

Therapeutic interventions for people living with dementia:

A review of informal carer training for the behavioural and psychological symptoms of dementia (BPSD) and an evaluation of virtual cognitive stimulation therapy (vCST)

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Thesis declaration form

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

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Overview

In a move away from overly medicalised models of care, non-pharmacological interventions including psycho-educational training and group-based psychological therapies are becoming more prevalent within dementia care. The main objective of this project is to add to the emerging literature and evidence-base of non-pharmacological modes of intervention for people living with dementia. This is a joint-project with fellow trainee clinical psychologist, Luke Perkins.

Part 1 constitutes a systematic review of the literature on training packages targeting the behavioural and psychological symptoms of dementia (BPSD). The review focuses specifically on informal-carer, group-based training packages and identifies ten papers meeting the criteria for review. This literature search highlights the breadth of varied methodological approaches to providing carer BPSD training and promotes the need for further rigorous research in this area.

Part 2 outlines the research procedures, outcomes, and evaluations of a proof-of-concept study delivering online, 'virtual' cognitive stimulation therapy (vCST). Quantitative pre-post measures assess initial trends and effects on cognition. Eleven qualitative interviews investigate vCST's acceptability, facilitators, and barriers using a thematic analysis approach. Quantitative data analyses did not find statistically significant benefits to cognition, however qualitative analyses provide support for the acceptability of such an intervention amongst people living with dementia.

Part 3 forms a reflective summary of conducting the empirical research project with a specific focus on the contextual impact of the COVID-19 pandemic. This critical appraisal outlines the researcher's perspectives on the challenges encountered and overcome, as well as a reflexive overview of the researchers' personal interests, assumptions and biases which are important to acknowledge and mindfully incorporate within a qualitative data analysis.

Impact Statement

This thesis contributes to the research literature on dementia interventions, offering value both academically and clinically. It highlights key areas of current research deficit and emphasises where future exploration would be worthwhile. The empirical paper adds to the growing, yet scarce pool of studies which directly involve the clinical population being investigated, namely people living with dementia. As identified in the body of this work it is vital that more research includes the views and direct participation of stakeholders and the people whom the research purports to benefit. Within clinical contexts this thesis also adds value to the growing evidence-base for real-world in-service interventions.

The literature review: Psycho-education and training is widely offered to family carers of people living with dementia in clinical practice across the UK. However, very little guidance is available, with clinicians often basing their programmes on individual clinical judgement and experience rather than evidence-based research literature. This is problematic in that training programmes vary considerably across settings and people living with dementia and their carers receive postcode-lottery inconsistent care. The information presented here promotes future research in this area, including the future development of a theoretically-driven manualised BPSD training protocol for informal carers which is rigorously tested using RCTs.

The empirical paper: Technology is playing an ever more important role within our lives, and the older adult population is becoming increasingly accustomed to the use of computers and the internet. The incorporation of technology within healthcare provision across the UK is inevitable in some form and making use of this resource to reduce costs, increase accessibility and develop new forms of treatment must form part of the future-proofing of NHS provision. Within this context, this empirical study sets the foundations for future exploration of the benefits, drawbacks, facilitators, and

barriers of delivering cognitive stimulation therapy to people living with dementia in their homes online.

This study impacts the direct care people living with dementia receive immediately within the COVID-19 pandemic where other forms of treatment have been completely suspended. In developing interim-guidelines for clinicians on how to adapt CST for online facilitation the study also contributes helpfully in supporting older-adult services across the UK to flexibly adapt their service-provision during this unprecedented time.

In addition, the research also impacts the potential accessibility of services for people living with dementia in the future, beyond the pandemic. The proof-of-concept study provides a base upon which further research into vCST can develop, with an aim to establish an evidence-base for this intervention in-line with traditional CST which is recommended within NICE guidelines. This study also contributes participant data for a larger RCT which is currently underway at UCL and which will constitute the first RCT into vCST of its kind.

Initially, the resources (e.g. PowerPoint slides, facilitators' guide) from the empirical study which can assist services' implementation of vCST has been disseminated, accessibly online. Applications are also underway to publish the findings from this research in peer-reviewed, academic journals.

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Part 1: Literature Review

A systematic literature review of group-based training interventions for informal carers: impact on the behavioural and psychological symptoms of dementia (BPSD).

Abstract

Aims: Caring for a relative with dementia can be challenging especially when someone presents with BPSD. The training and support provided to informal carers is varied and inconsistent. Group-based training programmes are often prescribed but their impact on care-recipient wellbeing and symptomology is yet to be established. This literature review aims to synthesise the literature on the effectiveness of informal-carer, group-based educational training programmes on BPSD symptoms.

Method: PsycINFO, EMBASE, Medline, and CINALH databases were searched for publications between years 2000-2020. Papers were quality assessed using the QualSyst critical appraisal tool. Data relating to training-programme characteristics, outcomes and results were pooled across studies for comparison.

Results: Ten papers were included in this review of which very few considered BPSD outcomes as their *primary* aim of investigation. Methodological and theoretical approaches across the empirical papers varied considerably and hence comparison between studies was difficult. Generally, studies of higher quality and with some positive results on BPSD outcomes tended to incorporate teaching on structured problem-solving skills. The length and duration of groups and the group sizes appeared inconsequential to BPSD outcomes. Studies measuring longer term changes (e.g. 12-months follow-up) also tended to conclude more positive outcomes.

Conclusions: This review highlights the lack of research into how group-based informal carer interventions impact on the people for whom they care; people with dementia. There is much more research available looking into carer outcomes and, although intuitive, there is little in the literature to evidence that improved carer-outcomes transfer directly to a reduction in BPSD. Future studies designed to measure BPSD as a primary outcome would be a welcome addition to the research literature.

1. Introduction:

1.1 Dementia and BPSD

Dementia is a progressive neurodegenerative condition which most often affects memory, language, and other cognitive functions which impact greatly on daily functioning. An estimated 50 million people are living with dementia globally at present. With an increasingly ageing population worldwide this figure is set to increase to 132 million by 2050 (World Health Organisation, 2017). Understandably, given the personal, emotional, social and financial costs, there is an increasing global research interest in developing effective interventions to support people living with dementia and their carers. In addition to the cognitive decline most commonly associated with dementia, the term 'behavioural and psychological symptoms of dementia' (BPSD) describes all other 'neuro-psychiatric' symptoms (Finkel, et. al., 1996). BPSD is an umbrella term descriptive of a group of non-cognitive clinical symptoms and behaviours common in dementia (Lawlor, 2002). BPSD symptoms can include agitation, inappropriate behaviour, irritability, inappropriate behaviours, depression, delusions and anxiety amongst others (Cerejeira, et. al., 2012; Taameeyapradit, et. al., 2014). Research suggests that BPSD contribute not only to high levels of distress amongst people living with dementia and their carers, but are also associated with accelerated disease progression (Paulsen, et. al., 2000), and earlier institutionalisation (Luppa, et. al., 2008).

BPSD are a common component of the dementia disease profile with an estimated 80% of people living with dementia experiencing such symptoms (Margallo-Lana, et. al., 2001; Aalten, de Vugt, et. al., 2003). The National Institute for Health and Care Excellence (NICE) recommend non-pharmacological assessment of environmental factors as the first-line treatment for agitation, aggression, distress and psychosis in people living with dementia (NICE, 2018). However, where symptoms pose a risk to person or severe distress, antipsychotic medication is recommended, often indicated,

and commonly used to treat BPSD with a prescription rate of 20-50% (Lee, et. al., 2004; Brimelow, et. al., 2019; Sturm, et. al., 2018). Such medications have widely recognised side effects and require specialist management and frequent review (Ohno, et. al., 2019).

Evidence suggests positive effects of non-pharmacological interventions delivered in dyads, groups and to a mixture of carer types (both paid and unpaid). For instance, a very recently updated meta-analysis (Meng et. al. 2021) showed significant effects of non-pharmacological interventions on BPSD amongst 31 randomised controlled trials. Cook et. al.'s Cochrane review (2012) also found positive effects of functional analysis training on the frequency of reported challenging behaviours. These studies suggest promising potential for the beneficial role of similar training interventions for family caregivers also.

When considering the potential for non-pharmacological interventions, the aetiology of BPSD is important to establish. Several different theoretical frameworks have been proposed to explain BPSD, without universal consensus. The 'Needs-Driven Dementia Comprised Behaviour' (NDB) model (Algase, et. al., 1996; Cohen-Mansfield, 2001) theorises that behaviours are a result of unmet physiological and social needs, common in dementia due in part to communication difficulties between care-recipient and care-provider. Hall and Buckwalter (1987) argue that BPSD are common due to a 'Progressively Lowered Stress Threshold' (PLST) in people living with dementia. Behavioural learning theory explains BPSD through operant conditioning, in which symptoms are positively reinforced through carer-attention (Teri, et. al., 1998). In addition, there is arguably a neurobiological component to BPSD aetiology also, whereby frontal neuropathology and cholinergic deficiencies directly result in behavioural changes (Boyle & Malloy, 2004; Cerga Pashoja, et. al., 2018). The models described here are by no means exclusive and may act in

combination to contribute to a BPSD profile, hence many non-pharmaceutical interventions aim to target the various different elements.

