID: 17127/001, see Appendix C). This approval included governance requirements for the Republic of Ireland arm of the study and involved applying for and gaining ethical approval from the ethics committee overseeing research within the organisation where this arm of the study was conducted. All participants gave informed consent prior to participation in the study (see Appendix D. for all participant information sheets and consent forms). They were informed that they could withdraw at any point throughout the study without having to give a reason. Their capacity and consent to take part was reviewed throughout the study.

Overview

The study followed the Medical Research Council's guidance on 'developing and evaluating complex interventions' (Craig et al, 2019). The guidance outlines four stages: development of an intervention, feasibility and piloting, evaluation, and implementation. The current study consists of intervention development, feasibility and piloting only. The project was split into two parts:

1. Development of the vCST intervention using the existing CST group manual (Spector et al, 2020) and stakeholder consultation.
2. Running a feasibility pilot study of the intervention, with treatment and control groups, to assess the feasibility and acceptability of delivering vCST to people living with dementia, to assess the feasibility of testing the intervention in future research trials and to measure changes in outcome measures related to mood and QoL

Part 1 – Development of vCST protocol for people living with dementia

The vCST protocol was developed by adapting the existing CST group manual (Spector et al, 2020) alongside stakeholder consultation. The final vCST protocol will be outlined in detail in the results section. The general session structure and content, including themes and activities, followed that which is outlined in the original CST group manual, with some activities being adapted for online delivery (i.e., showing pictures of childhood toys on the screen to discuss in the 'childhood' session instead of passing toys around the group as would happen for in-person CST). This was done in collaboration with the Hong Kong (HK) FaceCog team, a group of researchers from the University of Hong Kong who had started a trial of vCST in Hong Kong prior to the start of the current study (see https://ltccovid.org/wp-content/uploads/2020/06/Gloria-Wong-Tele-Cognitive-Stimulation-Therapy.pdf).

After initial consultation with the HK Facecog team, it was agreed that the current study would be run as the 'UK and Ireland' equivalent to their vCST study in order to facilitate comparisons at a later date. Both teams worked closely throughout the development stage of the project to ensure the vCST intervention and protocols were aligned as much as possible, whilst also accounting for specific cultural adaptations and needs of each project. Similarities included using the same general structure and themes of sessions, the same group sizes, the same

videoconferencing software ‘Zoom’ and the same measures whilst differences mainly came in the form of culturally adapted activities within the sessions. Unfortunately, it was not within the scope of the project to work closely throughout the implementation stage of the project so comparisons could not be made in of aspects of this stage such as recruitment methods.

Stakeholder consultations supported the development of the delivery and implementation components of vCST. This consultation was conducted through four focus groups involving different types of stakeholders: people living with dementia, caregivers of people living with dementia, CST group facilitators and service managers. Details regarding participant numbers for each group are outlined in the results section. Participants for the focus groups were recruited via email contact and attendance at service user meetings in collaboration with various third sector dementia organisations across the UK.

Questions for all consultations were developed using the Consolidated Framework for Implementation Research (Damschroder et al, 2009). This framework was developed from a synthesis of implementation research and theory. It consists of consolidated constructs that facilitate the identification and understanding of factors that impact the implementation of interventions in different contexts. Interview questions were developed in relation to the five main domains of the framework: intervention characteristics, outer setting, inner setting, characteristics of individuals and process. All focus groups were conducted via the online video conferencing platform ‘Zoom’ and were recorded for post-group analysis. The researchers then took field notes from these recording which were clustered together into key ideas. The data gathered from the focus groups was used to develop guidelines for delivering vCST (see Appendix E). These guidelines were used to inform the delivery of vCST for the feasibility pilot study in the current study, but were also available to be disseminated to external vCST group facilitators.

Part 2 – Feasibility pilot study

Design

This feasibility pilot study used an RCT design with a treatment group (vCST) and a control group (treatment as usual). The treatment group included two vCST groups conducted in the UK and one conducted in the Republic of Ireland. The control group was defined as treatment as usual (TAU), meaning that participants were not offered vCST sessions or any other intervention but could access their usual services and interventions outside of the study.

Participants

Participants were recruited from a variety of different sources. Participants in the UK either recruited by registering their interest in the study on the Join Dementia Research website or by contacting researchers through advertisement within different third sector services. Join Dementia Research (JDR) is a website that researchers can advertise and recruit people living with dementia for any current studies they need participants for and for people living with dementia to search for and sign up to studies that they may be interesting in participating in. The JDR website can be found at https://www.joindementiaresearch.nihr.ac.uk/ . Advertisement included study posters (see Appendix F) sent out to service users registered with the service and talks given by the researchers at group meetings hosted by the service. Participants in the Republic of Ireland were recruited from a pre-existing waiting list for face-to-face group CST that had been temporarily suspended due to the Covid-19 pandemic. This was conducted in collaboration with an Occupational Therapist working for a dementia service in the Republic of Ireland who recruited participants from the service's waiting list.

Once participants had registered interest in taking part in the study, participant information sheets were emailed to them and they were offered a 'Zoom' call with the researcher to discuss the study in more detail before deciding whether

to take part. Participants were only able to participate if they met the inclusion criteria below. If participants met these criteria and agreed to participate following this 'Zoom' call, they were emailed a consent form and statement of consent for them to sign and email back to the researchers.

Inclusion criteria

Individuals were able to take part in the study if they met the following inclusion criteria:

- Have a diagnosis of dementia as given in the Diagnostic and Statistical Manual of Mental Disorders V (DSM-V, American Psychiatric Association, 2013).
- Have the capacity and ability to be able to fully participate in vCST sessions online
- Be able to communicate verbally in English.
- Have capacity to consent to taking part in the study
- Have access to a device capable of videoconferencing and internet at home.
- Not accessing any other psychosocial intervention at the time of participation

Procedure

Once participants had given consent to participating in the study, they were assigned a unique code for randomisation and data collection. Participants were randomly allocated to the treatment group (vCST) or the control group (TAU) using their unique codes and the RAND function on Microsoft Excel. Both groups participated in a one-hour, individual assessment session on 'Zoom' within the week prior to the first vCST session to complete the battery of measures used in the study. Following this assessment, the treatment group participated in the bi-weekly 14 sessions vCST sessions and the control group continued with treatment as usual outside of the study. Both groups of participants then completed the same battery of

measures in a one-hour individual assessment session on 'Zoom' within two weeks following the final vCST session.

For the first UK group, both participants and researchers were informed of their group allocation before the pre-measures assessment. However, it was recognised that this likely introduced unnecessary bias into the study, so this was changed for the other two groups. Participants for the Republic of Ireland group and the second UK group were blinded to group allocation at their pre-measures assessment and were only informed once this was completed, whilst researchers conducting the pre- and post-measures assessments remained blind until after all data had been collected.

Capacity

Participants' capacity to take part in the study was assessed in accordance with the Mental Capacity Act (2005) at the initial 'Zoom' call, where participants were given information about the study. Potential participants were given clear written information prior to the meeting and this was discussed verbally in the meeting. Information about the study was discussed in detail, in small chunks and with repetition if necessary, to support participants' ability to receive and retain information. Potential participants were given ample opportunity to ask questions and were asked about their understanding of what has been discussed after each small section to support potential participants ability to understand and weigh up the information given. Consent forms were then given to potential participants who appeared to have capacity, which they were asked to read over before signing. Capacity to consent was continuously assessed throughout the study by the researchers at each subsequent meeting to check if there had been any significant decline in cognition or understanding of participation in the study.

Primary outcome measures - Feasibility and acceptability

Bowen et al (2009) defines feasibility as 'whether an intervention is appropriate for further testing; in other words, they enable researchers to assess

whether or not the ideas and findings can be shaped to be relevant and sustainable'. Acceptability is one area of focus when testing feasibility and is defined as 'how the intended individual recipients—both targeted individuals and those involved in implementing programs—react to the intervention'. The current study assessed whether vCST is feasible to deliver as an online intervention for people living with dementia, whether it is an acceptable intervention by the people participating in it and whether it is feasible to test in a research trial setting. Only quantitative measures of feasibility and acceptability will be reported in the current study (qualitative measures will be reported in the report by CF). This will include information on recruitment and retention, participant demographics at baseline, attendance and adherence, feasibility of outcome measures and fidelity. For the purposes of the study, the intervention will be deemed acceptable and feasible if retention rates, attendance rates and completion of outcome measures are higher than 75%. This figure was chosen as an indicator of feasibility and acceptability based on similar literature on trialling new interventions (i.e. Livingston et al, 2019).

Secondary outcome measures - Mood and QoL

All participants were asked to complete the same battery of tests at the pre- and post-measures assessments. Assessors remained blind to participants' groups allocations at both pre- and post-measures assessments. Participants were asked to complete one mood measure and one QoL measure, which will be discussed in the current study, alongside two measures of cognition which will be discussed within the report by CF. Both the mood and QoL measures were administered verbally to participants over video call on 'Zoom'.

Mood - The Geriatric Depression Scale short form (GDS-15) is a 15-item questionnaire used to measures Depression symptoms in older adults (Sheikh & Yesavage, 1986) (see Appendix G). Although there is no previous evidence that group-based CST can improve mood, the GDS-15 was used in the current study to investigate whether any mood difficulties would be evident in the sample, given the

isolation that participants may have faced during the Covid-19 pandemic, whether vCST had impact on this and whether this measure was a feasible measure to use in further trials of vCST. The questionnaire consists of 15 questions relating to different symptoms of depression and is self-rated by the people living with dementia. Answers are given in a yes/no format and scored a 0 if the answer indicates absence of depression symptom or 1 if the answer indicates presence of depression symptom. Total scores range from 0-15 with scores higher than 5 indicating likely signs of depression. The GDS-15 has been found to be a valid and reliable tool for measuring depression in dementia populations (Lach et al, 2010).

QoL - The Quality of Life – Alzheimer's Disease (QoL-AD) is a 13-item questionnaire that measures QoL in people with dementia (Logsdon et al, 1999). The QoL-AD consists of 13 questionnaires relating to different domains of life and is self-rated by people living with dementia. Domains assessed include physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, fun, ability to do chores around the house, ability to do things for fun, money, and life as a whole. Each item is rated on a four-point scale, where poor = 1, fair = 2, good = 3, and excellent = 4. Scores range from 13 to 52, with higher scores indicating better quality of life. The QoL-AD has been found to have high reliability and validity for use with dementia populations (Logsdon et al, 2002).

Data Analysis for Secondary Outcomes

Analysis for the secondary outcomes was conducted using SPSS version 27. Two mixed analysis of variances (ANOVAs) were employed to analyse the data from each questionnaire to determine whether there were any significant differences between the means of the pre-post test scores and between the treatment and control groups. For each ANOVA, the alpha was set at 0.05, time was set as the within subjects factor and group was set as the between subjects factor. Participant's data were only included in the analysis if they completed both the

baseline and follow up assessments. Participant's data were excluded from the analysis if they withdrew from the study at any point.

Results

Part 1 - Development of vCST protocol for people living with dementia

Stakeholder Consultation

Twenty participants took part in the consultation process across four focus groups. Group one was attended by three people living with dementia from the same third sector organisation in the south-west of England. One individual session was conducted by the researcher for a fourth people living with dementia from a different third sector organisation in the north of England. All four had attended group CST sessions in person before the first UK national Covid-19 lockdown before switching to virtual CST groups midway through the intervention. Group two was attended by four caregivers of people living with dementia, three recruited from a third sector organisation in the south-east of England and one from a third sector organisation in the south-west of England. Only one caregiver had cared for a people living with dementia who had previously attended vCST before. Group three was attended by Eight vCST facilitators, one of whom was recruited from the Facecog team and all others were recruited from various third sector dementia organisations across England. All had facilitated vCST sessions online previously. Group four was attended by four service managers recruited from various third sector dementia organisations across England, only one of whom worked for a service that had already implemented vCST sessions. The key ideas relating to each of the CFIR domains are outlined below (Tables 1. – 5.).

Table 1. Key questions and ideas relating to the 'Intervention' CFIR domain

Stakeholder Group	Key Questions	Key Ideas
People living with dementia	- What aspects of CST would need to be different to successfully implement in an online setting	- Need for sufficient access to technology - Limited access to physical objects for multisensory component of activities, however sessions still work well without this - Need for smaller group size than in-person CST. Optimal number of participants is four
Caregivers	- What aspects of CST would need to be different to successfully implement in an online setting	- Limited access to physical objects for multisensory component of activities. This could be resolved by asking group members to bring objects themselves to each session to enhance discussions. These could be posted to people living with dementia by facilitators, purchasing these themselves or bringing objects they already have. - Need to support people living with dementia transition to attending sessions in online platform as may have little to no experience of using computer technology. - Could be resolved by offering a one-to-one 'warm up' session with the facilitator before the group begins to give people living with dementia experience of being on a video call. - Need for facilitators to be more directive, slower and simplified with discussions and for caregivers to have more of a supportive role than would be the case for in-person sessions.
vCST Facilitators	- What is the optimal group size?	- Optimum group size is four to five
	- Which CST sessions work well virtually and which need adapting?	- Sessions that work well virtually include sessions like childhood that are predominantly discussion-based as requires no extra resources or adaptations. - Sessions that are more difficult to deliver virtually include sessions such as food or being creative as the multisensory components are restricted without access to physical objects - Adaptations for online delivery include showing online images using a 'share screen' function or asking group members to bring household objects to the sessions to supplement discussions and adapting the warm-up activity to include throwing a 'virtual ball' to group members, bringing a household object to discuss or listening to a song together
	- Are session handouts helpful to people living with dementia in vCST?	- Handouts could be helpful to supplement sessions but may be difficult to get to group members if unable to print them from home or facilitators are not able to post them.

	- Is it feasible for services to offer the recommended CST dose virtually, i.e., two sessions a week for seven weeks?	- Difficult for services to offer the recommended CST doses generally due to resource restrictions but easier for services to stick to this protocol in an online setting rather than in person as it did not require participants to travel.
	- Which video conferencing app is best to use to deliver vCST?	- 'Zoom' is the most popular video conferencing app to use for vCST delivery as it is most used and had some features that the make sessions more interactive and multisensory, including the share screen, whiteboard and clap functions.
Service Managers	- What are the advantages and disadvantages of implementing vCST in services?	- Advantage - vCST can increase attendance and access to CST compared to in-person sessions due to removal of travel and preparation time. - Advantage – vCST is relatively cheap to run so does not require large amounts of funding. - Disadvantage - Less peer support opportunities for caregivers as they are not able to spend time with each other whilst the people they care for attending sessions. This often occurs for people attended in-person CST. - Disadvantage - Increased role for caregivers in set up could mean that they become too involved if they participate and contributing in sessions themselves. - Disadvantage - Cohort of people living with dementia accessing vCST are generally less confident in or do not like using technology so maybe more likely to decline taking part or being able to engage in sessions. Engagement could be supported with smaller groups as this may encourage people to attend more. - Disadvantage - Having vCST sessions online may create difficulties in facilitating group cohesion compared to in-person sessions. Cohesion could be supported by facilitators being more directive in asking questions, encouraging group participation and having a second facilitator to support the process.
	- What investments are needed for services to implement vCST successfully?	- Investments required to implement vCST includes training staff in vCST delivery, allocating time for staff to prepare and evaluate the sessions and obtaining suitable technology for both group members and facilitators to access sessions. people living with dementia must have access to a laptop or tablet to make sure the screen is large enough.

Table 2. Key questions and ideas relating to the 'Outer Setting' CFIR domain

Stakeholder Group	Key Questions	Key Ideas
People living with dementia	- Are there dementia interventions available to people living with dementia when they are unable to attend services in person? - Would people living with dementia participate in vCST if it was available to them? What would influence this decision?	- No interventions/services for people who cannot access these in-person that people living with dementia are aware of but felt these are needed to increase access - Open to attending vCST if available if sufficient information given beforehand. This includes testimonials from previous attendees, being shown clips or demonstrations of previous sessions or attending with someone they knew.
Caregivers	- Are there dementia interventions available to people living with dementia when they are unable to attend services in person? - Would people living with dementia participate in vCST if it was available to them? What would influence this decision?	- Only aware of online interventions primarily for caregivers but included joint groups with the people they cared for, not aware of any online interventions directly for people living with dementia. - Offer of vCST likely to be taken up by people living with dementia due to perceived benefits of brain stimulation, however this would need to be initiated and organised by caregivers.
vCST Facilitators	- To what extent can people living with	- people living with dementia generally become more independent with using video conferencing as they gain experience with using it, although most always require caregiver support to set up.

	dementia independently access vCST?	- Caregivers are essential in ensuring people living with dementia can access and participate in vCST, although caregivers should not become too involved by not participating in sessions and not contributing on behalf of the people they care for.
	- What factors or characteristics of people living with dementia affect their ability to engage in vCST?	- Characteristics of the people living with dementia that decrease their ability to engage in vCST include aphasia, visual or auditory impairments, more severe levels of dementia and group members' abilities or concerns in using technology. - These can be supported by advising the use of headphones, using a bigger screen or using videos or testimonials from previous sessions to encourage new members to attend if they were not confident or had concerns about attending.
Service Managers	- Are there dementia interventions available to people living with dementia when they are unable to attend services in person?	- There were some local and some national services for people living with dementia who are not able to attend services in-person, such as telephone befriending and the Alzheimer's society helplines, but these are few and far between, have been suspended during the Covid-19 lockdown or are limited in the amount of support they can offer
	- What barriers are there for people living with dementia accessing dementia services?	- Barriers for people living with dementia accessing dementia services include knowledge of what services are available and how to navigate these, worries relating to expectations of interventions or feeling assessed by services and having the right technology or means of accessing these services. people living with dementia can be supported with access by advertising services and interventions in a way that is understandable, attractive and reassuring.
	- What local or government policies or incentives can support implementation of vCST	- Services are not aware of many policies to support vCST implementation however there are some policies to make local areas dementia friendly and national policies to digitalise health care in the NHS long term plan.

Table 3. Key questions and ideas relating to the 'Inner Setting' CFIR domain

Stakeholder Group	Key Questions	Key ideas
People living with dementia	- What factors would affect the likelihood that people living with dementia would attend vCST	- Factors increasing likelihood of participation include being easily accessible, being at a convenient time of the day, knowing that others in the group also had a diagnosis of dementia, other attendees living locally and having a group facilitator with good interpersonal skills to support efficient group facilitation. - Factors decreasing likelihood of participation include being a caregiver for another person as they would not have the time to attend or difficulty getting online because of poor internet or lack of knowledge around use of technology. - Some discomfort meeting others for the first time online as opposed to in-person but would not affect attendance.
Caregivers	- What factors would affect the likelihood that people living with dementia would attend vCST - What are the perceived benefits of vCST	- Factors increasing likelihood of participation include knowing or remembering other group members on the screen, being at a convenient time of day that also capitalises alertness levels, having regular session reminders and playing back recorded session. - Factors decreasing likelihood of participation include larger group sizes and having a smaller screen - Benefits of vCST include social interaction with others, could create more conversation with partners and families and could be better online than in-person for people living in rural places or people who are unable to leave the house.
vCST Facilitators	- What organisational resources are required to run vCST?	- The main organisational resources needed to run vCST are time for planning, adapting the sessions for online delivery, recruitment, group facilitation and administration alongside having access to the required technology, including a zoom subscription.

Service Managers	- How are decisions on dementia treatments made centrally and locally?	- Most NHS services offer treatments or interventions that are evidence based and in NICE guidelines, whereas third sector services have more flexibility to offer interventions based on service user need. - Investments tend to be made more for intervention at the acute stages of dementia, such as acute bed space or care homes, rather than at the more preventative, early stages which could be more cost-effective in the long run.
	- Is there any local support available for vCST implementation?	- There is no known local support for vCST implementation in services. Interventions such as vCST tended to be implemented from the bottom up rather than through top-down investments.
	- How essential is vCST implementation in dementia services?	- vCST implementation is essential in order to increase access for service users who are unable to travel.

Table 4. Key questions and ideas relating to the 'Individual' CFIR domain

Stakeholder Group	Key Questions	Key Ideas
People living with dementia	- How confident/able do people living with dementia feel about using video conferencing technology - What support is needed for people living with dementia to use video conferencing the access vCST? - Are people living with dementia able to stay engaged in vCST using video conferencing apps?	- Using video conferencing initially daunting due to lack of experience. - However, video conferencing apps like 'Zoom' perceived positively once experienced as enables people living with dementia to see other people when social distancing, thus reducing feelings of isolation. - Unable to access video conferencing independently, therefore friend, caregiver or family member required to support with access alongside 'how to' guide. - Able to engage in sessions for 60 minutes without becoming tired or distracted.
Caregivers	- How confident/able do people living with dementia feel about using video conferencing technology - What are the facilitators and barriers for people living with dementia using video conferencing apps to access vCST	- Video conferencing works well with people living with dementia but requires caregivers to set up and support in most cases. - Preference for 'Zoom' over other video conferencing apps due to experience. - Concerns with using this technology included sessions becoming interrupted if members are having internet issues and not being sure how private or secure using these apps were. - Engagement could be supported by caregivers giving gentle encouragement to engage and facilitators allowing some flexibility for participants to 'dip in and out' of sessions if needed.

	- What support is needed for people living with dementia to use video conferencing the access vCST? - Are people living with dementia able to stay engaged in vCST using video conferencing apps? - What factors affect people living with dementia's ability to engage in vCST?	- Concerns that people living with dementia would find it difficult to concentrate or stay engaged online for a 60-minute session. - Factors affecting people living with dementia's ability to engage in vCST include severity of cognitive impairment, facilitators integrating into the group rather than sitting outside of it and having a caregiver to support set up and attendance of sessions.
vCST Facilitators	- Do group facilitators require extra training to be able to run vCST groups?	- Extra training would be beneficial for group facilitators to support them to run groups, especially in being able to operate video conferencing apps for vCST as facilitators may lack experience in using this technology.
Service Managers	- Do facilitators need training in being able to deliver vCST?	- Training would be helpful for vCST facilitators, specifically in using zoom to deliver the sessions as this was something that staff had less experience with.

Table 5. Key questions and ideas relating to the 'Process' CFIR domain

Stakeholder Group	Key Questions	Key Ideas
People living with dementia	- What were are the positives and negatives of people living with dementia's experiences of vCST?	- Positive include social component of groups being enjoyable, activities feel stimulating and more convenient attending sessions from home than traveling to services. - Negatives include finding it difficult to see what was on the screen if it was too small, so important to have a big enough screen for the session - Preference for in-person CST over vCST as difficult not having physical contact with others, but better to offer vCST than offer nothing as it facilitated connection with others.
Caregivers	- How can caregivers support engagement in vCST for the people they care for?	- Engagement could be supported through encouragement, giving reminders close to the session, being present and prompting.
	- Do caregivers feel able to leave the people they care for to participate in vCST without caregivers present?	- Caregivers able to leave people they care for to participate in vCST without them but would need to be nearby to offer technical support if needed. Caregivers are essential for reminding participants about sessions and to bring any objects that were agreed with the facilitators.
vCST Facilitators	- What measures can be taken to ensure that vCST groups can start on time?	- Measures to support facilitators to ensure groups start on time include sending reminder emails on the day, inviting people living with dementia to log in 10 to 15 minutes early, practicing use of zoom with people living with dementia before attending the group and having a second facilitator to manage technological issues.
	- How many facilitators are required to run vCST?	- vCST requires two facilitators, one to lead on session delivery and one to offer practical and emotional support to facilitators and group members as required.
	- How can distressed group members be supported in vCST?	- Distressed group members can be supported by the second facilitator in a separate breakout room whilst the lead facilitator continues delivering the session and with a follow up telephone call after the session ends.

	- What feedback has been received by people living with dementia who have experienced vCST?	- people living with dementia prefer to have CST in-person, however they prefer to have vCST than nothing as it helped them feel less isolated. - vCST should continue to run past the Covid-19 pandemic as it increases access to groups for people living in rural areas or who are unable to leave the house.
	- Are people living with dementia able to stay engaged in vCST using video conferencing apps?	- people living with dementia can find it difficult to stay engaged for a 60 minute vCST session compared to in-person CST - Engagement can be supported by breaking the session up more, directing questions to people who have not spoken in a while and staying in 'gallery mode' of the video conferencing app for as long as possible so group members can see each other talking, rather than looking at images.
Service Managers	- How can services support people living with dementia to engage in vCST?	- Services can support people living with dementia engage in vCST by practicing zoom sessions beforehand to facilitate learning and confidence in using it for the group sessions and to offer meetings to service users before signing up in order to provide reassurance and answer questions about vCST.
	- Do services have the means to support vCST implementation?	- Services are generally able to provide the technology and resources to staff to be able to deliver the intervention. Two facilitators are required in case there are technological or other resource issues.

Finalised vCST protocol and adaptations – Key features and adaptations to CST to make it more suitable for online use

The feedback from the focus groups was used to make adaptations to the existing CST protocol and to create the finalised protocol for vCST, which is outlined below. Interestingly, there were no differences between the feedback from the UK facilitators and HK facilitator other than the cultural differences in activities, which was to be expected. Also, it was surprising to see the positive experiences reported by people living with dementia, given the lack of experience and trust in using technology also reported. This further highlighted the advantages and need of using technology for people who are not able to attend services in person as it can help facilitate interactions with others.

Finalised session structure - Sessions followed the same structure as outlined in the group CST manual (Spector et al, 2020). Sessions started with introductions which included welcoming members to the group, orienting participants to time, date and place, doing a warm-up activity, singing the group song and discussing a newspaper article. Next, sessions focused on group members choosing an activity based on the session theme which the group would then participate in. Suggested activities were taken from the manual and adapted for online use if needed (i.e., interactive PowerPoint presentations of a price matching task for the 'using money' session). The final part of the session involved summarising the content covered in the session, seeking feedback from participants, reminding participants of the next session theme, including activities and materials they may need to bring, and then saying goodbyes. Sessions lasted 45 - 60 minutes as stated in the manual, although participants were asked to log on 10 minutes before the start time, to enable facilitators to give IT support if required, so that all participants could be online and ready at the agreed start time.

Finalised session content - The programme followed the 14-session plan outlined in the CST group manual. Activity resources were developed by the author

based on the suggested activities in the manual and subsequent online adaptations developed alongside FaceCog HK. Some sessions contained activities that require facilitators to post or deliver additional materials to participants or for participants to source for themselves when agreed. However, in the current study researchers were unable to have additional resources sent or delivered to participants for practical reasons so any additional resources that might be required for an activity were discussed and agreed with participants at the end of the previous session to source for themselves. For example, session 8 'Being Creative' contained an activity that required pen and paper so participants were asked at the end of session 7 whether they would like to do this activity and whether they would be able to obtain these items themselves. Each session contained at least one activity that did not require additional resources needing to be obtained directly by participants in case participants felt unable to obtain these resources themselves. The final order of sessions matched the group CST manual (Spector et al, 2020) as outlined in table 6. The finalised vCST protocol is outlined in Appendix H.

Table 6. vCST Session Themes

1. Physical games	8. Being creative
2. Sounds	9. Categorising objects
3. Childhood	10. Orientation
4. Food	11. Using money
5. Current affairs	12. Numbers games
6. Faces/Scenes	13. Word games
7. Word association	14. Team quiz

Adaptions for delivery of vCST online - Based on the ideas identified through stakeholder consultation, the following adaptations were made to the final vCST protocol:

- The video conferencing app ‘Zoom’ was chosen to deliver the sessions as this was the app most people had experience with and preferred
- A ‘How to use Zoom’ guide was created and sent to participants before the group to support them with accessing the sessions (included in Appendix E.)
- Participants were advised that they would require a laptop or tablet to access the sessions and not use a mobile phone
- Sessions were set in ‘Gallery view’ so that all participants were on screen simultaneously
- All participants were offered a one-to-one session on ‘Zoom’ prior to attending the group to give them experience with using the platform, alongside additional telephone support as required
- Sessions ran for 45 to 60 minutes dependent on the group’s engagement levels during the session. Participants were able to dip in and out of the session if they felt unable to stay engaged but were encouraged to stay for the whole session if possible.
- Participants were asked to sign into the session 10-15 minutes before starting so to allow sessions to begin on time and to give time to the second facilitator to contact participants who had not signed in
- Reminder emails with the ‘Zoom’ link were sent to all participants the day before each session
- Each group ran with two facilitators, one to lead on delivering the content and one to provide practical and other types of support as required
- Each group ran with four participants as this was deemed as the optimum group size
- If a participant was unable to access ‘Zoom’ sessions independently, the people living with dementia identified a named caregiver with both of their

consent who would support them to access the sessions and to be contacted for any technical support

- Any caregivers that were involved in giving support were advised not to attend the sessions with the person they cared for but to be nearby (i.e., in the next room) for the duration of the session in case they needed to give technical support to the participant
- If activities required people to use physical objects, participants and their caregivers were told about this at the end of the previous session and asked to bring these to the session as required. This gave participants a week to gather these objects if needed. There was always at least one activity out of the activity options that did not require any objects or materials in case participants were unable to get these
- Participants were given a choice from two warm up activities at the beginning of each session:
    - Throwing a 'virtual ball' to each other to ask and answer questions related to the session theme
    - Choosing coloured cards (prepared by the facilitator on PowerPoint) and answering attached questions relating to the session theme

Part 2 – Feasibility Pilot Study

The feasibility of the developed protocol was tested on three vCST groups in a feasibility pilot study. Two groups were delivered by different researchers within the study in the UK and one of the groups was delivered by occupational therapists within a dementia service in the Republic of Ireland. All groups were facilitated by two facilitators, with one facilitator leading on delivering the content and structure of the group and the second facilitator offering technical and practical support to participants and the main facilitator. All sessions were conducted using the online video conferencing platform 'Zoom' so that participants could join from their own

homes. All sessions were recorded so that observational data could be analysed at a later date, however this will not be discussed in the current study.

Of the 32 people living with dementia expressing interest in taking part in the feasibility pilot study, 22 were recruited and completed baselines assessments (see Figure 1. for flow diagram of recruitment and retention of participants). Basic demographics at baseline are summarised in table 7. Following randomisation, 12 participants were allocated to receive vCST and 10 were allocated to the control group for treatment as usual (TAU).