Depending on the aetiological stance, BPSD could be argued to be an unhelpful, highly 'medicalised' terminology for what are essentially secondary consequences of dementia, rather than a primary 'symptom' rooted within the disease pathology. For instance, when considering the 'unmet needs model', BPSD presentations are understood as arising from an individual's difficulty to use their environment to meet their needs, or a difficulty in communicating those needs to others. Arguably this is not a medicalise-able 'symptom' of the condition, but instead an understandable response to a challenging lived-experience which could manifest from multiple complex and intertwining factors. When taking this stance on BPSD, it is clear how non-pharmacological interventions might be most beneficial and impactful in reducing individuals' distress, hence why the British Psychological Society (BPS) advocate 'non-pharmacological' approaches as a first-line treatment, over psychotropic medications (James & Moniz-Cook, 2018). Embedded within this psycho-social understanding of BPSD, NICE guidelines (2018) also recommend key principles in 'person-centred care' when supporting people living with dementia who may be in distress or who may present with behaviours that challenge. These guidelines consider a broader, more holistic best-practice approach taking into account each person's individuality, personality, life experience and relationships when considering how these might impact upon BPSD-type presentations. The term 'BPSD' was chosen within the search-terms of this systematic review due to its common and frequent use within the research literature to date. Despite the critique of such terminology, it remains a useful umbrella term in which to collate and categorise a host of non-cognitive 'features' of the dementia profile which sadly so commonly form part of the lived experience of those with dementia.

1.2 Informal caregiver training

An informal carer is anyone who provides care outside of a 'professional' or paid role; this could for example be a family member, friend, or neighbour. People living with dementia have complex difficulties often requiring support from others with activities of daily living. Support needs are also changeable due to the progressive nature of the disease. There are an estimated 700,000 informal caregivers providing support to people living with dementia in the UK (Lewis, et. al., 2014), the majority of whom are family members with little previous experience or knowledge of dementia care. More recent reports looking at informal carers, indiscriminate across health-conditions, have found that in the UK more people than ever are providing informal care (Carers Week Report, 2020), as well as increased hours of care (Carers UK Report, 2020) since the global Covid-19 pandemic. In moving away from an overly biomedical model to the treatment of dementia, guidelines in the UK recommend non-pharmaceutical interventions both for people living with dementia and their carers, alongside medication where indicated. NICE guidelines currently state that all informal carers should receive psychoeducation and skills training interventions to support them in their caring roles at the point of diagnosis (NICE, 2018). There is however very little guidance on how this should be delivered or what constitutes 'effective' support. The NICE guidelines also state that interventions are most likely to be effective when offered in 'group-settings', however no evidence is provided in the guidance to support this. In a systematic review of communication-based interventions for carers Morris, et. al. (2018) recently noted that some of the most effective interventions *were* group-based. However, there is also evidence from a recent systematic review, that 1:1 informal-carer interventions for BPSD are most effective, due to their adaptability to individuals' needs (Vandepitte, et. al., 2016). It is understandable that NICE guidelines should recommend group-based interventions, considering the resource benefits of group-delivery within often strained, multi-

disciplinary healthcare teams, compared to often resource-heavy 1:1 treatments. Hence this review focusses on studies which provide group-based interventions only.

1.3 Rationale for review

The limited research that exists in this area has routinely focussed on carer-wellbeing outcomes (e.g. carer quality of life, burden and depression), underpinned by a theoretical assumption that improved carer wellbeing should have an associative positive effect on those for whom they provide care. Black and Almeida (2004) did find a moderately strong association between BPSD, and caregiver burden and depression rates. However, their systematic review highlighted a paucity of data and methodological issues as well as a suggestion that carer outcomes are more predictive of people living with dementia institutionalisation than of BPSD.

There are several recent systematic reviews which have investigated the impact of psycho-educational and non-pharmaceutical interventions for family-carers' sense of burden, wellbeing, mood and quality of life, with evidence of positive effects (Frias, et. al., 2020; Cheng, & Zhang, 2020). Poon (2019) recently conducted a review and meta-analysis of dyadic psychological interventions which concluded that psychosocial interventions in clinical practice should aim to involve both the carer and the people living with dementia. Dual-participation however, is regrettably not always possible or warranted in clinical practice where the people living with dementia may present with apathy, disengagement or distress in receiving direct input. Hence the current review excludes interventions which provide dyadic care.

There are no reviews, up to now, which have specifically examined the effectiveness of informal-carer, group-based educational training programmes on, specifically, the BPSD symptoms of their care-recipient's dementia. A brief scoping of the literature found very few relevant articles prior to the year 2000. Considering this, the

researchers' limited time resources, and wishing to include the most up to date research, this review includes literature from 2000 to the present day only.

This review aims to address this gap in the literature, drawing inferences on the following research question; Are group-based informal carer programmes effective in reducing BPSD in people living with dementia? In addition, the review aims to describe common features such as content-type, dosage intensity, group size and consider whether any preliminary conclusions can be drawn as to their effectiveness on the success of the intervention.

2. Method:

2.1 Literature search methods

The systematic literature search was conducted across PsycINFO, EMBASE, Medline, and CINALH databases using OVID and EBSCO interfaces. The population search incorporated 'Alzheimer's', 'Dementia' and 'Vascular' terms. The intervention incorporated 'Group', 'Training', 'Education', 'Teaching', 'Learning', 'Psychoeducation', 'Carer', 'Caregiver', 'Family' and 'Informal' terms. And the outcomes constituted 'Behavioural problems', 'Psychological problems', 'Psychiatric problems', 'Agitation', 'Aggression', 'Depression', 'Anxiety' and 'Challenging behaviour' (see Table 1). The selected terms were identified based on search terms used in similar existing systematic reviews. They were tailored to the specific bibliographic databases being used and an iterative process was adopted in order to refine the search and limit unintended paper exclusion. A detailed outline of the search syntax for each database can be found in Appendix 1. Initially searches were carried out across the databases' entire store, results were then limited to only those outcomes written in the English language, and those published from the year 2000

until the search date of 26/03/2020. EndNote bibliographic software was used to extract and store the search results.

Table 1*Electronic Search Strategy*

Search Category	Terms Applied	Combined with
Population	Carer	}
	Caregiver	
	Family	}
	Informal	
	Alzheimer Disease	}
	Dement*	
	Vascular	
Interventions	Group	}
	Train*	
	Education	
	Teach*	
	Learn*	
	Psychoeducation	
Outcomes	Behavio?r* problem*	}
	Psycholog* problem* or symptom*	
	Psychiatric problem* or symptom*	
	Agitat*	
	Aggression	
	Depress*	
	Anxiet*	
	Challeng* behavio?r*	
	Behavio?r* problem*	

Diagrammatic representation of search strategy logic:

- Population terms (Carer, Caregiver, Family, Informal, Alzheimer Disease, Dement*, Vascular) are grouped by a bracket and combined with "OR".
- Interventions terms (Group, Train*, Education, Teach*, Learn*, Psychoeducation) are grouped by a bracket and combined with "OR".
- Outcomes terms (Behavio?r* problem*, Psycholog* problem* or symptom*, Psychiatric problem* or symptom*, Agitat*, Aggression, Depress*, Anxiet*, Challeng* behavio?r*, Behavio?r* problem*) are grouped by a bracket and combined with "OR".
- The three "OR" groups are further combined with "AND".

Notes: *Denotes truncation, searches for variants of words such as teach, teaches, teaching.

2.2 Inclusion/exclusion criteria

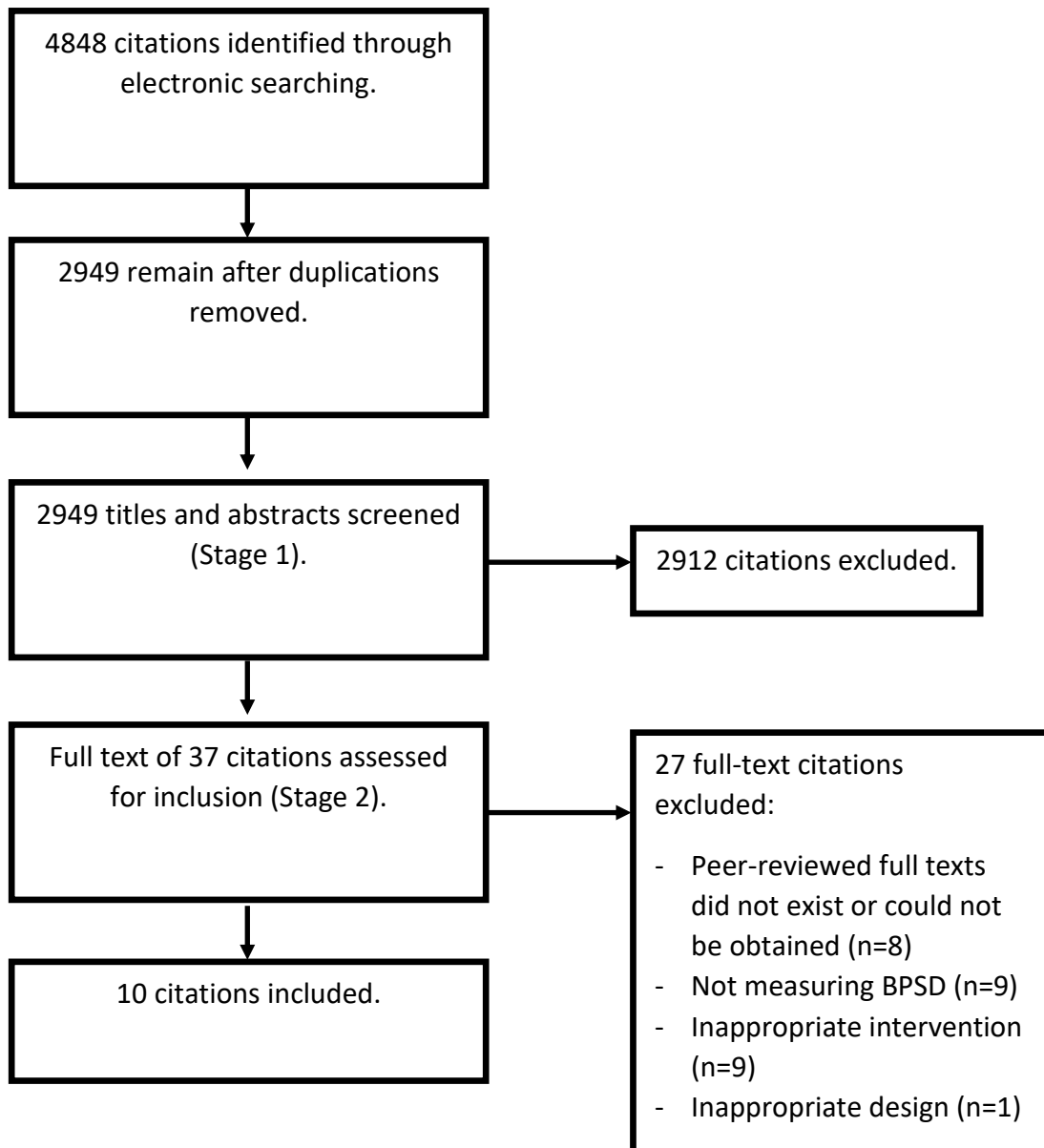
Inclusion and exclusion criteria were devised with reference to existing systematic reviews in this area (Spector, et. al., 2013). Figure 1 is a flow-chart illustrating how literature was excluded from the final selection. In the first instance duplicates were