Figure 1. Flow diagram of recruitment and retention of participants

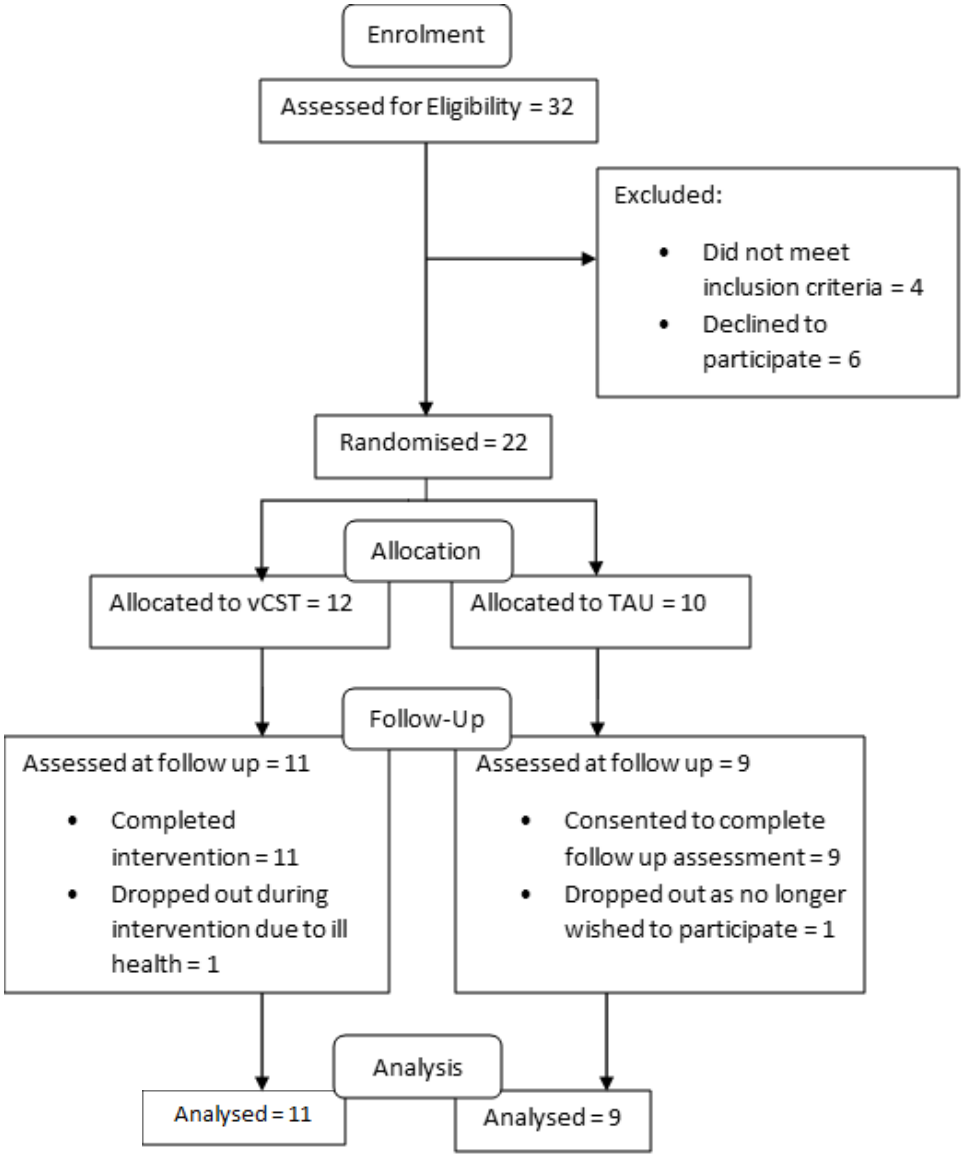


Table 7. Participant demographics at baseline

Characteristics	All participants (n = 22)	vCST (n = 12)	TAU (n = 10)
Age (years)			
Mean (SD)	72.36 (9.32)	73.75 (8.26)	70.70 (10.66)
Range	48 - 87	60 - 87	48 - 84
Gender			
Female (%)	14 (63.6)	8 (66.7)	6 (60.0)
Male (%)	8 (36.4)	4 (33.3)	4 (40.0)
Ethnicity			
White British (%)	14 (63.6)	7 (58.3)	7 (70.0)
White Irish (%)	6 (27.3)	4 (33.3)	2 (20.0)
White European (%)	1 (4.5)	1 (8.3)	0 (0.0)
Mixed White and Black Caribbean (%)	1 (4.5)	0 (0.0)	1 (10.0)
Diagnosis			
Alzheimer's Disease (%)	11 (50.0)	7 (58.3)	4 (40.0)
Posterior Cortical Atrophy (%)	1 (4.5)	0 (0.0)	1 (10.0)
Frontotemporal Dementia (%)	1 (4.5)	0 (0.0)	1 (10.0)
Korsakoff Syndrome (%)	1 (4.5)	0 (0.0)	1 (10.0)
Mixed Alzheimer's Disease and Vascular Dementia (%)	2 (9.1)	2 (16.7)	0 (0.0)
Mixed Alzheimer's Disease and Posterior Cortical Atrophy (%)	1 (4.5)	1 (8.3)	0 (0.0)
Mixed Vascular and Frontotemporal Dementia (%)	1 (4.5)	0 (0.0)	1 (0.0)
Dementia Unspecified (%)	4 (18.2)	2 (16.7)	2 (20.0)
QoL-AD Score			
Mean (SD)	35.82 (6.86)	36.17 (7.59)	35.40 (6.24)
Range	24 - 49	25 - 49	24 - 43
GDS			
Mean (SD)	4.55 (3.97)	4.42 (3.53)	4.70 (4.64)
Range	0 - 12	1 - 11	0 - 12

Primary outcomes - Feasibility and acceptability

Recruitment and retention

Thirty two people expressed initial interest in taking part in the feasibility pilot study. Four people (12.5%) did not meet the eligibility criteria to take part and, out of the remaining 28 people, six people (21.4%) declined to participate due to not wanting to attend a group online. Twenty two out of the original 32 people (68.8%) consented to take part in the feasibility pilot study. All 22 participants (100.0%) completed baseline measures of which 20 (90.9%) were retained by the follow up assessment. One participant from the vCST group withdrew before follow-up due to ill health and one participant from the control group withdrew before follow-up as they no longer wished to participate as they were finding it difficult getting online for the follow-up assessment.

Attendance and adherence

Of the twelve participants allocated to the vCST group, eleven (91.7%) completed the sessions to the end. Six (54.5%) participants attended all 14 sessions and overall attendance was 95.5%. Two participants missed two sessions and three participants missed one session with reasons for missing sessions including attendance at other appointments and forgetting to attend the session.

Feasibility of outcome measures

Both the QoL-AD and GDS measures had a 100% completion rate with no missing data on either. All of the participants were able to have both their baseline and follow up assessments completed by the same researcher.

Fidelity

No fidelity checklists were used in the study due to time constraints and researcher capacity, however none of the researchers reported any difficulties with following the vCST protocol.

Secondary Outcomes - Exploratory Analysis

Two mixed ANOVAs were employed to determine whether there were any significant differences between the means pre-post intervention and between groups. The means are presented in Table 8. below. For the QoL-AD, there was no significant differences between the means of the pre-post test scores, $F (1, 18) = 1.28$, $p > 0.05$, the two groups, $F (1, 18) = 0.09$, $p > 0.05$, or within the interaction of group and time, $F (1, 18) = 0.23$, $p > 0.05$. Similarly for the GDS, there was no significant differences between the means of the pre-post test scores, $F (1, 18) = 1.01$, $p > 0.05$, between the two groups, $F (1, 18) = 0.06$, $p > 0.05$, or within the interaction of group and time, $F (1, 18) = 1.01$, $p > 0.05$.

Table 8. Means and standard deviations for QoL-AD and GDS scores pre and post intervention for vCST and TAU groups

Measures	Pre-intervention scores		Post-intervention scores	
	vCST Mean (SD)	TAU Mean (SD)	vCST Mean (SD)	TAU Mean (SD)
QoL-AD	36.18 (7.96)	35.67 (6.56)	37.55 (4.72)	36.22 (8.38)
GDS	4.27 (3.66)	4.22 (4.66)	3.36 (2.38)	4.22 (4.27)

QoL-AD - Quality of Life – Alzheimer's Disease; GDS – Geriatric Depression Scale

Discussion

The current study aimed to investigate the feasibility and acceptability of a new vCST protocol by running a feasibility pilot study with 22 participants. It also aimed to investigate the impact of this intervention on measures of mood and QoL. The current study demonstrated that delivering vCST online to people living with dementia is both feasible and acceptable and that it is also feasible to test this

intervention in a research setting. However, there was no initial evidence found of the impact of vCST on mood or QoL, possibly due to sample size and other factors relating to assessing these outcomes in the context of a feasibility pilot study. These findings will be explored further below.

Feasibility and acceptability

The developed vCST protocol and guidelines appeared to be both feasible to be delivered as an intervention for people living with dementia and acceptable to the people participating in it. 21.4% of the people who initially showed interest in taking part in the study and were also eligible to participate declined to participate following the initial zoom meeting with the researcher. The main reason for this was that they did not wish to participate in a group intervention in an online setting. However, as 78.6% did consent to participate following this meeting, it suggests that vCST was generally acceptable as an intervention to people living with dementia at the 'sign up' stage.

However, this should be looked at with caution as the study used a sample of self-selected participants that were recruited either by responding to adverts for the study or by being asked to participate whilst waiting on a waiting list for in-person CST. Also, most participants required support from caregivers who had sufficient skills in using technology and who were able to give up their time in order to access vCST. This may have created bias in the sample and in the data as this would have excluded people living with dementia who are not able to independently access vCST and do not have a caregiver with these characteristics to support them. Both of these factors mean that it is difficult to generalise the findings to the wider dementia population.

Following participation in the groups, vCST appeared to be highly acceptable to people living with dementia and feasible to deliver as an intervention with this population as 91.7% of participants completed the sessions to the end, 54.5% participants attended all 14 sessions and overall attendance to sessions was 95.5%.

Even though only 54.5% attending every session, the remaining participants only missed one to two sessions each due to other health appointments or forgetting about the session, suggesting that it is still a highly acceptable intervention. In addition, the one person who was not able to attend vCST to the end terminated their participation for reasons unrelated to the study or intervention itself.

The current study also demonstrated that it is feasible to test the effects of vCST in a research trial context. The study had a good recruitment rate (68.8%) and an excellent retention rate (90.9%) suggesting that it is feasible to recruit and retain an appropriate number of participants in a study of this kind. As only one person withdrew their participation in the control group, the randomisation process appeared to be acceptable to people taking part even if they did not receive the intervention. For everyone who completed the study to the end, there was a 100% completion rate for all outcome measures (including the cognitive measures reported on in the report by CF) suggesting that they are both acceptable and feasible measures to be delivered as part of a vCST research study. Although assessing fidelity was beyond the scope of the current study, facilitators reported no difficulties with following the vCST protocol.

Further evidence supporting the feasibility and acceptability of vCST as an intervention for people living with dementia and as a focus for testing in research trials is demonstrated by comparing it to the original RCT for group, in-person CST by Spector et al (2003). In this trial, 84.4% of the treatment group completed the trial (compared with 91.7% in the current study), 81.4% of the control group completed the trial (compared with 90% in the current study) and the mean number of attended sessions was 11.6 (compared with 13.4 in the current study). Although some of the reasons for not completing the intervention in the original study by Spector et al (2003) were unclear, one reason for the disparity between the studies could be that participants are more likely to be able to attend vCST than in-person CST due to the convenience of being able to attend from their home. This is supported by ideas

emerging from the focus groups in stage one of the current study, as many of the stakeholders suggested that being able to attend from home would increase the likelihood of being able to attend sessions. However, this should be interpreted with caution as this comparison is made with a study that has a significantly larger sample than the one in the current study.

Mood and QoL

The current study did not find initial evidence that the developed vCST protocol had any impact on outcome measures relating to mood or QoL. This partially fits the findings of previous research that there is a lack of evidence for the impact of CST on outcomes of mood (Aguirre et al, 2013; Lobbia et al, 2018). However, the lack of evidence for change in QoL outcomes found in the current study contradicts evidence of improved QoL in this previous research. There a several factors that could explain these findings, the first of which lies in the study's sample size. As a feasibility pilot study, the current study only recruited very small samples as the main aim was to test the feasibility of the protocol and the feasibility of running a larger trial. However, this means that the sample is likely to be significantly underpowered and would therefore decrease the likelihood of being able to detect a true effect (Button et al, 2013).

The other explanation is that because the sample was not taken specifically from a population of people living with dementia who are also depressed and/or have a low QoL, the majority of participants in the current study started off scoring lower on the GDS and higher on the QoL-AD. This leaves little room for change in scores post-group unless mood and/or QoL significantly worsen, therefore and significant improvements in these areas are unlikely to be detected. If the sample had been taken from a people living with dementia population that was experiencing symptoms of depression or poorer QoL then it could have increased the likelihood of being able to detect a true effect. Given this finding, it does not seem feasible to use

the GDS-15 in future trials of vCST but further investigation is required for the use of the QoL-AD given the contradictions with previous evidence.

Strengths and limitations

There are several strengths identified in the current study. The final vCST protocol developed in the study is an adapted version of the current group CST protocol developed by Spector et al (2020), which already has a strong evidence base for benefitting people living with dementia in itself (i.e., Aguirre et al, 2013; Lobbia et al, 2018). This makes the findings from the current study easier to compare to previous research that uses the group CST protocol. These comparisons are further facilitated by the current study's use of the QoL-AD and GDS questionnaires as these are outcome measures that have been used in previous CST research. Another strength of the study is the use of stakeholder consultation in the development of the final vCST guidelines and protocol. This is especially important given that both the people living with dementia and the group facilitators had both experienced vCST sessions prior to attending the focus groups. Stakeholder consultation is essential in creating new interventions as it can help to identify problems, solutions and priorities in the development and implementation process that researchers may not be aware of (Cathain et al, 2019).

Despite these clear strengths, a number of limitations were also identified in the current study. Following the randomisation procedure for the first UK group, participants were informed of their group allocations before their baseline measures assessments. Researchers believed that it was not possible to blind participants to group allocations for this study given the limited time this would leave caregivers to organise support to participants between the assessment and first group session. However, this was reassessed for the Republic of Ireland and other UK groups as it was felt that it was actually possible to blind participants to group allocation at the baseline measures assessment by informing participants and their caregivers to prepare for the eventuality of being allocated to take part in vCST. By not blinding

the first group, this may have introduced unnecessary bias into the data as participants knowing which group they have been allocated to when they are completing baseline measures could have affected their performance (Karanicolas et al, 2010).

Another limitation relates to the collaboration with the HK Facecog team. Whilst collaboration at the development stage of the study was a strength of the current study as it could facilitate future comparisons, it was not within the scope of the study to consider more than the pragmatic approaches outlined in the methods or to consider comparisons at the implementation stage. Given that the evidence that people's experiences of dementia and their use of services differs between western and non-western cultures (i.e. Wong et al 2018), it is important to consider these approaches further and there may be further need for cross-cultural adaptations that were not identified in the current study.

Some limitations were identified in relation to the sample that was selected for the study. The first of these relates to the use of a small sample size for the study. Although having a small sample size was appropriate in the context of running of pilot feasibility study, the study was likely to be underpowered and less likely to detect a true effect as a result. Another limitation of the sample relates to the sample demographics. Although the sample was able to capture a good balance of genders and dementia types, almost all of the participants identified their ethnicity as white. This makes it difficult to generalise the findings to populations of people living with dementia from minority ethnic backgrounds. Also, there may be other biases present in the sample as the average age was relatively young for a dementia population (72.36) and the recruitment method of using a research website to find participants may have resulted in recruiting people living with dementia who are more computer literate and have a higher educational background than the general dementia population. Collecting demographic information on these characteristics could have helped to understand the

generalisability of the data. Therefore, future research should attempt to capture this information in order to support using a more diverse sample.

Implications

Despite CST being a popular, widely available and beneficial psychosocial intervention for people living with dementia, it still remains inaccessible to those who may be unable to travel due to health reasons, socioeconomic reasons and geographical reasons, as well as to those who are having to socially distance during the recent Covid-19 pandemic. The findings of the current study suggest that running CST groups virtually is feasible, acceptable and may still be beneficial to those taking part. As such, a larger RCT would be appropriate to establish the efficacy of vCST, to further investigate potential benefits and to establish the acceptability, feasibility and impact on different dementia populations. This would include conducting vCST research with larger sample sizes, with people living with dementia reporting high levels of depression and poor QoL and with people living with dementia from different minority and/or cross-cultural groups. It would also be important to include further stakeholder consultation to establish acceptability of both the vCST protocol as a whole and each individual session plan. This could be done through focus groups and through sessional feedback from participants.

In addition to further investigation of the factors identified in the current study, there are other outcomes that would be important to include in future research. One such outcome would be to measure the facilitators fidelity to the vCST protocol. Fidelity is defined as “the degree to which ….. program providers implement programs as intended by the program developer” (Dusenbury et al, 2003). Fidelity is important as it increases the reliability and validity of the data as all participants are more likely to receive the same intervention if all facilitators are able to follow the protocol as closely as possible. Fidelity is usually measured by creating or using a checklist relating to important elements of the intervention protocol that facilitators score if they were able to meet each requirement. Another outcome that

may be useful to measure would be observational data on recordings of vCST to investigate participants ability to stay engaged throughout the session. Gaining observational data on engagement is beneficial as the vCST protocol may need to be adjusted if people living with dementia are not able to engage in 45 to 60-minute session, however participant self-report measures of engagement may not be an accurate indicator of this (Parekh et al, 2018). This data could be collected either through development of a coding system for researchers to use when watching video recordings of sessions or by using face recognition technology.