removed. At stage one of the process, titles and abstracts were screened to determine the publication's eligibility for inclusion in the review against the following inclusion criteria:

- Randomised controlled trials (RCTs), quasi-experimental designs and patient as own comparison designs.
- Group-based, face-to-face training interventions only.
- Interventions for informal-carers, of a person living with dementia (people living with dementia), only.
- Peer-reviewed studies reporting quantitative results, published between 2000-2020. BPSD is evaluated, as either a primary or secondary outcome, using a measure which features in the most recent review of BPSD outcome-measures (Van der Linde, et. al., 2014).
- Papers written in English.

Figure 1

Flow-diagram illustrating literature identified, included, and excluded.



Literature was excluded if the intervention provided input directly to the people living with dementia in addition to the carer (e.g. dyadic interventions), and if the intervention had a 1:1 component, as opposed to being group-based. Where interventions were delivered online or 'virtually', papers were excluded as only group-based face to face interventions were of interest. Due to the paucity of research in

this area, no studies were excluded based on sample size, hence pilot studies were also included.

Initially the search included papers whose *primary* outcomes were related to the people living with dementia's BPSD, however this search resulted in too few results, and hence the criteria were modified to include studies whose primary focus may not have been BPSD, but who were considered to have secondary outcomes related to BPSD. As BPSD is not a distinct entity in and of itself, but an umbrella term for a large array of behavioural and psychological symptoms, the researchers were required to make a judgement as to the relevance of outcomes to BPSD. Van der Linde et. al. (2014) have provided an overview of the various instruments used in the research literature to measure BPSD. Their inventory of measures was used as a guide for inclusion within this systematic review.

At Stage two of the screening process, full texts were examined. At this stage, 27 citations were excluded from the final selection. Further details are outlined in section 3.1.

2.3 Quality rating

Considering the paucity of literature in this area and the limited number of papers identified through the search criteria, quality rating procedures were conducted for the purpose of evaluation only; as opposed to establishing a quality-threshold for inclusion in the review. Hence, literature included in this systematic review is assessed to be of variable quality. As not all of the studies included are RCTs, quality ratings were made using the Standard Quality Assessment Criteria – 'QualSyst' (Kmet, et. al., 2004) which was specifically designed for the quality assessment of a variety of different study designs.

The QualSyst checklist assesses quality based on 14-items including randomisation, blinding, robustness of measures, sample size and subject characteristics, analytical

methods, confound controlling and evidence-supported conclusions. Each item is scored a 2 for "yes", 1 for "partial", or 0 for "no", based on whether the specific criteria are met. Items not applicable to the study are excluded. Item number seven was omitted for all of the literature in this review, as it relates to blinding of participants which was not possible considering the nature of intervention being offered. Summary scores are calculated based on the total obtained score, divided by the total possible score. This produces a summary decimal score where 1.0 is the maximum, of highest quality. A random sample of 33% of the papers were independently counter-quality assessed by a second reviewer. Any discrepancies were resolved through discussion and consensus, and subsequently the same principles applied to the remaining papers for any agreed changes.

2.4 Data extraction

Based on previous similar reviews by the principal researcher (Spector, 2013), a data extraction form was developed in which to consistently extract data from the included studies. This form included sections of relevant information deemed appropriate to the review aims, for example 'intervention type', 'group size', 'duration of sessions', and 'significant BPSD findings'.

3. Results:

3.1 Included and excluded studies

In total 4848 studies were identified using the established search terms (see Figure 1). After duplicates were removed 2949 papers remained whose titles and abstracts were screened for eligibility. 2912 studies were removed at this Stage 1, due to an obvious contravention of the inclusion criteria. On screening the remaining full texts at Stage 2, 27 texts were omitted. Eight search results were excluded, as full papers could not be obtained through the usual search procedures across the various

literature databases. Of these; one constituted a clinical-trial registration outlining a future, planned piece of research (Cheng, et. al., 2012); two were brief supplements describing poster presentations (Allen, 2017; Gonyea, 2012); one was a preview of a dissertation (Smith, 2006); and four were brief supplements describing conference presentations (Creaser, 2009; Honda, 2017; Honda & Shimada, 2017, Yamada, et. al. 2011).

Nine papers were excluded as they did not measure BPSD as an outcome of the intervention. They did not report the use of any measures which are routinely used to record BPSD as outlined in van de Linde et. al.'s (2014) inventory (Krause, et. al., 2009; Schuster, et. al., 2012; Shigemori, et. al., 2013; Done & Thomas, 2001; Lai, et. al., 2013; Ostwald, et. al., 2003; Parveen, et. al., 2018; Samia, et. al., 2014; Dahlrup, et. al., 2011).

Nine papers were excluded as the intervention being evaluated did not meet inclusion criteria. Seven of these described interventions provided on a 1:1 basis, rather than being group-based (Burgio, et. al., 2003; Chien, & Lee, 2011; Ducharme, et. al., 2011; Gavrilova, et. al., 2009; Gerdner, et. al., 2002; Silvestri, et. al., 2004; Wawrziczny, et. al., 2019). Two of the studies were related to interventions which included the people living with dementia (Koivisto, et. al., 2016; Whitlatch, et. al., 2019). One paper was excluded as it comprised of a case-study description only (Mulkey, et. al., 2019).

The resultant total of identified papers for inclusion reached ten. Table 3 outlines an overview of the included literature containing design, control type, intervention description, group facilitator and size, sessions set-up, outcomes measures, significant results related to BPSD, and quality ratings.

3.2 Study characteristics

3.2.1 Aims

All the included publications described the aim of their research as investigating the 'effects', 'effectiveness' or 'efficacy' of their particular group-programme. Only three studies (Javadpour et.al. 2009; Chein et.al., 2008; & de Rotrou et.al., 2011) were judged to be investigating the effects on people living with dementia as their *primary* aim. Seven out of ten were investigating the effects on carer outcomes as their primary aim, with people living with dementia outcomes of secondary interest.

3.2.2 Settings

Studies were conducted across a diverse geography spanning three continents. Three studies were conducted in the United States of America, one in Canada, three in distinct European nations, and three in different Asian regions. Two studies did not explicitly state where the research was conducted, and this was inferred from the location of the publishing researchers. The papers were published between 2001 and 2020. Participants were selected mostly from clinical dementia services/memory clinics and third-sector organisations such as charities and societies. One study recruited participants through advertisement in newspapers and flyers.

3.2.3 Design

The majority of publications, seven in total, comprised randomised controlled trials (RCTs). One study was a pilot-RCT, and two were quasi-experimental pre-post designs with no control group. Studies with a control group opted mostly for a treatment as usual (TAU) control, or in the case of three studies, a 'waitlist' control group.

3.2.4 *Session characteristics (group sizing and duration)*

The makeup of the group interventions and dosages (intensity of treatment) varied considerably. Group sizes were not documented at all in three papers and in numerous publications only an average group size or range was provided. Groups ranged from four to 16 participants. Using group-range means, and absolute group sizes values, the mean group size for the interventions was calculated as 9.5 per group.

Treatment dosage varied and was calculated for the purpose of this review by multiplying number of sessions by duration of sessions in minutes. Dosage ranged from 12-30 hours, with an average dosage of 17.85 hours. The majority implemented a weekly programme of group sessions, whereas two studies opted for fortnightly meetings. Kurz et. al. (2010) facilitated a combination of bi-weekly sessions initially, with the addition of bi-monthly refresher meetings.

3.2.5 *Measures*

Across the ten publications, 36 different measures were used for both people living with dementia and their carers. The specific BPSD measures for each study are outlined in Table 3.

For carers, the most commonly used measure was the Zarit Burden Scale (ZBS) (Zarit, et. al., 1985), however a multitude of measures were used to quantify constructs such as, but not limited to; burden, depression, anxiety, stress, quality of life, general health, beliefs, mood, sense of competence, strain, family role, mutuality and resource utilisation.

For the outcome of interest in this systematic review (BPSD in people living with dementia), a majority (six in total) used the Neuropsychiatric Inventory (NPI) (Cummings, 1997). Of the remaining studies, three used the Revised Memory and Behaviour Problem Checklist (RMBPC) (Teri, et. al., 1992), and one the Dementia

Behaviour Disturbance Scale (DBDS) (Baumgarten, et. al., 1990). All studies used at least one, and in some cases multiple, outcome measures which were included in the recent systematic review of BPSD measures (van der Linde, et.al. 2014). In addition to these standardised measures, two papers also reported frequency of, or desire to, institutionalise as an outcome of interest related to BPSD.

3.3 Quality appraisal

Details of the quality appraisal can be found in Table 2. The quality assessment ratings ranged from 0.35 to 0.96. All studies scored maximum on reporting an estimate of variance, which in most instances was reported as standard deviations. Across the remaining quality items, the assessment was varied. For the purpose of description here the publications can be divided into those of 'low' quality (scoring between 0-0.59), 'medium' quality (scores of 0.6-0.8), and those of 'high' quality (scoring above 0.8). Those of low-quality appraisal (Seike et.al, 2016 & Javadpour et.al., 2008) were both quasi-experimental designs and were published as very brief summary papers in which much detail was missing. These studies scored poorly on evidently stating the study design and sample sizing. In both, references or detailed description of measures was omitted, speculative interpretations and conclusions were not indicated as such, and analyses and results were missing. Publications in the 'medium' range (Gonzalez et.al, 2014; Hepburn et.al., 2001; Chein et al., 2008; & Kurz et. al., 2009) all stated that randomisation had taken place, however failed to outline specific details about the process. Two studies failed adequate blinding of researchers, and some did not report details of all results sufficiently. Four were assessed to be of high quality and reached high scores in study design, methods of subject comparison, description of subject characteristics, randomisation, sample size, analytical methods, confound controlling, reporting of results in detail and conclusions supported by results. Due to the limited number of search results, no publications were excluded from this review based on quality appraisal score.

Table 2
Overview of Quality Assessment

	Seike, et. al. 2016	Javadpour, et. al. 2008	Gonzalez, et. al. 2014	Hepburn, et. al. 2001	Chein, et. al. 2008	Kurz, et. al. 2009	Terracciano, et. al. 2020	Rotrou, et. al. 2010	Hebert, et. al. 2003	Ulstein, et. al. 2007
1. Objective sufficiently described?	1	1	1	2	1	1	2	1	2	2
2. Study design evident and appropriate?	0	0	2	2	2	2	2	2	2	2
3. Method of subject/comparison appropriate?	0	1	1	2	2	1	2	2	2	2
4. Subject characteristics described?	1	1	2	2	1	2	2	2	2	2
5. Randomisation described?	n/a	n/a	1	1	1	1	2	2	2	2
6. Blinding of investigators reported?	n/a	n/a	0	0	2	2	1	2	2	2
8. Outcomes defined and robust?	1	1	2	2	2	1	1	1	2	2
9. Sample size appropriate?	0	0	1	1	2	2	1	2	1	1
10. Analytic methods appropriate?	0	1	1	2	2	2	2	2	2	2
11. Some estimate of variance is reported?	2	2	2	2	2	2	2	2	2	2
12. Controlled for confounding?	n/a	n/a	2	1	1	2	2	2	2	2
13. Results reported in sufficient detail?	1	1	2	1	1	1	2	2	2	2
14. Conclusions supported by the results?	1	1	1	1	2	1	2	2	2	2
Summary Score	0.35	0.45	0.69	0.71	0.75	0.77	0.82	0.92	0.96	0.96

Note: Criteria item number 7 of 'QualSys' tool (Kmet, et. al. 2004) excluded as not relevant in all studies.

3.4 Intervention content

The level of detail describing the treatment interventions varied amongst the included publications. Several studies provided very limited detail in the form of session titles only, brief one-sentence descriptions of the session 'headlines', or general overall themes. In most of these instances no further information was provided. Two studies reported that their intervention was 'based' on other available literature including the Alzheimer's Association Carers Guide (Javadpour et.al.2008). Hebert et.al. (2003) provided the most detailed outline of their intervention content, as well as a commentary citation with further detail which would render the intervention replicable. None of the papers provided a detailed implementation protocol or session-by-session delivery guidelines, save for one paper which referred readers to a purchasable manual (Terracciano, et. al. 2020). One paper outlined that manuals would be available 'shortly', however these were not obtainable at the time of this review (Hebert et.al. 2003). Only this study followed a previously developed manualised protocol, the Powerful Tools for Caregivers (PTC) intervention (Cleland, et. al, 2006). Two based their intervention on modified versions of previously developed psycho-education groups (Chein et.al. 2008; Gonzalez et.al. 2014). Most papers, seven in total, began from the conception phase by originally developing a new group-protocol.

Most programmes used integrative teaching approaches, utilising multiple modalities for learning. All ten studies incorporated a didactic approach in which information was presented to the caregivers in a 'teacher-pupil' style. Ulstein et.al. (2007) was the only programme which exclusively described this method of teaching. Eight studies described additional group discussions; four also incorporated practice exercises such as 'homework' tasks or real-life assignments, and two publications described the use of in-session role-playing. Hebert et.al. (2003) was the only study which described incorporating all of these elements within their teaching methods.

The training packages can be roughly divided into content-types; 'general dementia psychoeducation', 'cognitive skills-based interventions', and 'idiosyncratic'. For the purpose of synthesis, studies have been grouped as such below to describe the overall content.

3.4.1 General dementia psychoeducation

Three studies predominantly described classroom-style psychoeducation lectures in which several 'stand-alone' sessions were offered to participants providing information about different themes each session (Seike et.al. 2016; Javadpour et.al. 2008; Kurz et.al. 2009). Content includes; general information about dementia, its diagnosis, aetiology and treatments; common symptoms and challenging behaviours; examples of typical care-challenges, with strategies to help; and social support or other available resources. Kurz et.al. (2009) also incorporated a session on legal and insurance-related issues, while Javadpour et.al. (2008) included sessions on person-centred care, and oral care. All three studies also described incorporating group discussion as part of their teaching methods.

3.4.2 Cognitive skills-based

Five studies were considered to be predominantly cognitive skills-based in their intervention style (Hebert et.al. 2003; Terracciano et.al.,2020; Hepburn et.al. 2003; Gonzalez et.al. 2014; Ulstein et.al. 2007). Overall, these programmes provided some limited lecture-style general knowledge about dementia but focussed in the main on skills-based cognitive techniques and strategies; their theoretical underpinnings, implementation, and evaluation. These papers tended to provide a more thorough grounding in psychological theory such as self-regulation theory, behavioural theory, stress and coping frameworks, and cognitive theory.

Hepburn et.al. (2003) focused on carers' self-appraisals and beliefs about carer-identity, role, and coping abilities. Instruction, exercises and discussion were used in

a 'workshop' fashion to foster carer-identities separate from their familial role. Abilities, and the importance of self-care were reinforced in the sessions, thereby theoretically mediating caregivers' responses to stressful situations. In the case of the PTC programme (Terracciano et.al. 2020), the focus was on carer self-care, emotional awareness and regulation, and self-efficacy. Here, carers were encouraged to develop an individualised self-care action plan and practice relaxation exercises including progressive muscle relaxation. The programme incorporated elements of assertiveness training, tools for decision making and 'tools for optimism' (Boise, et. al., 2005).

The remaining three publications focused more on the cognitive appraisal of caring challenges, with the additional focus on solution-based problem-solving, and decision making. The cognitive techniques included; shifting from a global stressor to a specific stressor; breaking down a problem into distinct elements; labelling changeable and unchangeable factors; reframing; identifying and modifying dysfunctional thoughts; and developing more realistic expectations. In all cases, problem-solving techniques involved clarifying or defining a problem in the first instance. Ulstein et.al. (2007) and Gonzalez et.al. (2014) then provided a structured framework in which carers 'brainstormed' multiple possible solutions, considered possible outcomes, weighed up pros and cons, and planned detailed implementation and evaluation. Participants in Hebert et.al.'s (2003) groups were guided to integrate behavioural assessment techniques (Zarit & Zarit, 2011) to assess the 'problem' before choosing an appropriate solution. In all cases, the group attendees were encouraged to practice and implement new skills at home independently in between sessions and collaboratively evaluate through group discussion.

3.4.3 Idiosyncratic

The remaining two publications were not easily classified into either a distinct psychoeducation or cognitive skills-based model. Chein et.al. (2008) provided limited

detail about the sessions' content with reference to previously developed family-programmes upon which their intervention was 'based' (Belle, et. al, 2006; Fung & Chien, 2002). However, four key phases included; orientation to dementia care; education about dementia; family role and strength rebuilding; and community support resources. This overview suggests that the programme incorporated a mixture of psychoeducational teaching and cognitive appraisal techniques. A distinctive feature of this training compared to all other studies, was that the content was 'tailored' to the individual group needs, as the groups consisted of family members caring for the same individual. De Rotrou et.al. (2010) similarly provided limited information about their group intervention, stating only that it covered education, problem-solving techniques, coping strategies, behaviour and crisis management, communication skills and resource information. A key component of this training was in teaching ecological stimulation (ES) (de Rotrou & Wenisch, 2009) skills, encouraging carers to stimulate care recipients with tailored activities of interest which reinforce residual abilities.