Conclusion

Overall, a 14 session vCST protocol developed in the current study was feasible and acceptable as a psychosocial, e-health intervention for people living with dementia. We therefore recommend that vCST is offered as an intervention across dementia services in order to increase access to a CST programme for those who are otherwise unable to access CST in-person, for reasons including health, mobility and transport problems. This is especially important when services are not able to offer in-person CST due to social distancing needs during current and future pandemics. Larger trials on vCST are required to further investigate benefits on mood and QoL and to assess the intervention's impact on a variety of factors.

References

Aguirre, E., Hoare, Z., Streator, 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, 284 – 290.

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, 253 – 262.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. American Psychiatric Association. Downloaded on 22/03/21 from https://doi.org/10.1176/appi.books.9780890425596

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L., Fabrizio, C., & Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventative Medicine,* 36(5), 452 – 457.

Burton, R. L., & O'Connell, M. E. (2018). Telehealth rehabilitation for cognitive impairment: Randomized controlled feasibility trial. *JMIR Research Protocols,* 7(2), e43.

Button, K. S., Loannidis, J. P. A., Mokrysz, C., Nosek, B. A., Flint, J., Robinson, E. S. J., & Munafò, M. R. (2013). Power failure: why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience,* 14, 365 – 376.

O'Cathain, A., Croot, L., Duncan, E., Rousseau, N., Sworn, K., Turner, K. M., Yardley, L., & Hoddinott, P. (2019). Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open,* 9, e029954.

Charness, N., & Boot, W. R. (2009). Aging and information technology use: Potential and barriers. *Current Directions in Psychological Sciences,* 18(5), 253 – 258.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2019). Developing and evaluating complex interventions. *Medical Research*

Council, Downloaded on 04/03/2021 from https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

Cuffaro, L., Di Lorenzo, F., Bonavita, S., Tedeschi, G., Leocani, L., & Lavorgna, L. (2020). Dementia care and COVID-19 pandemic: A necessary digital revolution. *Neurological Sciences,* 17, 1 - 3.

Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsch, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science,* 4(50).

Di Carlo, F., Sociali, A., Picutti, E., Pettoruso, M., Vellante, F., Verrastro, V., Martinotti, G., & di Giannantonio, M. (2021). Telepsychiatry and other cutting-edge technologies in COVID-19 pandemic: Bridging the distance in mental health assistance. *International Journal of Clinical Practice,* 75(1).

Donker, T., Bennett, K., Bennett, A., Mackinnon, A., van Straten, A., & Cuijpers, P. (2013). Internet-delivered interpersonal psychotherapy versus internet-delivered cognitive behavioral therapy for adults with depressive symptoms: Randomized controlled noninferiority trial. *Journal of Medical Internet Research,* 15(5), e82.

Dores, A. R., Geraldo, A., Carvalho, I. P., & Barbosa, F. (2020). The use of new digital information and communication technologies in psychological counseling during the COVID-19 pandemic. *International Journal of Environmental Research & Public Health,* 17.

Dusenbury, L., Brannigan, R., Falco, M., & Hansen, W. B. (2003). A review of research on fidelity of implementation: Implications for drug abuse prevention in school settings. *Health Education Research*, 18(2), 237 – 256.

Fairburn, C. G., & Patel, V. (2017). The impact of digital technology on psychological treatments and their dissemination. *Behaviour Research & Therapy,* 88, 19 - 25.

García-Casal, J. A., Loizeau, A., Csipke, E., FrancoMartín, M., Perea-Bartolomé, M. V., & Orrell, M. (2017) Computer-based cognitive interventions for people living with dementia: a systematic literature review and meta-analysis. *Aging & Mental Health,* 21(5), 454 - 467.

Giebel, C., Cannon, J., Hanna, K., Butchard, S., Eley, R., Gaughan, A., Komuravelli, A., Shenton, J., Callaghan, S., Tetlow, H., Limbert, S., Whittington, R., Rogers, C., Rajagopal, M., Ward, K., Shaw, L., Corcoran, R., Bennett, K., & Gabbay, M. (2020). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging & Mental Health,* 10.

Hall, M., Orrell, L., Stott, J., & Spector, A. (2013). Cognitive stimulation therapy (CST): Neuropsychological mechanisms of change. *International Psychogeriatrics,* 25(3), 479 – 489.

Ho-yin Lai, F., Wai-hung Yan, E., Ka-ying Yu, K., Tsui, W., Ting-hoi Chan, D., & Yee, B. K. (2020). The protective impact of telemedicine on persons with dementia and their caregivers during the COVID-19 pandemic. *American Journal of Geriatric Psychiatry,* 28(11), 1175 – 1184.

Karanicolas, P. J., Farrokhyar, F., & Bhandari, M. (2010). Blinding: Who, what, when, why, how? *Canadian Journal of Surgery,* 53(5), 345 – 348.

Lach, H., Chang, Y., & Edwards, D. (2010). Can older adults with dementia accurately report depression using brief forms? Reliability and validity of the Geriatric Depression Scale. *Journal of Gerontological Nursing,* 36(5), 30 - 37.

LaMonica, H. M., English, A., Hickie, I. B., Ip, J., Ireland, C., West, S., Shaw, T., Mowszowski, L., Glozier, N., Duffy, S., Gibson, A. A., & Naismith, S. L. (2017). Examining internet and eHealth practices and preferences: Survey study of Australian older adults with subjective memory complaints, mild cognitive impairment, or dementia. *Journal of Internet Medical Research*, 19(10), e358.

Lazar, A., Thompson, H., & Demiris, G. (2014). A systematic review of the use of technology for Reminiscence Therapy. *Health Education & Behaviour,* 41, 51 - 61.

Livingston, G., Barber, J., Kinnunen, K., Webster, L., Kyle, S., Cooper, C., Espie, C. A., Hallam, B., Horsley, R., Pickett, J., & Rapaport, P. (2019). DREAMS-START (Dementia RElAted Manual for Sleep; STrAtegies for RelaTives) for people with dementia and sleep disturbances: A single-blind feasibility and acceptability randomized controlled trial. *International Psychogeriatrics*, 31(2), 251 - 265

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. *European Psychologist,* 24, 257 - 277.

Logsdon, R., Gibbons, L., McCurry, S. & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging,* 5, 21 – 32.

Logsdon, R., Gibbons, L., McCurry, S., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine,* 64, 510 - 519.

Marinho, V., Bertrand, E., Naylor, R., Bomilcar, I., Laks, J., Spector, A., & Mograbi, D. C. (2021). Cognitive stimulation therapy for people with dementia in Brazil (CST-Brasil): Results from a single blind randomized controlled trial. *International Journal of Geriatric Psychiatry,* 36(2), 286 - 293.

Mauricio, R., Benn, C., Davis, J., Dawson, G., Dawson, L. A., Evans, A., Fox, N., Gallacher, J., Hutton, M., Isaac, J., Jones, D., Jones, L., Lalli, G., Libri, V., Lovestone, S., Moody, C., Noble, W., Perry, H., Pickett, J., Reynolds, D., … & Therapeutics for Dementia Consortium (2019). Tackling gaps in developing

life-changing treatments for dementia. *Alzheimer's & Dementia: Translational Research & Clinical Interventions,* 5, 241 – 253.

Mkenda, S., Olakehinde, O., Mbowe, G., Siwoku, A., Kisoli, A., Paddick, S., Adediran, B., Gray, W. K., Dotchin, C. L., Adebiyi, A., Walker, R. W., Mushi, D., & 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.

NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers. Downloaded on 12/02/2021 from https://www.nice.org.uk/guidance/ng97

Orrell, M., Aguirre, E., Spector, A., Hoare, Z., Woods, R. T., Streater, A., Donovan, H., Hoe, J., Knapp, M., Whitaker, C., & Russell, I. (2014). Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial. *The British Journal of Psychiatry,* 204, 454 – 461.

Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I., de Waal, H., Woods, R. T., & 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).

Parekh, V., Foong, P. S., Zhao, S., & Subramanian, R. (2018). AVEID: Automatic video system for measuring engagement in dementia. *23rd International Conference on Intelligent User Interfaces,* 409 – 413.

Peel, N. M., Russell, T. G., & Gray, L. C. (2011). Feasibility of using an in-home video conferencing system in geriatric rehabilitation. *Journal of Rehabilitation Medicine,* 43(4), 364 – 366.

Pots, W.T.M., Fledderus, M., Meulenbeek, P.A.M., ten Klooster, P.M., Schreurs, K.M.G., & Bohlmeijer, E.T. (2016). Acceptance and commitment therapy as a

web-based intervention for depressive symptoms: Randomised controlled trial. *British Journal of Psychiatry,* 208, 69 – 77.

Pywell, J., Vijaykumar, S., Dodd, A., & Coventry, L. (2020). Barriers to older adults' uptake of mobile-based mental health interventions. *Digital Health,* 6.

Rai H. K., Prasetya, V. G. H., Sani, T. P., Theresia, I., Tumbelaka, P., Turana, Y., Schneider, J., & Orrell, M. (2021). Exploring the feasibility of an individual cognitive stimulation therapy application and related technology for use by people with dementia and carers in Indonesia: A mixed-method study. *Dementia,* 15, Epub ahead of print.

Sheikh, J. I., & Yesavage, J. A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 5(1-2), 165 – 173.

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.

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.

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

Spector, A., Woods, B., Stoner, C. R., & Orrell, M. (2020). *Making a difference 1: An evidence-based group programme to offer Cognitive Stimulation Therapy (CST) to people with Dementia (2nd Ed.)*. Hawker Publications.

Staples, L. G., Fogliati, V. J., Dear, B. F., Nielssen, O., & Titov, N. (2016). Internet-delivered treatment for older adults with anxiety and depression:

implementation of the Wellbeing Plus Course in routine clinical care and comparison with research trial outcomes. *BJPsych Open,* 2(5), 307 – 313.

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. *Progress in Brain Research,* 138: 345 – 375.

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, 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.

World Health Organization (2005). *Fifty-Eighth World Health Assembly: Resolutions and Decisions Annex.* WHO: Geneva, Switzerland. 108 – 109.

Wuthrich, V. M., & Frei, J. (2015). Barriers to treatment for older adults seeking psychological therapy. *International Psychogeriatrics,* 27(7), 1227 – 1236.

Part Three: Critical Appraisal

Introduction

This appraisal outlines some reflections from my journey through the research process of developing a new intervention protocol for virtual Cognitive Stimulation Therapy (vCST). It will begin by describing the personal and professional experiences that led me to develop interest in researching this area. It will then discuss some of the benefits of conducting this type of research and some of the challenges I experienced relating the Covid-19 pandemic, recruitment and piloting the vCST intervention. Lastly, I will give some recommendations for future facilitators of vCST and some reflections on the learning that I have taken from the research process.

Locating myself in the research

My interest in working with older adults and, specifically, working with people living with a diagnosis of dementia (people living with dementia) has stemmed from both personal and professional experiences of this client group. Prior to beginning the Doctorate in Clinical Psychology, I worked in health services that catered predominantly for older adults and people living with dementia. This included an inpatient stroke neurorehabilitation service and an outpatient memory clinic. Working in these services exposed me to several aspects of this client group's experiences that I had previously lacked awareness of and fuelled my drive in contributing to the support of older adults and people living with dementia in both clinical and research contexts.

One aspect that I was particularly disheartened by was how excluded older adults often were in making decisions about their life and how their voices were easily dismissed. This was particularly the case in settings where I found myself working with people living with dementia. I observed this exclusion occurring within the numerous systems that any particular individual found themselves in. I noticed that this would occur in interactions between the individual and clinical staff where

decisions around the individual's care would often be deferred to their partner and family. I also noticed this within the individual's own family system, where partners and children would often answer questions or speak on behalf of the individual, would get frustrated with or shut down the things they had to say and would 'infantilise' them by speaking to them using a form of 'Elderspeak' (Kemper, 1994). Whilst I appreciated that issues relating to capacity and language impairments often meant that family and caregivers needed to be involved to support care decisions, this was not always done in a way to give people living with dementia a voice.

Another aspect of the experience of people living with dementia that really struck me is the frequency in which communication breakdown occurs between them and their caregivers and the impact this can have on both parties. When meeting with people living with dementia and their families during my time in dementia services, I often noticed each party becoming easily frustrated with the other when trying to communicate. Similar to what has been reported in the literature (Savundranayagam et al, 2005), this seemed to occur most when caregivers were reporting high levels of perceived caregiving burden and stress alongside care receivers developing difficulties with memory and language. This would result in both parties becoming highly critical towards each other, not listening to each other and reporting an increase in difficulties within the relationship.

I also have experiences of observing this in my personal life, often feeling sad and frustrated at observing these communication breakdowns in the knowledge that the situation could be improved if both parties were able to work on communicating better with each other. Despite frequently observing these communication difficulties in my personal and professional lives, none of the services I worked for or were aware of offered any specific interventions to support communication improvement between people living with dementia and their caregivers. As I feel passionately about such interventions being more widely

available, I have become interested in supporting the development and implementation of such through research and clinical practice.

Another intervention that I became interested in through my clinical work was Cognitive Stimulation therapy (CST) (Spector et al, 2003). Through my professional and personal experiences, I felt saddened at observing the decreasing opportunities, motivation and encouragement from others to engage in mentally stimulating activities for a large number of people living with dementia following the onset of dementia symptoms. As a result, I would see a lot of people living with dementia conversing less with others and increasingly engaging in less stimulating activities despite evidence that engaging in more stimulating activity and discussion can be beneficial to their cognition and quality of life (Woods et al, 2006). Being involved in facilitating CST groups prior to training showed me how it important it was for it to be widely available and accessible to people living with dementia in order to not only provide mental stimulation, but also to provide a space to be social, have fun and feel heard when these may be missing or minimal in their day to day lives. I distinctly remember being touched by one group member saying that they were thankful for the opportunity to be able to express their opinion when discussing current affairs as this is something they no longer felt able to do with their family since the onset of their dementia. As such, I feel passionately at working towards making CST increasingly more available and accessible to people living with dementia. This project appealed to me as it spoke to my passions and interest in developing psychosocial interventions for both people living with dementia and their caregivers, as well as being able to engage in clinical work in a research setting.

Benefits of implementation and feasibility research

When selecting a thesis project, it was important for me to be able to be participate in research that involved being able to deliver an intervention or to

consult with people with lived experience directly, as this fit with my strengths as a clinician and with my passions for increasing access to psychological interventions. Implementation and feasibility research enabled me to do just this. Feasibility studies play a crucial role not only in psychological research but also in many other research domains as they shape the foundations of the larger scale trials that inform the evidence-based interventions used in clinical settings around the world (Tickle-Degnen, 2013). Conducting feasibility research can have multiple benefits. For example, Elridge et al (2016) found that conducting a feasibility study before a larger trial can reduce problems related to recruitment, attrition, compliance, inadequate outcomes measures and smaller than expected effect sizes. Other benefits include 'bridging the research to practice gap' by trialling interventions in real world settings, improving the quality for larger research trials by testing out optimal research designs and reducing the chances of wasting resources on trials that would not produce worthwhile results (Gadke et al, 2021). Despite this importance, feasibility research is often conducted in an inappropriate manner as studies tend to focus too much on outcomes rather than looking at acceptability and feasibility of the intervention, assessment and research design itself (Gadke et al, 2021).

There are multiple elements of feasibility and implementation research that fit with my identity as a clinician and as a researcher. Designing an intervention protocol from the ground up meant that I was able to work creatively, flexibly and collaboratively with others and garnered a sense of investment, freedom and reward that fit with my values. Being able to work with smaller samples and looking at a mix of quantitative and qualitative data meant that I was able to assess outcomes at both a group and individual level. This was important as I see the value in both statistical data that evaluates amalgamated outcomes to provide evidence that can be more generalised to larger populations, but also in qualitative data that helps understand nuances that need to be considered at an individual level.

One element of this research that was particularly important to me was being able to collaborate with experts by experience in the intervention development process. Involving experts by experience in research, especially in feasibility and implementation studies, is crucial as it makes the outcomes of studies more meaningful to those it may benefit, bring researchers' attention to ideas that may not be in their awareness and can lead to higher rates of recruitment and retention (Domecq et al, 2014). Being able to consult people living with dementia who had lived experience of taking part in groups, alongside caregivers and professionals, were some of the most rewarding parts of the research process as I was able to learn about the elements of vCST that were most important to those who it would benefit. This consultation was also essential for developing best practice guidelines to be disseminated to future vCST facilitators that focused on creating the optimal group conditions based on lived experiences. However, I feel that we did not maximise the extent to which experts by experience could input into the finalised vCST protocol as we did not consult them on the final draft. Although this consultation did not occur due to the time constraints of conducting the study as part of a doctoral thesis, it would have been important to share the final draft of the protocol with experts by experience in order to gain feedback and increase the acceptability and feasibility of the intervention.

Challenges in conducting dementia research during the Covid-19 Pandemic

Despite the overall success of the project, I encountered several challenges throughout different stages of the research journey. Some of these were challenges that regularly occur when conducting dementia research, such as recruitment difficulties resulting from reduced awareness of research opportunities and need for a research partner (Bartlett et al, 2018). However, there were some very specific challenges that occurred throughout the process that resulted from conducting this

type of research during the Covid-19 pandemic. These will be outlined in more detail below.

Impact of the Covid-19 pandemic on the project

Prior to the start of the Covid-19 pandemic, the original project proposal was to develop and trial a new group-based communication training programme for caregivers of people living with dementia. The components of the intervention were to be designed following a systematic review of the current evidence base and stakeholder consultation with people living with dementia and their caregivers, before trialling this in a feasibility pilot study. This was to be a joint project with Cerne Felstead (CF). Following acceptance of the project proposal by the department, we went on to write and submit UCL ethics to the Research Ethics Committee and I began work on finding relevant papers for the systematic review. However, following the first UK national Covid-19 lockdown, a decision was made between myself, CF and our primary supervisor Aimee Spector to cease working on the project and to develop and propose a new project to begin working on. This decision was based on conversations with dementia services who reported that it had become increasingly difficult to engage caregivers in online groups and interventions, as caregivers felt less able to attend alongside an increase in caregiver burden and responsibilities. This is further support by recent studies that found caregiving burden and intensity had increased significantly as a result of Covid-19 (Kohen et al, 2021).

Making this decision was very difficult and frustrating as we had already put months of work into the original project and would mean having to start again with a new project proposal and ethics application. I was particularly worried about the prospect of having to start a new systematic review as I had already put a significant amount of work into my literature search. However, to my relief, it was agreed with my supervisors and the department that I could continue with my original systematic review as planned given the progress I had already made on it and the decisions on

changing the project being based on exceptional circumstances outside of my control. Despite these difficulties and stressors, it was ultimately felt that to be the right decision to take as the uncertainty of the pandemic had increased the risk that it would not be feasible to pilot this intervention with caregivers.

Challenges with Recruitment

At the outset of the project, we opted to apply for ethical approval through the university's Research Ethics Committee as NHS ethical applications are often found to be a lengthy and complex process (van Teijlingen et al, 2008). We felt that this would benefit the research process as it would enable us to have more time for recruitment and data collection if we were able to gain ethical approval swiftly. Whilst ethical approval was achieved in this timely manner, there were a number of unanticipated recruitment difficulties that ultimately led to a delay in data collection regardless.

The first of these relates to the initial recruitment method that was proposed which was designed to reduce the risk of participants feeling coerced into taking part in the study. As research indicates that people living with dementia are less likely to have capacity to consent to participate in treatment or research as cognitive impairment increases (Warner et al, 2008), it was important to develop a recruitment process that provided the best conditions for supporting this population to participate in the study. This included trying to empower people living with dementia to make their own choices about their participation to mitigate any sense of feeling coerced into taking part (Cowdell, 2006). One way of achieving this was to design the recruitment pathway so that potential participants are required to make initial contact with the researchers after receiving information via advertisements, rather than the researchers making initial contact after receiving referrals from others.

Whilst this was thought to be helpful to reduce coercion and increase autonomy, it appeared to create some difficulties with the recruitment process.

Despite trying to reach as many people living with dementia as possible through advertisements and attendance at service user meetings within third sector organisations, we received only two responses back from potential participants over a two-month period. Although we were not able to gain any specific feedback about why this was the case, it was hypothesised that the recruitment process was creating a barrier for potential participants due to cognitive impairments, lack of caregiver support and beliefs about help seeking reducing the individual's ability to make first contact (Bartlett et al, 2018; Werner et al, 2014). Due to the time limits of the project and the barrier that this recruitment design had created, we decided to change this via an ethics amendment so that researchers were able to make first contact upon receiving contact details from referrers with the consent of participants. Once this amendment had been approved, we noticed a significant increase in uptake at the initial recruitment step. Whilst making this ethics amendment improved recruitment into the study, we remained mindful of continuing to try to reduce feelings of coercion throughout the rest of the process.

Another difficulty we faced with recruitment was with trying to mitigate selection bias. Selection bias occurs when there is a 'systematic difference between the characteristics of those selected for the study and those who are not' (Henderson & Page, 2007). People who volunteer to take part in dementia research trials tend to be white, more highly educated, have higher socio-economic status and be more sociable (Dodge et al, 2014; Wong et al, 2019). Dementia research that requires the use of computer technology is also more likely to attract volunteers who are already computer literate (Dodge et al, 2014). As there is often this disparity between dementia research populations and clinical dementia populations, results can fail to generalise to those who do not fall within these demographics (Mendelson et al, 2016). Given the time constraints that occurred within the current study, this was a barrier that we were not able to work around and, as a result, our final sample

consisted of volunteers possessing the characteristics mentioned above. In hindsight, this is something that I wished we had spent more time thinking about as a research team, in order to diversify a research sample that can be more generalised to the general dementia population. Specifically, I would have liked to focus on trying to recruit more participants from minority ethnic backgrounds in order to have a more representative sample.

Challenges with the intervention

Despite the overall success of the intervention, there were several challenges that we faced in its delivery. One such challenge relates to the reliance of caregivers on people living with dementia being able to access vCST. Caregivers have always played an essential role in people living with dementia being able to access dementia services and interventions, so the challenges that this brings are well known (White et al, 1995). However, there were additional caregiver characteristics that were highlighted throughout the study that factored into the people living with dementia's participation in the intervention. The main two characteristics that appeared to create the biggest challenges were the caregivers' ability to use technology and the caregivers' ability to give up their time to support the people living with dementia to participate. Although we were successful in recruiting and retaining enough participants for the study, there were many potential participants that did not end up taking part. This was due to the people living with dementia only being able to access vCST with the support of the caregivers who were either not literate in using computer technology or were unable to give up their time due to work commitments or travelling distance.

Another challenge that we faced was with the use of technology to deliver the vCST sessions. Although the use of computer technology in the study went better than expected considering how many people were able to fully participate with very little problem, there were some occasional, minor problems encountered that

made sessions run less smooth in comparison to in-person sessions. For example, the sessions relied heavily on both participants and facilitators having a good enough internet speed to enable videoconferencing with others. However, if a group member's internet speed was slow during a particular session, this not only affected the person's ability to engage in the session as the video would freeze, but it would also disrupt and slow down the flow of the session as whole. Another example relates to the use of the 'sharescreen' function on 'Zoom' to support the multisensory principle of CST (Spector et al, 2020). Microsoft PowerPoint materials were created to support activities in each session that could be shown to participants using the 'sharescreen' function on 'Zoom', in order to supplement discussions with visual information. However, when this was shared in practice, it would often result in part of the screen being obscured from view from participants because of the way that the 'Zoom' display was set up. As participants felt that they were not proficient in using 'Zoom' themselves, there was no way to change this. Whilst this did not detract away from the being able to participate in the activity itself, it again disrupted the flow of the session and took up valuable time trying to overcome.

Recommendations for the sessions

Whilst the project focused heavily on developing a protocol and guidelines for delivering vCST sessions, it is important to remain flexible to the needs of the group. Facilitators should try to ensure they are able to cover each section of the session plan, however they should try to shift focus to the activities that group members are finding most stimulating in line with feedback being received, as long as this remains concordant with CST key principles (Spector et al, 2020). For example, group members from one of the vCST groups in the study reported that they particularly found the current affairs discussion on news articles more mentally

stimulating and enjoyable than other activities in the session, so there was more time allocated to focusing on this than suggested in the session protocol. This heavily leans into the principle of giving choice, which I found to be one of the most important principles to keep in mind throughout the sessions, as I noticed that it gave group members a sense of agency and investment in participating in the sessions.

Another recommendation that is important to keep in mind is that, whilst group facilitators are by no means required to have significant skills and experience in using computer technology, being able to maximise the technology's potential will improve group members experience of vCST. When inviting potential group members to take part in vCST, facilitators should ensure that they have access to an internet connection with sufficient speed, a laptop rather than a phone or tablet with a big enough screen to be able to see other participants well, access to 'Zoom' or the videoconferencing app that will be in use for sessions and a caregiver, if needed, who is literate in using computer technology in order to support the group member to access the sessions with relatively little difficulty. It will also greatly benefit the session if the facilitator is able to make use of video conferencing app functions, such as 'screenshare' or 'whiteboard' that is available on 'Zoom', and if session materials that can be shown to participants are prepared beforehand using applications such as Microsoft Word or PowerPoint.

Conclusion

Whilst this project has been a source of stress and frustration at times, it has overall been an enjoyable experience that I have learnt a lot from. Being my first encounter with conducting research on intervention development, it has given me an understanding of the decisions and thought process that are involved at each step of

creating a new intervention, which will benefit me should I go on to conduct future intervention-based research trials. I have learnt the importance of including experts by experience in the research process to ensure that interventions can be tailored and optimised to suit the needs of the people that they are designed for. The difficulties that I encountered in my experiences with ethics applications, recruitment and piloting a new intervention have given me a new understanding of the types of barriers that present in the research process and taught me how to think flexibly and creatively to overcome these. Overall, this project has reignited my passion and interest in working with people living with dementia and has reinforced my interest in conducting dementia research in the future.

References

Bartlett, R., Milne, R., & Croucher, R. (2018). Strategies to improve recruitment of people with dementia to research studies. *Dementia,* 18(7–8), 2494 – 2504.

Cowdell, F. (2006). Preserving personhood in dementia research: a literature review. *International Journal of Older People Nursing,* 1(2), 85 - 94.

Dodge, H. H., Katsumata, Y., Zhu, J., Mattek, N., Bowman, M., Gregor, Wild, K., & Kaye, J. A. (2014). Characteristics associated with willingness to participate in a randomized controlled behavioral clinical trial using home-based personal computers and a webcam. *Trials,* 15, 508.

Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M. A., & Murad, M. H.(2014). Patient engagement in research: a systematic review. *BMC Health Services Research,* 14**,** 89.

Eldridge, S. M., Lancaster, G. A., Campbell, M. J., Thabane, L., Hopewell, S., Coleman C. L., & Bond, C. M. (2016). Defining feasibility and pilot studies in preparation for randomised controlled trials: Development of a conceptual framework. *PLoS ONE* 11(3), e0150205.

Gadke, D. L., Kratochwill, T. R., & Gettinger, M. (2021). Incorporating feasibility protocols in intervention research. *Journal of School Psychology,* 84. 1 – 18.

Henderson, M., & Page, L. (2007). Appraising the evidence: what is selection bias? *Evidence-Based Mental Health,* 10(3), 67 - 68.

Kemper, S. (1994). Elderspeak: Speech accomodation to older adults. *Aging and Cognition,* 1(1), 17 – 28.

Kohen, S. A., Kunicki, Z. J., Drohan, M. M., & Greaney, M. L. (2021). Exploring changes in caregiver burden and caregiving intensity due to COVID-19. *Gerontology and Geriatric Medicine*, 7, 1 – 9.

Mendelson, A. F., Zuluaga, M. A., Lorenzi, M., Hutton, B. F., Ourselin, S., & Alzheimer's Disease Neuroimaging Initiative (2016). Selection bias in the reported performances of AD classification pipelines. *NeuroImage: Clinical.* 14, 400 – 416.

Savundranayagam, M. Y., Hummert, M. L., & Montgomery, R. J. V. (2005). Investigating the effects of communication problems on caregiver burden. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences,* 60(1), 48 – 55.

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

Spector, A., Woods, B., Stoner, C. R., & Orrell, M. (2020). *Making a difference 1: An evidence-based group programme to offer Cognitive Stimulation Therapy (CST) to people with Dementia (2nd Ed.)*. Hawker Publications

Tickle-Degnen L. (2013). Nuts and bolts of conducting feasibility studies. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association,* 67(2), 171 – 176.

van Teijlingen, E.R., Douglas, F., & Torrance, N. (2008). Clinical governance and research ethics as barriers to UK low-risk population-based health research? B*MC Public Health,* 8, 396.

Warner, J., McCarney, R., Griffin, M., Hill, K., & Fisher, P. (2008). Participation in dementia research: rates and correlates of capacity to give informed consent. *Journal of Medical Ethics,* 34,167 – 170.

Werner, P., Goldstein, D., Karpas, D. S., Chan, L. C. K., & Lai, C. (2014). Help-seeking for dementia, A systematic review of the literature. *Alzheimer Disease & Associated Disorders,* 28(4), 299 – 310.

White, H., Clipp, E.C., Hanlon, J.T., & Schmader, K. (1995). The role of the caregiver in the drug treatment of dementia. *CNS Drugs,* 4, 58 – 67.

Wong, R., Amano, T., Lin, S., Zhou, Y., & Morrow-Howell, N. (2019). Strategies for the recruitment and retention of racial/ethnic minorities in Alzheimer disease and dementia clinical research. *Current Alzheimer Research,* 16(5), 458 – 471.

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.

Appendices

Appendix A. Manual for Quality Scoring of Quantitative Studies from the Qualsyst' critical appraisal tool (2004).

How to calculate the summary score

- Total sum = (number of "yes" * 2) + (number of "partials" * 1)
- Total possible sum = 28 – (number of "N/A" * 2)
- Summary score: total sum / total possible sum

Criterion	Scoring Guidelines
1. Question or objective sufficiently described?	• Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific intervention(s)/association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is not considered sufficiently described. • Partial: Vaguely/incompletely reported (e.g. "describe the effect of" or "examine the role of" or "assess opinion on many issues" or "explore the general attitudes"...); or some information has to be gathered from parts of the paper other than the introduction/background/objective section. • No: Question or objective is not reported or is incomprehensible. • N/A: Should not be checked for this question.
2. Design evident and appropriate to answer study question? (If the study question is not given, infer from the conclusions).	• Yes: Design is easily identified and is appropriate to address the study question / objective. • Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question. • No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified. • N/A: Should not be checked for this question.
3. Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is	• Yes: Described and appropriate. Selection strategy designed (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., "cancer" -- ICD code or equivalent should be provided). Studies of volunteers: methods and setting of recruitment reported. Surveys: sampling frame/strategy clearly described and appropriate.

described and appropriate.	• Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identifi ed all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as “volunteers” or “healthy volunteers”. Surveys: target population mentioned but sampling strategy unclear. • No: No information provided. Or obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). Or presence of selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study). • N/A: Descriptive case series/reports.
4. Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?	• Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). Decision analyses: baseline estimates for input variables are clearly specified. • Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). Or incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). Decision analyses: incomplete reporting of baseline estimates for input variables. • No: No baseline / demographic information provided. Decision analyses: baseline estimates of input variables not given. • N/A: Should not be checked for this question.
5. If random allocation to treatment group was possible, is it described?	• Yes: True randomization done - requires a description of the method used (e.g., use of random numbers). • Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true). • No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done). • N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.
6. If interventional and blinding of investigators to intervention was possible, is it reported?	• Yes: Blinding reported. • Partial: Blinding reported but it is not clear who was blinded. • No: Blinding would have been possible (and was possibly done) but is not reported. • N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

7. If interventional and blinding of subjects to intervention was possible, is it reported?	• Yes: Blinding reported. • Partial: Blinding reported but it is not clear who was blinded. • No: Blinding would have been possible (and was possibly done) but is not reported. • N/A: Observational studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports.
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	• Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, "objective" criteria (e.g., death, test completion - yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. Surveys: clear description (or reference to clear description) of questionnaire/interview content and response options. Decision analyses: sources of uncertainty are defined for all input variables. • Partial: Definition of measures leaves room for subjectivity, or not sure (i.e., not reported in detail, but probably acceptable). Or precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. Or instrument/mode of assessment(s) not reported. Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). Surveys: description of questionnaire/interview content incomplete; response options unclear. Decision analyses: sources of uncertainty are defined only for some input variables. • No: Measures not defined, or are inconsistent throughout the paper. Or measures employ only ill-defined, subjective assessments, e.g. "anxiety" or "pain." Or obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the "unexposed" but requires clinical assessment of the "exposed"). Surveys: no description of questionnaire/interview content or response options. Decision analyses: sources of uncertainty are not defined for input variables. • N/A: Descriptive case series / reports.
9. Sample size appropriate?	• Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors (SE > ½ effect size) and/or problems with multiple testing are evident. Decision analyses: size of modeled cohort / number of iterations specified and justified. • Partial: Insufficient data to assess sample size (e.g., sample seems "small" and there is no mention of power/sample size/effect size of interest and/or variance estimates aren't provided). Or some statistically significant results with standard errors > ½ effect size (i.e., imprecise results). Or some statistically significant results in the absence of variance estimates. Decision analyses: incomplete description or justification of size of modeled cohort / number of iterations.