Table 3
Overview of included studies

Authors / Date / Location	Design	Control type	Intervention Description	Group Facilitator	Group Size	Sessions setup / Total Duration	Outcome Measures of Interest	Sig. Results	Quality Rating / Comments
Chien & Lee. (2008) Hong Kong	RCT. Repeated measures design. N=88 Participants randomly selected from lists from two dementia centres. Groups are family members only. Not strangers.	TAU	Education and support group. Bespoke to family groups based on their needs. Five phases: 1. Orientation to dementia care. 2. Educational workshop about dementia. 3. Family role and strength building. 4. Community resources 5. Review and evaluation.	Nurse 'case managers.'	Unknown	<u>Set up:</u> 12 sessions Fortnightly 2hrs each <u>Total Duration:</u> 6 months duration	Neuropsychiatric Inventory (NPI)	Significant differences in: - patients' symptom severity (NPI) (p<0.01). - frequency of institutionalisation (p<0.01). - length of institutionalisation (p<0.001).	<u>Score:</u> 0.75 <u>Pros:</u> Randomisation Blind researcher. <u>Cons:</u> Limited baseline characteristics reported. Post-hoc results not provided in detail.
De Rotrou, Fauconau, Wenisch, Chausson, Jegou, Grabar & Rigaud. (2011) France	RCT N=157 Multi-centre. Participants recruited from 15 memory clinics.	Waitlist control.	Psycho-education: Education, problem-solving techniques, and emotion-centred coping strategies, management of behaviour, communication skills, crisis management and resources. Information, debriefing, ecological stimulation.	Geriatricians, psychiatrist, psychologists, social workers, SLTs, OTs.	6-10	<u>Set up:</u> 12 sessions Weekly 2hrs each <u>Total Duration:</u> 3 months duration	Neuropsychiatric Inventory (NPI) Alzheimer Disease Assessment Scale (ADAS)	No significant functional, cognitive or behavioural changes on NPI (p=0.92 & 0.57) in people living with dementia.	<u>Score:</u> 0.92 <u>Pros:</u> Randomisation Blind researcher. Controlled for confounding factors. <u>Cons:</u> Validity and Reliability of measures not discussed. Blinding of participants not possible.

Table 3 (Continued)

Authors / Date / Location	Design	Control type	Intervention Description	Group Facilitator	Group Size	Sessions setup / Total Duration	Outcome Measures of Interest	Sig. Results	Quality Rating / Comments
Gonzalez, Polansky, Lippa, Gitain & Zauszniewski. (2014) ?USA*	Pilot RCT N=102 Participants referred by a neurologist research team member.	TAU	Resourcefulness Training Sessions: problem identification, coping, problem solving, priority setting and decision making. 6 Modules: F: Finding the fact O: Optimism C: Creativity U: Understanding S: Solution	Registered nurse.	5-7	<u>Set up:</u> 6 sessions Weekly 2hrs each <u>Total Duration:</u> 6 week duration	Revised Memory and Behaviour Problem Checklist (RMBPC).	Fewer behavioural problems in intervention group but did not reach significance (p=0.83 and p=0.11).	<u>Score:</u> 0.69 <u>Pros:</u> Randomisation. Effect sizes provided. <u>Cons:</u> No blinding of researchers.
Hebert, Levesque, Vezina, Lavoie, Ducharme, Gendron, Preville, Voyer & Dubois. (2003) Canada	RCT N=144 Multi-centre. Participants recruited from AD societies and home care organisations.	TAU	Education two components: 1. cognitive appraisal 2. coping / problem-solving strategies.	'Health professionals in dementia care'.	12-16	<u>Set up:</u> 15 sessions Weekly 2hrs each <u>Total Duration:</u> 15 week duration	Revised Memory and Behaviour Problem Checklist (RMBPC). Desire to institutionalise, ordinal scale.	'Nearly' (p=0.06) significant decrease in frequency of behaviour and memory problems in intervention group (RMBPC). 'Desire to institutionalise' significantly increased in both intervention group (p=0.04), but greater in control group (p=0.003). Difference between the groups not sig (p=0.10).	<u>Score:</u> 0.96 <u>Pros:</u> Randomisation Blind researcher. Controlled for confounding factors. <u>Cons:</u> Blinding of participants not possible.

Table 3 (Continued)

Authors / Date / Location	Design	Control type	Intervention Description	Group Facilitator	Group Size	Sessions setup / Total Duration	Outcome Measures of Interest	Sig. Results	Quality Rating / Comments
Hepburn, Thornatore, Center & Ostwald. (2001) USA	RCT N=117 Participants were referred from community services.	Waitlist control.	Minnesota Family Workshop (MFW): Classroom instruction with exercises and strategies. Stress and coping framework. - Information provision - Concept development - Role clarification - Belief clarification - Mastery-focused coaching	MDT (nurse, educator, family therapist & occupational therapist).	4-7 primary group members + family.	<u>Set up:</u> 7 sessions Weekly 2hrs each <u>Total Duration:</u> 7 week duration	Revised Memory and Behaviour Problem Checklist (RMBPC).	The groups did not differ significantly (p=0.192) in frequency of behaviour problems.	<u>Score:</u> 0.71 <u>Pros:</u> Randomisation. Control group. <u>Cons:</u> Confounding controls not described in detail.
Javadpour, Ahmadzadeh & Bahredar. (2008) ?Iran*	Quasi-experimental Design. N=29 Pre-post-test design.	No control.	30mins Education re. dementia, challenging behaviours and problems encountered. 90mins interactive group activities. Incl. group sharing, discussion and practice of caregiving.	'Trained senior psychiatry resident'.	14-15	<u>Set up:</u> 8 sessions Weekly 2hrs each <u>Total Duration:</u> 8 week duration	Neuropsychiatric Inventory (NPI)	Significant decrease in NPI scores (p<0.001).	<u>Score:</u> 0.45 <u>Cons:</u> No control. Small sample size. No clear sampling measures. CDR results not reported.

Table 3 (Continued)

Authors / Date / Location	Design	Control type	Intervention Description	Group Facilitator	Group Size	Sessions setup / Total Duration	Outcome Measures of Interest	Sig. Results	Quality Rating / Comments
Kurz, Wagenpfeil, Hallauer, Schneider-Schelte & Jansen. (2010) Austria, Germany and Switzerland.	RCT N=292 Multi-centre	TAU	<p>Psychoeducation:</p> <ol style="list-style-type: none"> 1. General info about AD. 2. The early stages of AD 3. The middle stages. 4. The late stages. 5. Legal and Insurance issues. 6. Getting help / resources. 7. Review, questions and discussions. <p>Refresher meeting did not re-cover material, but instead focussed on individual's needs and problems.</p>	Psychologists and social workers.	8 average	<p><u>Set up:</u> 7 sessions Bi-weekly 90mins each + 6 sessions Bi-monthly refresher meetings.</p> <p><u>Total Duration:</u> 15 months duration</p>	Neuropsychiatric Inventory (NPI)	<p>No NPI results reported.</p> <p>Time spent caregiving lower in intervention group, but not sig (p=0.19).</p> <p>No sig. results on number of permanent admissions (p=0.25) or time remaining in community (p=0.25).</p>	<p><u>Score:</u> 0.77</p> <p><u>Pros:</u> Randomisation. Control group. Blind researcher. Large sample size.</p> <p><u>Cons:</u> Not all measures' results are reported.</p>
Seike & Sakurai. (2016) Japan	Quasi-experimental Design. Pre-post-test design. N=10	No control	Classroom-style education. Covering medicine, dementia care, psychology and welfare. Group work and discussions.	Unknown	?10*	<p><u>Set up:</u> 12 sessions Fortnightly</p> <p><u>Total Duration:</u> 6 months duration</p>	Dementia Behaviour Disturbance Scale (DBDS)	Behaviour disturbance scores increased from pre-post (25.5 -> 28). No statistical analysis.	<p><u>Score:</u> 0.35</p> <p><u>Cons:</u> Convenience sample. Sample size small for inferential statistics. No participant inclusion/exclusion criteria. Letter to editor - no full paper available.</p>

Table 3 (Continued)

Authors / Date / Location	Design	Control type	Intervention Description	Group Facilitator	Group Size	Sessions setup / Total Duration	Outcome Measures of Interest	Sig. Results	Quality Rating / Comments
Terracciano, Artese, Yeh, Edgerton, Granville, Aschwanden, Luchetti, Glueckauf, Stephan, Sutin & Katz. (2020) USA	RCT N=73 Participants recruited through advertisement in newspapers, flyers etc.	Waitlist control.	Powerful Tools for Caregivers (PTC): 1. Taking care of you. 2. Identifying and reducing personal stress. 3. Communicating feelings, needs and concerns. 4. Communicating in challenging situations. 5. Learning from our emotions. 6. Mastering caregiving decisions.	Trained and certified PTC leaders	10 average	<u>Set up:</u> 6 sessions Weekly 2hrs each <u>Total Duration:</u> 6 week duration	Neuropsychiatric Inventory (NPI) Cohen-Mansfield Agitation Inventory (CMAI) Revised Memory and Behaviour Problems Checklist (RMBPC)	No significant effects on BPSD (NPI or CMAI). (P-values not provided)	<u>Score:</u> 0.92 <u>Pros:</u> Randomisation. Control group. <u>Cons:</u> No blinding of researchers after consent stage.
Ulstein, Sandvik, Wyller & Engedal. (2007) Norway	RCT N=180 Multi-centre. Participants recruited from 7 memory clinics.	TAU	3hr Education programme, teaching about: symptoms, dementia, treatments. + 2hr weekly sessions on communication techniques and problem-solving strategies, cognitive techniques to manage carer's expectations.	Geriatricians and psychiatrist.	Unknown	<u>Set up:</u> 3hr one off + 6 sessions Weekly 2hrs each <u>Total Duration:</u> 4.5months duration	Neuropsychiatric Inventory (NPI)	Significant difference in the NPI scores in favour of the intervention group at the 12-month assessment (in female people living with dementia only) (p=0.03).	<u>Score:</u> 0.96 <u>Pros:</u> Randomisation Blind researcher. Controlled for confounding factors. <u>Cons:</u> Blinding of participants not possible.

*Information inferred as not overtly stated.

3.5 Results of significance in reducing BPSD

The majority of studies in this review, six in total, did not find any significant beneficial effects of the intervention on BPSD. Seike et.al.'s (2016) quasi-experimental design was limited to descriptive statistics. They reported a trend in which Dementia Behaviour Disturbance Scores (DBDS) increased from pre-post measurement, indicative of worsening symptomology. This most probably quantifies the progressive nature of dementia and hence, inferences about intervention effects were infeasible in the absence of a control group. Two studies exclusively used the Revised Memory and Behaviour Problem Checklist (RMBPC) to measure BPSD. Neither study found significant effects. Gonzalez et.al. (2014) documented a non-significant observable trend of fewer behavioural problems in the intervention group of negligible effect size (0.05 immediately after intervention, 0.11 six-weeks post-intervention). Three publications administered the Neuropsychiatric Inventory (NPI) as a measure of BPSD. In de Rotrou et.al. (2011) people living with dementia did not show significant functional, cognitive or behavioural changes compared to the control group at neither three ($p=0.92$), nor six ($p=0.57$) weeks post-intervention. Kurz et.al. (2010) omitted to report on their NPI end-point data, hence it is assumed that no significant results were obtained. They reported that 'time spent caregiving' was lower in the intervention group post-intervention, also without significant effects ($p=0.19$). The Powerful Tools for Caregivers (PTC) programme (Terracciano et.al. 2020) also concluded no significant effects on behavioural and psychological symptoms measured using the NPI, RMBPC and the Cohn-Mansfield Agitation Inventory (CMAI), despite encouraging results in relation to carer burden and depression outcomes. P-values were not provided.

Only four of the included studies reported *some* statistically significant results related to BPSD intervention. Javadpour et. al. (2008) reported significantly reduced NPI scores ($p=0.001$) from pre to post intervention, a mean score of 32.41 to 28.59. Chien

et. al. (2008) documented a significant difference ($p < 0.01$) in mean between-group NPI scores at 12 months in favour of the intervention group. They also reported a positive significant difference in number of instances of institutionalisation ($p < 0.01$) and duration ($p < 0.001$). Ulstein et. al. (2007) being the highest rated paper at quality assessment in this review, did not report significant results related to the intervention group on all primary outcomes analyses including overall NPI scores ($p = 0.37$ at 12 months). However, on sub-group analyses they found a significant between-group difference at 12 months in female people living with dementia only ($p = 0.03$), in favour of the intervention group. In their discussion they highlight that this result must be interpreted with caution due to the post-hoc nature of the analysis. The final publication (Hebert, et. al. 2003) reported results which may be described as 'borderline' significant. This paper obtained the second highest rating in the quality appraisal and used the RMBPC as their primary measure of BPSD. They reported that the frequency of behaviour and memory problems increased by 8% in the control group post-intervention and decreased in the intervention group by 4%; a difference which very nearly reached significance ($p = 0.06$). The cross-product, between frequency of behaviours and the intensity of the carer reaction, between the two groups reached statistical significance ($p = 0.02$) in favour of the intervention.

4. Discussion

4.1 Summary

This systematic literature review set out to investigate the effectiveness of group-based informal carer training interventions on BPSD in people living with dementia. Specifically, the aim was to consider whether such treatments have positive effects on BPSD symptoms, and whether the intervention characteristics affect outcomes. This review has highlighted the paucity of literature in this area. Research considering

how interventions impact *carer* outcomes is much more widespread and, although intuitively assumed, there is little in the literature to evidence that improved carer-outcomes transfer to a reduction in BPSD in people living with dementia.

Ten papers were identified for inclusion, all of which shared to some degree (mostly as secondary aims), the same goal of reducing BPSD symptoms in people living with dementia. The publications evaluated group-based teaching interventions delivered to informal carers and did not include direct involvement of the people living with dementia themselves. The interventions utilised a mixture of teaching approaches including didactic education, role play, structured activities, and group discussion. Whilst the content of the groups could be roughly separated into two main 'types' consisting of general dementia education and cognitive-based strategies, there was much variability in the level of detail outlined with regards to the interventive approaches. This, along with the variability of outcome measures used to assess BPSD, and the variable quality of the research, made direct comparisons between the publications difficult. This inconsistency in approach, research quality and the difficulty in integrating findings between studies, is similar to previous findings in reviews looking at non-pharmacological intervention on the effects of care-giver outcomes (Cheng et. al., 2020; Vandepitte, et. al., 2016).

Only three studies were found in which people living with dementia's BPSD symptomology was a primary measure, indicating this this is a highly under-researched field. It is likely that researchers are deterred from measuring outcomes related to people living with dementia directly due to the complexities of doing so logistically, ethically and practicably. Researchers have called for consensus in this area to address the challenges such as; concerns about informed consent and capacity due to cognitive impairment; safeguarding issues; a lack of accessible, valid and reliable dementia-specific measures; as well interpreting results in the context of a progressive disease (Westet. al, 2017; Beuscher, & Grando, 2009).

Despite many of the publications in this review reporting positive effects on *carer* outcomes (i.e. wellbeing, sense of burden and depression rates) they did not generally and convincingly find statistically significant positive results on BPSD outcomes. Three papers *did* report limited significant results on BPSD outcomes, and one paper reported results which were very close to reaching significance. This result is of particular note as it was drawn from the study rated second highest in research quality (Hebert, et. al. 2003). With a reported p-value of 0.06, this is extremely close to the arbitrary threshold ($p < 0.05$) we so often deem necessary in order to reject a null hypothesis (Andrade, 2019).

It is of note that the interventions described within this review are predominantly psycho-educational or cognitive-skills based, rather than specifically designed to enable carers to respond to behaviours that challenge. The papers appear to target BPSD indirectly at the informal carer-wellbeing level. It is theorised that a carer's reduced understanding of, and negative cognitive appraisal of BPSD renders them less sympathetic to and less able to cope with managing BPSD in the day to day. Psycho-education and a focus on altering cognitive appraisals is therefore the mechanism-of-change targeted within the included interventions. This is in contrast to Cook et. al.'s review (2012) on 'formal' caregivers training, which was notably 'behavioural' in orientation and incorporated the implementation of functional analysis (FA) techniques. FA techniques involve exploring the purpose and meaning behind a person's behaviour, hence FA is embedded within the 'unmet needs' model of BPSD, which is advocated within BPS and NICE guidelines. It would be of interest to see future research examining the role of direct behavioural techniques such as FA within the informal-carer population also. It is not clear why this notable omission exists within the informal caregiver literature, however there may be an underlying assumption that FA techniques are too 'technical' in nature for a 'non-professional' demographic.

4.2 Methodological issues

Of those studies describing statistically significant results multiple methodological issues were of note, and hence a clear evaluation of 'intervention-efficacy' is unsubstantiated here given the lack of quality of the research conducted in this area. More high-quality research must be conducted in this area to establish a consensus on the most likely effective 'active ingredients' of group-based carer interventions on BPSD, if any.

In two of the lower-quality papers, no control group was applied, and only pre-post within-group data were evaluated. Hence the reported trends cannot be attributed with confidence to the experimental intervention and multiple confounding variables may have been at play. Seven of the papers in this review were full-scale RCTs, in theory allowing for a more robust analysis and evaluation of results. The majority of these *did* conduct power analyses, however only three managed to recruit and retain the adequate number of participants outlined in their sample size calculations. Hence, many may have been underpowered and at increased risk of Type-II error. One of the RCTs did not report any power analysis and therefore may equally be assumed to lack sufficient power.

Another methodological issue of note when control groups were applied is that there is no consistency on what constitutes an appropriate control within this population. For ethical reasons most studies applied a 'treatment as usual' control or 'wait-list' control. Hence, there is no certainty about what additional treatments were prescribed within the research window. Most of the studies provided very little detail about what other services were being offered or accessed, and it is likely that these would vary considerably across the different countries and clinical services in which the research took place. This was similar to previous reviews undertaken on informal-carer interventions (Vandepitte et. al. 2016).

Due to the nature of the interventions it was not possible for participants to be blinded and hence they would be aware of allocation to either a control or treatment group. This may have contributed to a bias in outcomes, especially as results were based on self-completed measures in which informal carers rated BPSD subjectively. There is, as yet, no consensus on how to measure the construct of BPSD especially as there is no unified definition of the construct, or of the individual symptoms. Some symptoms may overlap and some may be more or less visible, or more or less likely to be recalled by informal carers who are dealing with the behavioural and personal consequences (van der Linda et. al., 2014). Terracciano et. al. (2019) proposed that participation in group psycho-education may reduce the stigma associated with reporting BPSD and hence intervention-recipients may rate BPSD more readily than those in control groups. It may also be the case that with increased knowledge from interventions, informal care-givers are more attuned to notice signs of BPSD. Such hypotheses may explain instances in which results find no effect, or even adverse effects of training programmes.

A majority of publications measured outcomes only immediately post-intervention. Of those that *did* consider follow-up, the follow-up period was often short at six weeks, or six months post-intervention. Hence it is not possible to draw conclusions about the longer-term effects of group-interventions as disease progresses. Two papers which found significant results, one of which was of the highest quality rating (Ulstein et. al., 2007), considered outcomes at 12-months post-intervention, and found significant results at this time point. This tentatively suggests that any active components of the group-interventions which are effective in reducing BPSD may take time to embed within a caregiver's daily practice, or that they may be more impactful at the later stages of disease progression. This is of particular note, as it is rare to find significant positive results in high-quality dementia studies as late as at one-year follow up. Research investigating psychoeducational interventions and

carer outcomes for instance, report efficacy in the short term, and then diminishing effects over time (Zabalegui, et. al., 2008; Yarnoz, et. al., 2008).