	• No: Obviously inadequate (e.g., statistically non-significant results and standard errors > ½ effect size; or standard deviations > _ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). Decision analyses: size of modeled cohort / number of iterations not specified. • N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.
10. Analysis described and appropriate?	• Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”/“Kaplan-Meier with log rank tests”, etc.) and appropriate. • Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. Or minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). Or multiple testing problems not addressed. • No: Analysis methods not described and cannot be determined. Or obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). Or a study with a descriptive goal / objective is over-analyzed. • N/A: Descriptive case series / reports.
11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/objective upon which the conclusions are based)?	• Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model. • Partial: Undefined “+/-“ expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model. • No: No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis. • N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.
12. Controlled for confounding?	• Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc). Decision analyses: dependencies between variables fully accounted for (e.g., joint variables are considered). • Partial: Incomplete control of confounding. Or control of confounding reportedly done but not completely described. Or randomized study without report of comparability of baseline characteristics. Or confounding not considered, but not likely to have seriously distorted the results. Decision analyses: incomplete consideration of dependencies between variables.

	• No: Confounding not considered, and may have seriously distorted the results. Decision analyses: dependencies between variables not considered. • N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.
13. Results reported in sufficient detail?	• Yes: Results include major outcomes and all mentioned secondary outcomes. • Partial: Quantitative results reported only for some outcomes. Or difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate. • No: Quantitative results are reported for a subsample only, or "n" changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data - i.e., the category of "unknown" is not used where needed). Or results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as "more likely" without quantitative report of actual numbers). • N/A: Should not be checked for this question
14. Do the results support the conclusions?	• Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren't based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in addition to rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., "suggesting," "possibly"). • Partial: Some of the major conclusions are supported by the data, some are not. Or speculative interpretations are not indicated as such. Or low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy). • No: None or a very small minority of the major conclusions are supported by the data. Or negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. Or conclusions are missing. Or extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy). • N/A: Should not be checked for this question.

Appendix B. Statement of contributions from trainees involved in the project

Luke Perkins (LP) and Cerne Felstead (CF) 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
Literature Review search and analysis	LP
Literature Review Quality Checklist	LP and CF
Design of empirical study	LP and CF, under supervision of Professor Aimee Spector and Dr Joshua Stott (internal supervisors) and in collaboration with the Hong Kong Facecog team and stakeholder consultation.
Ethics Application	LP and CF
Design of intervention	LP and CF LP took lead on facilitating focus groups and designing vCST session plans and resources CF took lead on analysis of focus group data and development of vCST guidelines with assistance of Carey Fagan (Assistant Psychologist)
Recruitment	LP recruited 13 participants CF recruited 9 participants
Delivery of vCST	LP, CF and Claire Rooney (Occupational Therapist) delivered vCST to 4 participants each
Creation of assessment packs	CF
Assessments	LP and CF jointly responsible, assisted by Nur Diyanah Abdul Wahab (Trainee Clinical Psychologist) and Wing Gi Leung (Trainee Clinical Psychologist)
Semi-structured feedback interviews	CF, assisted by LP, Nur Diyanah Abdul Wahab (Trainee Clinical Psychologist) and Wing Gi Leung (Trainee Clinical Psychologist)
Data Entry	LP and CF
Analysis	LP completed analysis of mood and quality of life measures CF completed measures on cognition and qualitative feedback interviews

Appendix C. Ethics Approval Letter

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

22/07/2020

Professor Aimee Spector
[department]
UCL

Dear Aimee Spector

Notification of Ethics Approval
Project ID/Title: 17127.002 / Virtual CST – A collaborative proof of concept study with FaceCog HK in response to the Covid-19 pandemic.

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **22/07/2023.**

Ethical approval is 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. 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.

Covid-19
In view of the fast developments of the pandemic, the numerous projects being initiated and the constantly changing framework, please provide us with regular updates **every 4 months** regarding the ethical aspects of your project and the specific problems (if any) that you have encountered. At the end of the study, as part of the final report you have to submit to the UCL REC, please include

alongside a brief outline of the research outcomes, any experiences which would be valuable for informing the fast-track COVID review process, and in turn subsequent fast-tracked studies.

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: www.ucl.ac.uk/srs/governance-and-committees/research-governance
- 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

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix D. Participant Information Sheets and Consent forms

Participant Information Sheet for CST Participants
UCL Research Ethics Committee Approval ID Number: 17127.002

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Group CST using zoom: A proof of concept study

---

Department:
Clinical, Education & Health Psychology, Division of Psychology & Language Sciences

---

Name and Contact Details of the Researcher(s):
Luke Perkins – luke.perkins.15@ucl.ac.uk
Cerne Felstead – cerne.felstead.18@ucl.ac.uk

Name and Contact Details of the Principal Researcher:
Professor Aimee Spector – a.spector@ucl.ac.uk

Invitation Paragraph
You are being invited to take part in a research project. This research is being conducted by University College London in collaboration with Hong Kong University. Before you decide, it is important for you to understand why the research is being done and what participation 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.

What is the project's purpose?
Cognitive Stimulation Therapy (CST) is a group-based dementia treatment that has been found to have positive effects in cognitive skills (such as memory) and quality of life, as well as being fun and enjoyable. However, practical issues such as transport may stop people being able to access CST, especially during the Covid-19 crisis. In this study, we aim to test out whether it is possible to run CST groups online via video conferencing in a similar way to running them face-to-face, and still have positive treatment effects.
Why have I been chosen?
We are looking to recruit people in the earlier stages of dementia. You must have access to the video conferencing app 'Zoom' and be comfortable joining a virtual group with approximately 3 other people for 60 minute sessions,

twice a week for 7 weeks. We are also looking for people who are able to speak English, as we are regretfully unable to deliver the training in any other language at the moment.

Do I have to take part?

If you have the capacity to do so, then it is up to you to decide whether or not to take part. Your choosing to participate or not, will not in any way effect the care you receive from the health or charity service you access. If we are unsure about your capacity to decide, we might ask you some questions and give you some more information to check capacity. If we feel that something about your dementia makes it difficult for you to decide, then we will not ask you participate. This is because we want to make 100% sure that this is ***your*** informed decision.

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 any benefits that you are entitled to. If you decide to withdraw, you will be asked what you wish to happen to the data that you have provided up to that point.

If you decide to withdraw at any point during the study or decide not to take part at all, your relationship with the organisation that you were recruited through will not be affected in any way.

What will happen to me if I take part?

If you choose to take part, you will be randomly assigned to either a 'zoom CST' group or a 'control' group. There is an equal, 50/50 chance of you being in either group. If you are in the control-group you will not receive zoom-CST.

- In the week before the first CST session, we will complete some questionnaires with you individually in a phone or zoom session. This will take approximately one hour.
- If you have been randomly allocated to the 'zoom-CST' group, we will then invite you to take part in the CST sessions online. This involves attending two, 60 minute sessions per week for seven weeks (14 sessions in total) via zoom. These are group-sessions that will be attended by approximately three other people.

If you have you been randomly allocated to the 'control' group, we will not ask you to do anything, or attend our group during this time. You can access your usual treatment as you would if you were not taking part in this study.

- In the week after the last CST session, we will complete the same questionnaires with you individually in a phone or zoom session.

- We may then ask you to complete a feedback interview individually via phone or zoom about your experience of the group. This will last one hour or less.

Will I be recorded and how will the recorded media be used?
Except for the questionnaire sessions, all sessions will be video-recorded so that we can analyse how easy it is to engage with the group and the feedback you give. These recordings will only be used for the purposes described, will be anonymised as much as possible and will be destroyed once the analysis is complete. We will be using the video conferencing app 'Zoom'. Please read Zoom's privacy notice before consenting to take part. It can be found at: https://zoom.us/privacy.

What are the possible disadvantages and risks of taking part?
We do not expect that taking part in the study will cause you any distress. However, if we believe that you may be feeling distressed for any reason, we will try to check in with you, to see if we can support you in any way.

In the unlikely event that you become distressed during the sessions, one of our facilitators will try to call you to offer you support. If we are unable to reach you or we feel that you need further support once we have spoken to you, we will contact your carer or next of kin. We will seek to discuss this with you as best as we can before we do this but may not always be able to do so, for example if we are unable to contact you directly.

What are the possible benefits of taking part?
Our aim is to test whether running such groups via Zoom is feasible and if taking part has any benefits to your cognition (e.g. memory and language) and quality of life. This could lead to new methods of delivering treatments and improving access within health and care services for people diagnosed with dementia in the future.

What if something goes wrong?
We do not expect for anything to go wrong during the study, but if something should happen then please contact the researchers immediately using the contact details provided so that they can support you to try to resolve this. If you have any complaints regarding your treatment by researchers at any point, please contact the principal researcher at a.spector@ucl.ac.uk. If you feel that your complaint has not been handled to your satisfaction, please contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk.

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 secure and confidential. You will not be able to be identified in any reports or publications as your data will be fully anonymised. The

researchers will be the only people who will have access to your data. All confidential information will be disposed of securely once it is no longer needed for the study.

Limits to confidentiality

Confidentiality will be maintained as far as it is possible, unless during our conversation we hear anything which makes us worried that you or someone else might be in danger of harm. In these cases, we will ask your permission to inform the relevant service to support you (e.g. your GP).

What will happen to the results of the research project?

Once you have completed the sessions and we have collected all of your information, we will analyse the results and write a report. If you have so requested, we will send you a copy of the findings. Your data will be fully-anonymised in any report or publication. You can choose to opt-out and have your data removed from the study up until Spring 2024. To do this please contact Prof. Aimee Spector using the details below.

Local Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer oversees how we process your personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

> https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-notice-participants-and-researchers-health-and-care-research-studies

The information that we are required to give to you under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

Name, Address, Telephone number, Email address, Age, Gender, Ethnicity, Type of dementia (if known), Name, relationship and phone number of carer/next of kin, GP Name and contact details

The lawful basis that we use to process your personal data is that the study is being carried out in the public interest. The lawful basis used to process special category personal data will be for scientific and historical research or statistical purposes.

Your personal data will be used as long as it is required for the research project. All identifiable data will be destroyed upon completion of the project in Spring 2024. All fully-anonymised data will be kept and archived 5 years following completion of the study. We will seek to anonymise the data as much as possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Who is organising and funding the research?
This research is organised and funded by UCL as part of the Clinical Psychology Doctoral programme.

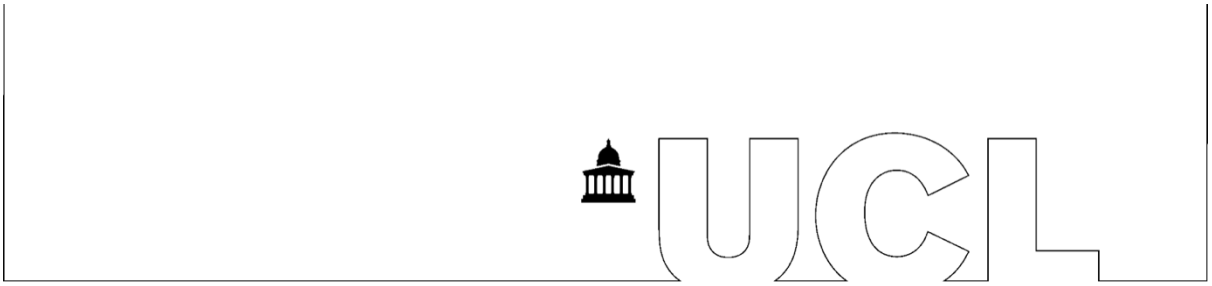
Contact for further information
Should you wish to contact the researchers for further information, please use the following contact details:

***Principal Researcher**: Professor Aimee Spector*
***Address:** Clinical, Education & Health Psychology, Division of Psychology & Language Sciences, 1-19 Torrington Place, London, WC1E 7HB*
***Telephone:** 0207 679 1844*

If at any time you are feeling low in mood, please visit your GP in the first instance. If you feel unable to keep yourself, or someone else, safe then please attend A&E and seek support. You can also seek support with the Samaritans (24hours) by telephoning 116 123.

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

CLINICAL, EDUCATIONAL & HEALTH
PSYCHOLOGY



CONSENT FORM FOR ONLINE CST GROUP PARTICIPANTS

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

Title of Study: Group CST using zoom: A proof of concept study

Department: Clinical, Educational and Health Psychology
Name and Contact Details of the Researcher(s):
Ms. Cerne Felstead – cerne.felstead.18@ucl.ac.uk
Mr. Luke Perkins - luke.perkins.15@ucl.ac.uk
Name and Contact Details of the Principal Researcher:
Professor Aimee Spector **-** a.spector@ucl.ac.uk
Tel: 020 7679 1844
Name and Contact Details of the UCL Data Protection Officer:
Alex Potts - a.potts@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee:
Project ID number: 17127/002

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 by emailing the researcher the following statement I am consenting to the 16 elements of the study written below:

"I NAME and my carer NAME, have read the information sheet and consent forms for the study titled 'Group CST using zoom: A proof of concept study'.

With this email, I hereby electronically 'sign' and consent to taking part in the study and to the 16 items outlined on the consent form."

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: • *an appointment to complete questionnaires prior to my attendance at the online CST group sessions.* • *14 sessions of an online CST group intervention, if allocated to the 'zoom-CST' group.* • *an appointment to complete questionnaires after attendance at the online CST group sessions.* • *an appointment at the end, where I will be asked some questions about my experience of participating in the group.*
2.	I understand that my personal information (*name, age, gender, ethnicity, address, telephone number, email address, dementia type, questionnaire answers and session recordings)* will be used *only* for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.
3.	I understand that the online CST sessions will be video-recorded for research purposes only. I consent to this recording.
4.	I confirm that I have read the 'Zoom' privacy policy (Here: https://zoom.us/privacy) and that I consent to the use of 'Zoom' for the delivery of the online CST sessions.