4.3 Content-type and effectiveness

Given the caveats described above in relation to study quality and variability it is difficult to draw any conclusions within this review on the effectiveness of content-approach. However, it is of note that the two studies of highest quality rating, and with significant or near-to significant results had a key element in common; structured problem-solving skills (Ulstein et. al., 2007; Hebert et. al., 2003). Using structured problem-solving to define a problem and work through active steps to resolution is a practical skill which informal carers can obtain from training interventions. As problem-solving is 'task-oriented' it is likely to have more of a direct impact on people living with dementia and not solely on carer-outcomes. As a result of the intervention carers may be better placed to notice triggers for some of the more noticeable BPSD symptoms such as behavioural distress and agitation, and proactively intervene before an escalation occurs. As a somewhat generalising observation, those studies which exclusively offered general psycho-education about dementia in a classroom-style format, appeared to have been of lower quality or have minimal effects on BPSD outcomes.

4.4 Dosage / group size and effectiveness

Regarding dosage, it is equally challenging to draw conclusions from the varied approaches taken in which sessions offered totalled between 12 and 30 hours of intervention. It appears therefore, that time exposed to treatment may not be an important factor related to effectiveness and that instead, the approach and content may be more salient. The same can be said of group sizing, as no discernible trends can be drawn from the studies which ranged in group size considerably from five and up to 16 participants. Two of the studies which concluded significant findings did not

report their group-sizings, suggesting that the researchers did not note this to be of key importance. Where it may be of importance, is in relation to clinical practice where resources are so often scarce. It would be of interest for future research in this area to consider whether dosage or group size truly are an irrelevance, in which case, shorter dosages can be offered to a higher number of service users at once; thereby providing the most efficient use of resources at lowest cost to providers.

4.5 Clinical implications

Two high-quality studies indicated positive findings, however three studies which found no significant BPSD results were rated of 'medium' quality (Kurz, et. al. 2009; De Rotrou, et. al. 2010; Terracciano, et. al. 2020). Sample sizing within these three studies was appropriate for the power estimates and hence non-significant results are less likely attributable to a Type-II error. These studies therefore may provide weight to an argument that group-based informal carer training interventions are in fact wholly ineffective in reducing BPSD symptoms.

If we are targeting people living with dementia outcomes clinically, we are at risk of wasting limited resources across services by delivering group-based interventions to informal carers, rather than delivering treatments 1:1. None of the studies in this review compared results with comparable individualised approaches. There is evidence to suggest for example that individualised interventions are more effective than group-based treatments on informal carers' outcomes such as depression (Selwood, et. al., 2007). If the same applies to people living with dementia outcomes and BPSD, then resources may be far better funnelled into tailor-made individualised approaches and hence research into this area should be prioritised.

Future research needs also to incorporate more diverse groups of recipients and consider how diverse participant demographics impact the efficacy of treatment. In this review, Ulstein et.al. (2007) found a significant positive effect on BPSD symptoms

in *female* people living with dementia, only in post-hoc analysis. Due to the retrospective nature of this analysis it must be interpreted with caution, but nonetheless it raises questions about the potential differential effects of treatments on different groups of individuals who may seek support from clinical services. The researchers proposed that differing coping styles between genders may help to explain the differential results. The 'problem-solving, solution-based' approach, which formed the basis of their intervention, was proposed to appeal more to male caregivers who are most often caring for female care-recipients (i.e. their wives). It is an interesting hypothesis, but one that would require further research in order to inform differential treatments in clinical practice.

4.6 Limitations of the review

Although an important contribution to the literature in this area, this review has several limitations not least the inclusion of several studies which were rated to be of low or medium research quality. As with all instruments, the quality assessment QualSyst tool used here was not exhaustive, and omits many factors related to research quality (e.g. power calculations, replicability, sampling procedures, attrition rates), whilst prioritising others. In their discussion, Kmet et.al. (2004) discuss the limitations of this tool including its degree of subjectivity in relation to what are deemed 'important' components of quality research, as well as the limited sample size of their inter-rater reliability assessment. However, considering the absence of a 'gold standard' in this area, and the relative subjectivity of all tools, the QualSyst remains a useful resource for the assessment of studies of varying design.

Despite incorporating studies from across several continents, this review may have been limited by the exclusion of studies which were not written in English, thereby reducing the generalisability of the findings to other cultures and settings. Although all attempts were made for a comprehensive literature search, it was limited by the strategy adopted, and by the exclusion of grey literature or literature which was

excluded due to unavailability. A considerable variation in approaches, research description detail, and data offered in the included publications meant that reviewers were limited in their ability to synthesise quantitative results. For example, very few studies provided effect sizes which would enable more informative comparison. Therefore, results were synthesised only by extracting observable themes in a descriptive and somewhat subjective manner.

8. Conclusion:

Generally, the publications in this review do not provide convincing evidence regarding the efficacy on BPSD symptoms of group-based, informal carer training programmes. It is also not possible to conclusively differentiate active components which are more efficacious than others. As a tentative observation it may be that programmes with a 'problem-solving' focus are most helpful. Also, that effects are more measurable after some time post-intervention when strategies have been embedded into practice. There is existing research within the literature which investigates the impact of such interventions on *carer* outcomes. This review highlights the lack of research investigating the impact on outcomes which directly relate to people living with dementia and their disease presentation. Although perhaps intuitive, there is little in the literature to evidence that improved carer-outcomes transfer directly to improved outcomes for those living with the disease. Future studies designed to measure BPSD as a primary outcome would be a welcome addition to the research literature

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Part 2: Empirical Paper

Virtual Cognitive Stimulation Therapy (vCST) – A ‘new-norm’ for supporting people with dementia during a global pandemic and beyond?

Abstract

Aims: Cognitive Stimulation Therapy (CST) is an evidence-based group intervention for people living with dementia, which has proven benefits for cognition and quality of life when delivered face-to-face. Online delivered, 'virtual' CST (vCST) has never been empirically examined before now, however a clear need for an online protocol and evidence of its efficacy has emerged during the COVID-19 pandemic. As a preliminary response to this urgent need, this study aimed to assess vCST acceptability, and potential cognitive benefits.

Method: This research consisted of a controlled, proof-of-concept study, mixed in design by incorporating pre-post quantitative cognitive measures and qualitative interview data. Descriptive and inferential statistics were used to tentatively explore initial effects and trends. A thematic analysis was conducted to explore the acceptability of vCST and facilitators and barriers of access.

Results: Twenty two participants were recruited; 12 formed a treatment group; 10 formed a treatment-as-usual (TAU) control group. Two participants dropped-out due to worsening health. 11 participants were interviewed for feedback about their experiences. Quantitative analyses found no significant differences in change scores between groups. Some descriptive trends indicated a stabilisation of cognition within the vCST group. Thematic analysis identified 13 sub-themes across four main themes; 'being online'; 'connections with others in vCST'; 'feelings about vCST'; and 'transfer of CST processes and outcomes to a virtual modality'.

Conclusions: This research did not find statistically significant benefits of vCST on cognitive measures. Attrition rates and qualitative feedback demonstrated that vCST is a feasible and acceptable intervention for some people living with dementia. However, a majority still prefer face-to-face groups, despite acknowledging the potential benefits of a vCST provision beyond the COVID-19 pandemic. Multiple

factors are considered in interpreting these results, and further research is recommended to determine the efficacy of vCST.

1. Introduction:

Dementia is a neurodegenerative syndrome which is chronic and progressive in nature (World Health Organisation, 2020). Symptoms commonly affect cognitive functions such as memory, attention, orientation, new learning abilities, and language skills. Behavioural and psychological symptoms of dementia (BPSD) are also common and can include agitation, inappropriate behaviour, irritability, inappropriate behaviours, depression, delusions, and anxiety (Cerejeira et. al., 2012). Ultimately dementia-related neurodegeneration impairs an individual's abilities in every day functional tasks, rendering them progressively more dependent on others. Due to an increasingly ageing population worldwide, prevalence rates of dementia are rising exponentially. Recently published government data establish prevalence rates of around 430,000 people in the UK (NHS Digital, 2021). As a major cause of disability and dependency the World Health Organisation (WHO) have outlined dementia as one of the world's foremost health challenges and a public health priority (WHO, 2017). Understandably given the personal, emotional, social, and financial costs of this disease, research has been galvanised to develop effective interventions for people living with dementia. Routinely, pharmacological treatments are offered where appropriate however, not without the usual caveats related to inconsistent efficacy, negative side effects, and frequent psychiatric review. In a shift away from an overly biomedical model to the treatment of dementia, NICE guidelines in the UK currently recommend cognitive stimulation therapy (CST) in group form to people living with mild to moderate dementia (NICE, 2018).

1.1 Cognitive stimulation therapy

CST is an internationally implemented, group-based psychological treatment for dementia which has well evidenced positive effects on cognitive function and wellbeing (Gibbor et. al., 2020). In its original form CST comprises 14 face-to-face

group sessions delivered across seven weeks. It was developed with Kitwood's (1997) influential work at its core and thereby endeavours to protect and nurture participants' 'personhood' through the interpersonal processes within the group-setting (Dewing, 2008; Spector et. al., 2020). Although the specific content of the groups can be flexibly modified to suit the cohort's cultural, generational, and individual attributes, 16 key-principles always form its basis. Stimulation of cognitive functions is promoted through challenging, yet enjoyable activity and discussion. CST emphasises the reflective sharing of opinions rather than the certainty of facts and promotes the development of new ideas, thoughts, and associations.