5.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.
6.	I understand that if I disclose anything which indicates that I, or someone else may be at risk of harm, that the researchers have the responsibility to report this to the relevant services.
7.	I understand the direct/indirect benefits of participating and any potential risks. I am aware of the support that I can access should I become distressed during the course of the research. I consent for the facilitators to contact my carer/next of kin in the unlikely event that I become distressed during the study and the facilitator is unable to contact me directly or believes that I may need further support once they have spoken to me. I understand that they will seek to inform me before they do this but this may not always be possible.
8.	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.
9.	I consent to my fully-anonymised data being shared with collaborating researchers.
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 the information I have submitted will be published as a report and that I can request to receive of copy of this report.
12.	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.
13.	I am aware of who I should contact if I wish to lodge a complaint.
14.	I voluntarily agree to take part in this study. I understand that I can withdraw at any time, in which case any personal data I have provided up to that point will be deleted unless I agree otherwise.
15.	I would be happy for the fully-anonymised data I provide to be archived at UCL and may be used for future research
16.	I consent to be contacted by the researchers in order to arrange pre/post appointments.

If you consent to the above 16 items, and you would like to participate in the study please email cerne.felstead.18@ucl.ac.uk or luke.perkins.15@ucl.ac.uk with the statement below. Please insert your name and the name of your carer (if appropriate).

"I NAME and my carer NAME, have read the information sheet and consent forms for the study titled 'Group CST using zoom: A proof of concept study'. With this email, I hereby electronically 'sign' and consent to taking part in the study and to the 16 items outlined on the consent form."

Appendix E. Interim Guidelines for Virtual Cognitive Stimulation Therapy (vCST)

Interim Guidelines for Virtual Cognitive Stimulation Therapy (vCST)

August 2020

The purpose of these guidelines:

The following interim guidelines have been written to support facilitators who wish to offer Cognitive Stimulation Therapy (CST) via an online format. They have been developed in response to the global Covid-19 pandemic, when many service-users have been shielding at home and hence have been unable to access treatments face-to-face as they ordinarily would. These guidelines are likely to be superseded by more detailed and evidence-based publications in due course, following the completion and dissemination of our University College London (UCL) - based randomised control trial which is adapting CST for 'virtual' (online) facilitation (vCST).

The following information is provided as a useful resource for planning and implementing CST groups online via video-conferencing apps. The information presented below should be interpreted in the context of local service policies and considering any local population demographics and needs. The pre-existing guidelines and key-principles of in-person group CST should continue to apply for vCST. These interim guidelines should therefore be interpreted in conjunction with the CST *'Making a Difference'* manual (Spector, Woods, Stoner & Orrell, 2020).

The development of these guidelines:

These guidelines have been developed in consultation with a range of stakeholders through online focus groups held in July and August 2020. This includes professionals (including mental health nurses, occupational therapists and mental health support workers) who have trialled vCST in practice, academics with expertise in CST research and practice, service managers who are responsible for making decisions about implementing interventions within their organisations and service users (including people living with dementia and carers).

Page Break

References:

Spector, A., Woods, B., Stoner, C.R., & Orrell, M. (2020). *Making a Difference 1: An Evidence-Based Group Program to Offer Cognitive Stimulation Therapy (CST) to People with Dementia.* Hawker Publications Ltd.

Authors:

Cerne Felstead – Trainee Clinical Psychologist (UCL)
Luke Perkins – Trainee Clinical Psychologist (UCL)
Prof. Aimee Spector – Professor of Old Age Clinical Psychology (UCL)
Dr. Joshua Stott - Associate Professor (UCL)
Dr. Gloria Wong – Assistant Professor (University of Hong Kong)
Ruizhi Dai – Postdoctoral Fellow (University of Hong Kong)
Carey Fagan – Assistant Psychologist (Camden and Islington NHS Foundation Trust)

Page Break

In order to run vCST groups successfully we advise the following to be taken into consideration:

1. Technology

1. Any video-conferencing app can be used in compliance with local service-policy. The most commonly used platform amongst focus group attendees was 'Zoom', due to its ease of use, and participants' pre-existing familiarity with Zoom's functionality. A subscription to the platform may be required by the facilitator to enable all features.
2. The app used should allow participants to see and hear one another and allow for multiple attendees to be present in the group.
3. Participants may benefit from a brief document which outlines how to use the video-conferencing app of choice. This leaflet can include screenshots and a step-by-step guide. See Appendix 1 for an example 'how-to guide' for Zoom.
4. Functions which have been known to be useful during vCST include; 'share-screen', 'whiteboard', 'waiting-room', the Zoom 'clapping function' and 'raise hand function'.
5. Protecting participants' privacy and safety whilst online is important. Facilitators can use a meeting-password or unique joining-link for each session. The 'waiting room' function can be used to ensure that only those who are intended to join the meeting are admitted. Sometimes family members might share a video-conferencing app account; make sure that participants' usernames are set up as *their own* full name so that they can be easily recognised. This will also aid memory and communication between group members, as individuals' names are displayed on screen.
6. Participants will require a laptop or large tablet device with a camera and microphone to access the video-conferencing app, as well as a suitably stable internet connection. It is not advisable for group members to partake in vCST using a smartphone.
7. All facilitators and participants should set their display as 'gallery view'. This enables participants to see other group members continuously.
8. For those new to the technology, the prospect of vCST groups may seem daunting initially. Facilitators may notice a reduced uptake in recruitment on invitation to the treatment compared to face-to-face groups. A 1:1 telephone call or online meeting with participants to allay any worries, offer reassurances and upskill participants to increase self-confidence can be helpful in encouraging participants to try this new approach. Offer reassurances that this format is new to facilitators also, promoting a culture in which mistakes are anticipated, and accepted by all. Other resources which may help to promote the groups include; a short video of a session taking place, screenshots from previously run groups and testimonials from earlier group members.
9. Group participants may benefit from a separate initial 1:1 'set-up session' prior to the group commencing in order to access the technology platform for the first time.

2. Group Set-Up

1. The group format should follow the original evidence-based CST protocol as closely as possible given your service resources and needs.

2. Groups therefore should aim to run twice weekly for 14 sessions if possible. Some services have run vCST groups once weekly, and even fortnightly over an extended period.
3. Sessions are normally 45-60 minutes in duration. It may be helpful to allocate 10 minutes either side to allow time for set-up and goodbyes.
4. Ask participants to join the meeting 10-15 minutes prior to the group start time. Use the 'waiting-room' function on your video-conferencing app to check who has joined and to ensure that groups start on time. It is advisable that a group facilitator telephone calls any participants who have not joined the waiting room five minutes before group start, to check if they require assistance.
5. Reminder emails or calls to participants and carers/supporters on the morning of the session can be helpful in ensuring timely attendance.

3. Group Participants

1. The optimum number of group members for vCST is four to five. This is to allow for optimum visual display of other members' cameras, and to enable the participation of all group members.
2. Group members should remain consistent throughout the 14-week programme in order to promote group-cohesion, as is recommended in face-to-face CST.
3. People with dementia (PwD) should attend the groups independently, as much as is possible (see section 4.1).
4. Experienced CST facilitators should assess vCST's suitability for individual group members prior to invitation to the groups, as they would ordinarily for face-to-face CST. Participants' cognitive, sensory, communication and attention abilities should be considered and discussed with the participant and their carer/supporter.

4. Support from others

1. The majority of participants will require support from a carer or supporter to help them access vCST. The role of a participants' carer/supporter can vary dependent on the PwD's cognitive ability and prior skills with the technology. Carers/supporters input should be valued and encouraged in supporting the PwD's attendance and technological set-up. Carers/supporters should however provide participants with privacy and autonomy once the sessions begin, as would be customary in face-to-face CST.
2. Inform carers/supporters about the key principles of CST to help them appreciate the value of the PwD's independent attendance at the group.
3. Carers'/supporters' contact details should be obtained prior to the groups so that they can be contacted should participants require assistance. Reassure carers/supporters that the facilitator will contact them should they feel that the PwD requires support whilst attending the group.
4. Request that carers/supporters are available nearby, and that they keep their telephones with them during the group, should their assistance be required.
5. It can be helpful to develop a 'carers/supporters agreement' document in which the facilitators' expectations of carers/supporters are

outlined clearly prior to the group commencing. See Appendix 2 for an example carers'/supporters' agreement.

6. It may be helpful to provide some brief training to carers/supporters to assist them with setting up the technology and to help them learn about their role in supporting participants to access vCST.

5. Group Facilitators

1. Groups should be led collaboratively by a minimum of two facilitators; one to lead the vCST sessions, and one to assist with supporting participants' access to the group and any technological problems.
2. Each facilitator will require a desktop or laptop device with a camera and microphone, as well as a video-conferencing app subscription and reliable internet connection.
3. Group facilitation should take place in a quiet environment, preferably a private room.
4. Staff training on how to use the technology would be helpful. Dedicated time for facilitators to familiarise themselves with the technology prior to groups commencing is essential.
5. Dedicated time for facilitators to plan the group sessions' content (e.g. visual, audio, slides etc.) is also essential (see section 6.5).
6. In order to facilitate group cohesion, facilitators should aim to integrate as part of the group rather than taking an external position of leadership.

6. Group Content

1. Paperless vCST facilitation is possible, using the share-screen function on the video-conferencing app to share visual and audio content.
2. It can be helpful in some instances to email session resources to participants prior to the sessions. Participants can read the resources in their own time before the meeting, or choose to print them at home if they prefer.
3. Posting a resource-pack to participants is also an option, however, is resource-heavy and by no means essential for vCST sessions to run online successfully.
4. A warm-up activity can be successfully facilitated in vCST. Some examples which have worked well include:

- Each participant miming throwing a 'virtual' ball to another group member.
- Numbered cards for participants to select with different topics for sharing (e.g. favourite food, singer, etc.).
- A facilitated seated exercise routine.
- Group members sharing in turn what they can see around them.

5. Some activities may require participants to pre-prepare and bring objects or materials with them to the group. It is important therefore, at the end of the session, to discuss what the activity options are for the upcoming session. Facilitators are advised to inform carers/supporters of what has been decided so that they can support participants to prepare effectively for the next session.
6. All sessions in the CST manual may need some adjustment for adapted use online. Facilitators are encouraged to think creatively and plan the sessions in advance.

7. Using a slide-show format can provide a helpful focus for the sessions. For example, creating a 'PowerPoint' presentation with photos, discussion topics, videos, news articles etc. and sharing this with participants using the 'share-screen' function.
8. For some sessions which require props (e.g. household treasures), ask participants to source and bring items (e.g. photos) from their home environment to the sessions.
9. For the food session, facilitators can provide a recipe in advance and ask participants and carers/supporters to bake/cook the same recipe prior to the session. Participants can then discuss this process, share photographs, or taste the food together during the group.
10. Most importantly, have fun with the group content by encouraging facilitators and participants to be creative (e.g. wearing a different hat to each session).

7. Tips for Potential Barriers

1. CST and vCST are not the appropriate treatments for everyone with a diagnosis of dementia. However, participants with visual or hearing impairments, aphasia, or a different language to the group facilitation, *can* partake in vCST, but may require additional support. These additional needs should not automatically exclude someone from participation in vCST and instead must be assessed on an individual-basis at the initial screening appointment.
2. Some participants with hearing difficulties may benefit from the use of headphones.
3. Visual content should always be clear, using large font writing, clear quality images and clear-contrast colours.
4. When using share-screen; once visual content is no longer required, ensure that the facilitator returns to 'gallery-view' so that participants can observe and engage with one another.
5. Some participants may struggle with concentration and video-fatigue. Take short breaks in between the activities and ensure that sessions adhere to a 45minute duration.
6. Ensure that facilitators are observant to maintaining participants' engagement. Address group members individually in turn to encourage participation, and to reduce the chances of participants speaking over one another.
7. If participants struggle with maintaining attention, allow flexibility with joining and leaving the session if needed.
8. Participants may have different energy levels at different times in the day. Ask participants beforehand what time of day they are able to concentrate best to aid group planning.
9. Participants may be more likely to attend sessions if they can build relationships with the other participants. However, memory difficulties may interfere with remembering other participants between sessions. To help build memory associations, it can be helpful for participants to select an object to represent them that they can bring to each session.
10. Participants may be reluctant to join vCST due to anxieties/concerns about using online technology and meeting new people. It is important to not only provide written information about vCST beforehand, but to try to speak directly with participants to give further information, testimonials and answer any questions or concerns they may have.

How to use 'Zoom' Guide

This guide has been written to support participants and their carers in joining our 'virtual' online Cognitive Stimulation Therapy (CST) groups.

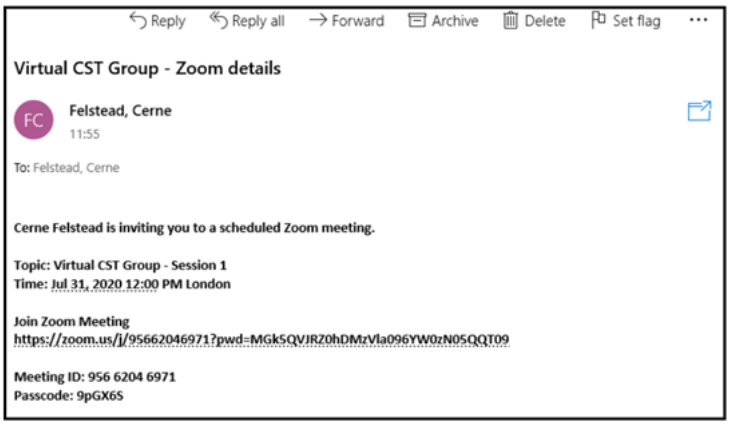
Try to get connected 10-15minutes before the group start time.

You do not need to download anything to join a 'Zoom' meeting.

If you are new to using 'Zoom', take your time to get to grips with the technology. It might take a while to get connected and that's completely fine, don't worry. It will get quicker and easier with more practice.

If you have some technical issues don't feel pressured, these things happen, and we will be on hand to support you if needed.

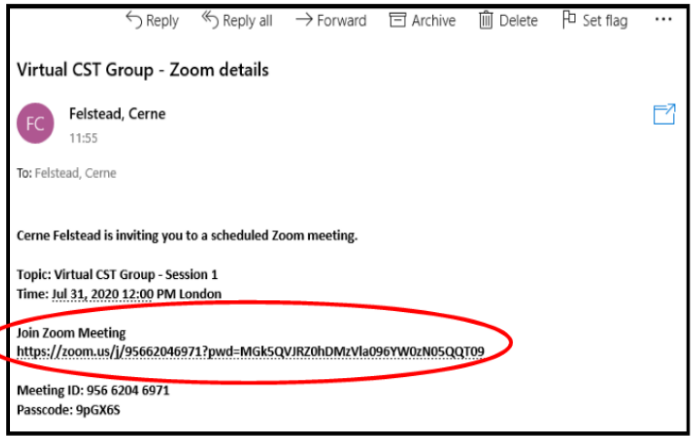
Each week you will receive an email invitation that looks similar to this:



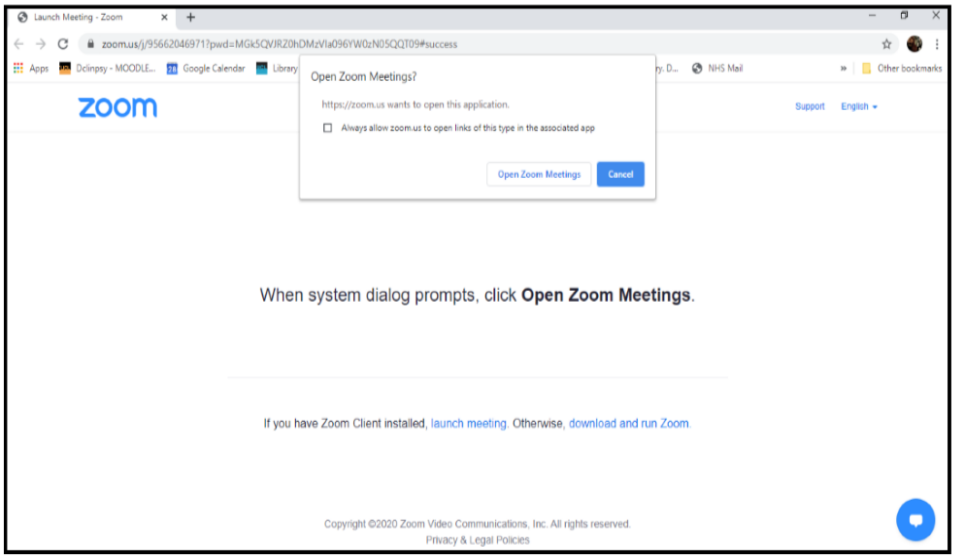
Appendix 1:

Step 1:

Click on the link in the email labelled *'Join Zoom Meeting'*:



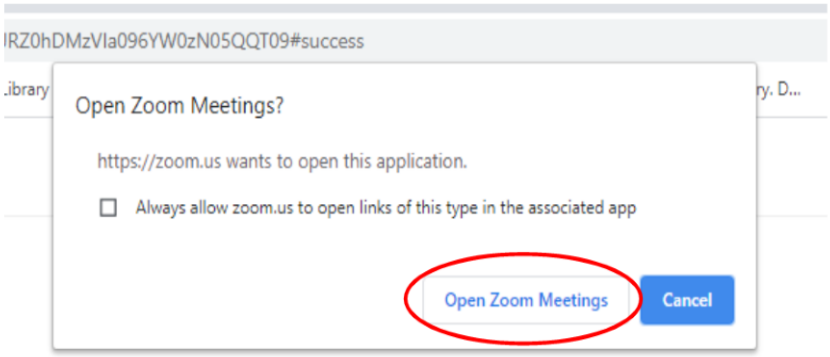
Your internet browser should pop open and look similar to this:



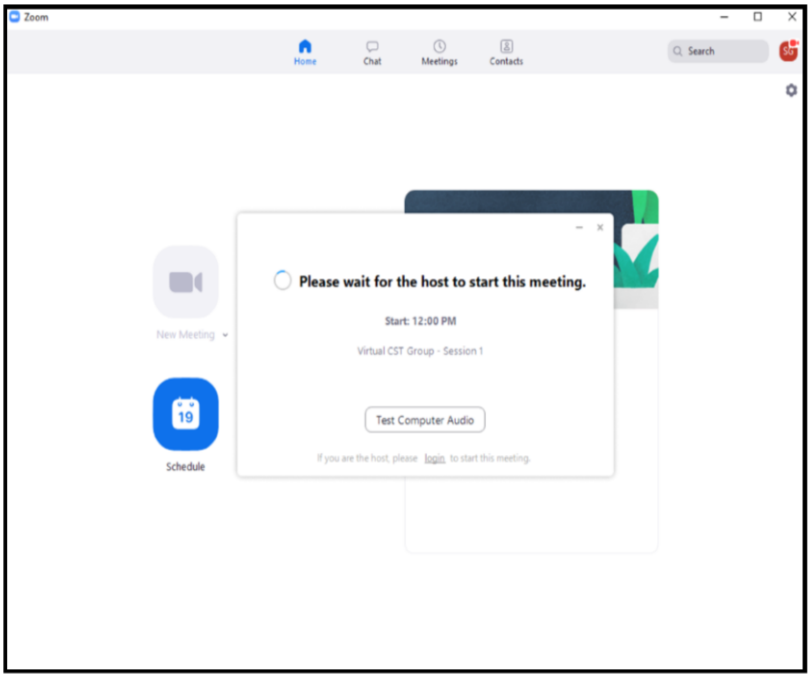
2

Step 2:

Click on *'Open Zoom Meetings'*:



You should see a message saying *'Please wait for the host to start the meeting'* similar to this:



3

Appendix F. Recruitment Poster

CLINICAL, EDUCATIONAL & HEALTH PSYCHOLOGY

UCL

Do you have dementia and would like to receive support online?
Would you like to take part in our research study?

Cognitive Stimulation Therapy (CST) is an evidence-based brief treatment for people with dementia.
CST is usually offered as face-to-face group sessions, often within memory services.
The groups are intended to be fun, engaging and social, whilst following structured activities.
We are trialling a CST group online through 'video-call' so that people with dementia can access this treatment from their home.

We are looking for…

- People with mild-moderate dementia.
- People who speak English.
- People who have access to a computer & internet at home.
- People who would be happy to attend two sessions a week, over seven weeks in November 2020 – January 2021.

If you would like to know more please **contact us.** Or ask your carer, support worker etc. to pass on your contact details to us.

luke.perkins.15@ucl.ac.uk
cerne.felstead.18@ucl.ac.uk

UCL Research Ethics Committee Approval ID: 17127.002

Appendix G. Geriatric Depression Scale (Short Form)

Geriatric Depression Scale (Short Form)

Patient's Name: _____ Date: _____

Instructions: Choose the best answer for how you felt over the past week. Note: when asking the patient to complete the form, provide the self-rated form (included on the following page).

No.	Question	Answer	Score
1.	Are you basically satisfied with your life?	YES / ***NO***	
2.	Have you dropped many of your activities and interests?	***YES*** / NO	
3.	Do you feel that your life is empty?	***YES*** / NO	
4.	Do you often get bored?	***YES*** / NO	
5.	Are you in good spirits most of the time?	YES / ***NO***	
6.	Are you afraid that something bad is going to happen to you?	***YES*** / NO	
7.	Do you feel happy most of the time?	YES / ***NO***	
8.	Do you often feel helpless?	***YES*** / NO	
9.	Do you prefer to stay at home, rather than going out and doing new things?	***YES*** / NO	
10.	Do you feel you have more problems with memory than most people?	***YES*** / NO	
11.	Do you think it is wonderful to be alive?	YES / ***NO***	
12.	Do you feel pretty worthless the way you are now?	***YES*** / NO	
13.	Do you feel full of energy?	YES / ***NO***	
14.	Do you feel that your situation is hopeless?	***YES*** / NO	
15.	Do you think that most people are better off than you are?	***YES*** / NO	
		TOTAL	

(Sheikh & Yesavage, 1986)

Scoring:

Answers indicating depression are in bold and italicized; score one point for each one selected. A score of 0 to 5 is normal. A score greater than 5 suggests depression.

Sources:

- Sheikh JI, Yesavage JA. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clin Gerontol*. 1986 June;5(1/2):165-173.
- Yesavage JA. Geriatric Depression Scale. *Psychopharmacol Bull*. 1988;24(4):709-711.
- Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: a preliminary report. *J Psychiatr Res*. 1982-83;17(1):37-49.

Appendix H. Finalised virtual Cognitive Stimulation Therapy (vCST) protocol

Introduction

- vCST consists of 14 sessions, delivered twice weekly
- Sessions should last 45 to 60 mins in length, with 10 minutes allocated prior to the session for
- Each group should have no more than four to five participants with similar stages of Dementia
- Each group should be run by two facilitators
- A choice of activities for each session theme are outlined in this manual. These should be presented to group participants each session to enable group members to have choice over the activities they which to participate in. Group facilitators should create or organise resources and materials appropriate for each chosen activity

Key vCST Principles (based on key principles outlined in the group CST manual (Spector, Woods, Stoner & Orrell, 2020)

1. Mental Stimulation
2. New ideas, thoughts and associations
3. Using orientation sensitively and implicitly
4. Opinions rather than facts
5. Using reminiscence as an aid to the here and now
6. Physical Movement
7. Providing triggers and prompts to aid recall and concentration
8. Continuity and consistency between sessions
9. Implicit (rather than explicit) learning
10. Stimulating language
11. Stimulating executive functioning
12. Person-centred
13. Respect
14. Involvement and Inclusion
15. Choice
16. Fun
17. Maximising potential
18. Building/strengthening relationships

Structure of each session

- Introduction including welcome/introductions, warm up activity and sing the group song (10 minutes)
- Current affairs including reality orientation and discussion of a news article (10 – 15 minutes)
- Main Activity (20-25 minutes)

- Wrap up including a note of thanks, reminder of next session's theme and discussion of choice of next session's activity (5-10 minutes)

Session 1 – Physical Games

Warm up Activity

- Introductions including name and one fact about you (or another agreed warm up question)
- Group chooses group name and group song

Main Activity

Group chooses from one of the following activities

- Group members throw a pretend ball to each other and say something about themselves
- Colour card exercise - Facilitator has a set of different cards in different colours / numbers. Each card has a topic for sharing: e.g name and where you come from; your favourite exercise; your exercise habit / routine; benefits of exercise; your thoughts on healthy life etc. Participants take turns to choose one card from the facilitator and the group will do sharing according to the topic of the chosen card.
- Practice chair exercises together (from a youtube video for example)

Wrap Up

- Reminder of next session – Sounds
- Ask participants whether they would like to bring an instrument or favourite CD/Tape/Record to discuss next session
-

Session 2 – Sounds

Warm up Activity

- Show other participants instrument/tape/cd/record that they brought to session
- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to sounds
- Use the colour card resource to ask/answer questions about sounds.

Main Activity

Group chooses from one of the following activities

- Play the sounds of different musical instruments (e.g., piano, violin, saxophone, etc), ask participants to (1) state/choose from a list of answer the names of the instruments and (2) demonstrate how to play these instruments (using gestures). Could ask members to bring any musical instruments they may have to demonstrate how to use it

- Sound-picture matching – play sounds of everyday objects (e.g., car, doorbell, dog, etc) and ask participants to state/choose from a list of answers
- "Remember this song?" - play songs participants are familiar with and discuss

Wrap Up

- Reminder of next session – Childhood
- Ask to bring childhood toy/object or food reminding them of childhood or to complete childhood memory worksheet for next session

Session 3 – Childhood

Warm up Activity

- Show other participants childhood toy/object/food that they brought to session
- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to childhood
- Use the colour card resource to ask/answer questions about childhood.

Main Activity

Group chooses from one of the following activities

- Ask participants to fill in childhood memory page, and introduce family members to the group
- Ask participants to draw their homes from childhood memory and show the group
- Show the participants some childhood toys or pictures of the toys and ask them to describe/demonstrate how to play. Ask participants if they have any childhood toys they brought to the session
- Show the group some childhood snacks or pictures of the snacks, and ask them to describe the taste

Wrap Up

- Reminder of next session – Food
- Ask to bring food/drink reminding them of childhood or agree a recipe to cook at home/buy foods to try next session

Session 4 – Childhood

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to food
- Use the colour card resource to ask/answer questions about food.

Main Activity

Group chooses from one of the following activities

- Show participants some food labelled with price, and ask them to shop for a theme (e.g., breakfast/lunch/dinner preparation for a family of 4)
- Show participants pictures of different food and ask them to group them and name the category
- Show participants cookery videos online and discuss. Ask participants to choose food or chef that are meaningful to them and watch relevant youtube videos using sharescreen function
- Ask members to bring some food items to sample that trigger particular memories, i.e. Bovril, ginger beer
- Try the food that participants agreed to bring last session and discuss taste/texture/smell/what it reminds them of

Wrap Up

- Reminder of next session – Current Affairs
- No preparatory tasks for next session

Session 5 – Current Affairs

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to current affairs
- Use the colour card resource to ask/answer questions about current affairs

Main Activity

Group chooses from one of the following activities

- Watch news clips online and discuss
- Voting and discussion on different current affairs topics (thoughts on the royal family for example)

Wrap Up

- Reminder of next session – Faces/Scenes
- Ask to bring favourite photos/pictures to next session

Session 6 – Faces/Scenes

Warm up Activity

- Ask participants to share and discuss favourite photos/pictures brought to session
- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to faces/scenes
- Use the colour card resource to ask/answer questions about faces/scenes

Main Activity

Group chooses from one of the following activities

- Present photos that show the past and present of the same place (using the sharescreen function), ask participants to compare the two and describe the differences.
- Show the group photos of some famous people (using the sharescreen function), ask the group to name these people and discuss freely (who is more popular for example)

Wrap Up

- Reminder of next session – Word Association
- No preparatory tasks for next session

Session 7 – Word Association

Warm up Activity

- Play a word association game
- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to words and language
- Use the colour card resource to ask/answer questions about words and language

Main Activity

Group chooses from one of the following activities

- Show participants some well known sentences with blanks, ask the group to fill in the blanks
- Play/sing the beginning of songs that group members would know and ask the group to continue

Wrap Up

- Reminder of next session – Being creative
- Ask to bring pen/pencil, paper and scissors to next session

Session 8 – Being Creative

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to art or creativity
- Use the colour card resource to ask/answer questions about art or creativity

Main Activity

Group chooses from one of the following activities

- Teach the group to do some simple paper folding, such as folding an airplane or a jumping frog (using youtube videos for example
- Lead the group to make some paper snowflakes, and encourage them to develop their own designs (using a youtube video for example)
- Ask members to draw pictures of each other

Wrap Up

- Reminder of next session – Categorising objects
- No preparatory tasks for next session

Session 9 – Categorising Objects

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to categories
- Use the colour card resource to ask/answer questions about categories

Main Activity

Group chooses from one of the following activities

- Ask the group to come up with a category / choose from a list (animals for example) and ask the group to name a few items under the category.
- Show 10 pictures of daily objects on the using screenshare and ask participants to group the objects based on different categories (colour, usage, or where to find them for example)

Wrap Up

- Reminder of next session – Orientation
- Ask participants to print out a map of the UK/world and bring a pen/pencil to next session

Session 10 – Orientation

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to geography/places
- Use the colour card resource to ask/answer questions about geography/places

Main Activity

Group chooses from one of the following activities

- Show the group a UK map on the screen and ask members to have the map print outs discussed last session along with a pen/pencil. Ask participants to find/mark the areas they live in. Discuss whether they had moved from an area to another, and how the areas have changed over the years.
- Show the group a world map on the screen and ask members to have the map print outs discussed last session along with a pen/pencil. Ask participants to find/mark countries they have visited or would like to visit.
- Ask the group members what the places are that they would like to recommend to a person from a different country who's visiting the UK for the first time.

Wrap Up

- Reminder of next session – Using Money

- Ask participants to bring old/new British/non-British banknotes/coins that they may have around the house

Session 11 – Using Money

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to money/currency
- Use the colour card resource to ask/answer questions about money/currency

Main Activity

Group chooses from one of the following activities

- 'Price guessing task' - ask people to guess the price of objects (things to buy for a summer holiday for example) and total price
- 'Price matching task' - ask people to match the price of each object with the prices.
- Discuss how the price of everyday items/food has changed in the past 30 years.
- Ask members to bring old or new coins or banknotes they have around the house (from inside or outside the UK) to discuss

Wrap Up

- Reminder of next session – Number games
- Ask participants bring a pack of cards or to print out bingo cards to bring to next session alongside a pen/pencil

Session 12 – Number Games

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to numbers
- Use the colour card resource to ask/answer questions about numbers

Main Activity

Group chooses from one of the following activities

- Randomly draw 2 playing cards for each participant or ask them to draw 2 from their own pack of cards. Ask them to add up the points of their cards. The member who gets the largest point wins.
- Play bingo
- Guess 'higher or lower' from a deck of cards
- Play snap using everyone's deck of cards - everyone takes a card off the top of their card pile and holds it up to the camera. If anyone has matching cards then they say snap and get a point. Facilitator keeps a note of the points.

Wrap Up

- Reminder of next session – Word games
- Ask participants to bring riddles to next session

Session 13 – Word Games

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to words
- Use the colour card resource to ask/answer questions about words

Main Activity

Group chooses from one of the following activities

- Ask participants to describe a word for others to guess (but not tell others what the word is)
- Prepare some riddles or ask the group members to share some riddles they know.
- Show the group some pictures on the screen and ask them to guess the idioms depicted in the pictures.
- Play hangman or crossword on the screen

Wrap Up

- Reminder of next session – Quizzes
- No preparatory tasks for next session

Session 14 – Team Quiz

Warm up Activity

- Pretend to throw a ball at each other, by saying name of person they want to throw to, and ask a question related to words
- Use the colour card resource to ask/answer questions about words

Main Activity

Group chooses from one of the following activities

- Have some tea/snacks together as agreed in last session and have a group competition i.e. choice of game from previous sessions or a new game such as true or false or mythbuster quiz
- Have some tea/snacks together as agreed in last session and discuss how participants have found the group i.e. which sessions did they like best/least

Wrap Up

- Say final goodbyes to group