Over two decades' worth of research has established the efficacy of this intervention through numerous randomised controlled trials (RCTs) (Lobbia et. al., 2018; Woods et. al., 2012). The mechanisms of change are likely to be multifaceted. It is widely evidenced that sustaining intellectually-stimulating and socially-rich activities in older age maintains overall cognitive function, and slows the progression of neurodegenerative disease-related cognitive decline (Treiber et. al., 2011; Hall et. al., 2009; Woods, et.al., 2012). Research examining specific cognitive domains suggests that CST is particularly effective in promoting language skills, most likely owing to the repeated encouragement of opinion-expression within group sessions (Spector et. al., 2010). In addition to language, memory and orientation domains may also be enhanced by CST engagement (Hall et. al., 2012). Researchers in this field speculate that, consistent with the '*use it, or lose it*' principle (Swaab et. al., 2002), the recurrent activation of domain-specific neuronal networks, not only helps to preserve neuronal pathways, but also that CST uniquely challenges people living with dementia in a way that cultivates new neuronal pathways and network growth. It is proposed also that reduced negative self-evaluation may contribute to the mechanisms at play (Hall,

et. al., 2012). This is important because social, self-evaluative, and situational factors are proven to impact memory test performance in older adults (Hess et. al., 2004). CST is de-stigmatising of negative age-stereotypes as it values participant engagement and contribution, without judgement or appraisal of 'correctness'.

CST's standardised, published protocol renders it easily applicable and replicable across settings and numerous studies have indicated its successful adaptation and use cross-culturally (Marinho et. al., 2021; Mkenda et. al., 2018; Wong et. al., 2018; Alvares Pereira et. al., 2020). It has also more recently been modified for facilitation by informal carers with individuals (Orrell et. al., 2017), and in an extended 'maintenance' format which shows promising effects on longer-term wellbeing outcomes such as quality of life (Orrell et. al., 2014). Up until now, the CST research literature has focussed on face-to-face group delivery, as was outlined in the original protocol.

1.2 Online interventions

With technological advances and improved high-speed internet access in people's homes it is understandable that a growing interest has arisen in the potential for virtually delivered healthcare generally. Videoconferencing psychotherapy has been evidenced in numerous RCTs to be as effective as face-to-face psychotherapy when applied to the treatment of depression (Berryhill et. al., 2019a), anxiety (Berryhill et. al., 2019b), substance misuse (King et. al., 2014), post-traumatic stress disorder (Yuen et. al., 2015; Acierno et. al., 2016), and pain (Chavooshi et. al., 2016). None-the-less the use of videoconferencing in mental-health care has divided opinion amongst clinicians, with some remaining cautious and calling for greater regulation and training in this area (Vincent et. al., 2017). Evidence suggests however that the processes of online therapy are similar to that of traditional methods (Barak et. al., 2008), and that therapeutic alliances can

be formed, maintained (Berger, 2017), and are often of greater concern to the clinician than the client (Lopez et. al., 2019). This modality offers exciting promise as a solution to the access-barriers which exclude many individuals from accessing real-life mental health services, potentially broadening the reach of services in a cost-effective manner. Initiatives in rural Australia for example, have been implementing remote-based treatments with great success since 2018 to reach marginalised groups who would otherwise be neglected due to geographical distance (Knott et. al., 2020).

People living with dementia may not be the first clinical population to come to mind when considering the applications of technology and virtually delivered interventions, and indeed emphasis has predominantly been on the use of such technologies with adolescents and children. However, there is great potential for the utilisation of technology in dementia care; from the stages of assessment, diagnosis, and through to monitoring; interventive cognitive and functional maintenance; facilitation of leisure and social activity; and in supporting caregivers (Astell et. al., 2019; Moyle, 2019). For people living with dementia, comorbidities which contribute to poor physical health and mobility can make accessing local health and social services particularly challenging. Cognitive impairments which prohibit some people living with dementia from driving inevitably impose a dependency on others for wider community access and transportation. Furthermore, underpinned by the often complex 'behavioural and psychological symptoms of dementia' (BPSD) profile of people living with dementia, a resistance to leave the 'safety' of home is also common and has been established as a contributing barrier to accessing services (Macleod et. al., 2017).

A recent systematic review of internet-based interventions for *caregivers* of people living with dementia reported overall positive outcomes specifically in relation to peer support-groups using online videoconferencing applications

(apps) (Hopwood et. al., 2018). However, outcomes relating directly to people living with dementia are severely lacking (Gately et. al., 2019) and up to now very few research trials have directly involved people living with dementia in video-based online interventions. Findings suggest that several dementia assessment tools used clinically, are as reliable when utilised via a video-based platform (Lindauer et. al., 2017), and a recent review of video-interpreting, concluded that older adults were satisfied and able to engage with video-assisted assessments as reliably as those conducted face-to-face (Haralambous et. al., 2019). Regular videoconferencing with loved ones has shown positive effects compared to controls, on symptoms of depression and loneliness in elderly nursing home residents (Tsai et. al.2010). Hence, it seems that over recent decades some dementia researchers have tentatively begun to explore the applications of videoconferencing apps in clinical care for people living with dementia. However, such research into the applicability and efficacy of online-facilitated dementia-care has trailed slowly behind other areas of mental health service provision, up until now.

1.3 Present research

During the global COVID-19 pandemic vulnerable older-adults have been advised to stay-home and shield from society, whilst memory services across the UK and worldwide have suspended treatments and closed their doors to face-to-face contact. Understandably, acute physical and medical needs of the population take precedence in the immediate response and provision of resources, more so than the needs relating to social and mental wellbeing (Galea et. al. 2020). However, preliminary evidence suggests that social distancing measures have had devastating implications for people living with dementia's cognitive, behavioural, social, mental and physical health (Canevelli et. al., 2020). An early review of the literature concluded that older adults generally, and people living with dementia,

were more likely to experience the onset and exacerbation of neuropsychiatric symptoms such as depression, apathy, irritability and severe agitation (Manca et. al., 2020). An informant-based, carer survey also reported subjective accounts of cognitive decline in care-recipients (Canevelli et. al., 2020). With visitor restrictions in place people living with dementia in nursing homes have experienced intense loneliness in the absence of loved ones and reduced social activities and engagement with fellow residents (Numbers & Brodaty, 2021). Experts in the field have disseminated their concerns in 'point-of-view' statements highlighting the longer term consequences for wellbeing and frailty (Devita et. al., 2020; Killen, Olsen et. al., 2020). A UK-wide telephone survey also showed that reduced access to services contributed to worsening anxiety and quality of life (Giebel et. al., 2021). The complex needs of people living with dementia and confusion owing to cognitive impairments, in combination with prolonged periods of isolation, put people living with dementia at increased risk. This is the case not only in the short term but potentially beyond lockdown as behavioural difficulties become embedded and chronic (Manca, et.al. 2020). Postponing referrals in clinical settings has also led to ever-increasing waitlists and the potential for demand to severely outstrip supply if services continue to remain suspended (Cuffaro et. al., 2020). Now more than ever, an acute urgency has arisen for the implementation of specialist remote services which can meet the needs of people living with dementia in their homes and mitigate the impact of COVID-19 on people's lives.

Providing continuity of care, Molyneux et.al. published perspectives and reflections on adapting their music therapy sessions for people living with dementia to online delivery during the pandemic (Molyneux et. al., 2020). Computer illiteracy, reluctance to engage onscreen initially, and communication difficulties posed notable challenges. However, with adaptations, their concluding

statement highlights the practical potential for this modality in reaching participants who would otherwise be physically unable to attend sessions due to disease progression. Di Lorito et. al. (2021) analysed perspectives from people living with dementia and their carers following receipt of an online exercise programme during the pandemic. They found that people living with dementia can engage with therapeutic video-calling, however noted that the success of this was in many cases reliant on carer-support. An early case-study of online CST delivered in New Zealand is the first (and only to our knowledge) to provide guidance on how to mitigate some of the challenges of online CST groups, and how to utilise app functions to best deliver content to participants. The clinicians were able to successfully deliver CST via 'Zoom' to ten participants who had pre-existing relationships and described the platform as 'easy to use' (Cheung & Peri, 2020). They highlight the pressing need for future research investigating the efficacy of 'virtual' CST (vCST), whilst Devita et. al. (2020) also endorse the development of a replicable online-CST protocol and validity testing. Anecdotally, clinicians across the UK, who ordinarily deliver CST in local services are calling out for an evidence-base and innovative guidance on how to promote social-connectedness and maintain cognitive stimulation at a time when it is most absent.

This research is the first vCST examination of its kind and constitutes a proof-of-concept study in advance of a larger RCT which is now also underway. This is a joint piece of work done in collaboration with fellow UCL trainee clinical psychologist, Luke Perkins. In addition to this paper, Luke Perkins' thesis focuses on the development and feasibility of vCST and preliminary effects on mood and quality of life outcomes. This study aims to make inferences about the following research questions:

1) Does the vCST programme, compared to TAU, lead to any changes in cognition?

2) Is vCST an acceptable intervention for people living with dementia?3) What are the barriers and facilitators of delivering and accessing vCST?

2. Methods:

2.1 Setting and ethical approval

This research was conducted online with participants accessing the intervention via the videoconferencing software 'Zoom' (2021) on their personal computers or tablet devices. Participants were individuals living in their own homes from across the UK and in Dublin, Ireland. Ethical approval was sought and obtained from the University College London ethics committee (Appendix 2).

2.2 Participants

Participants were people living with dementia residing in their own homes who were able to access a suitable device with internet. The inclusion criteria for participation were as follows:

- Diagnosis of dementia within the 'mild-moderate' stages of disease progression.
- Ability to communicate verbally in English.
- Capacity to consent to taking part.

Those eligible to take part in the qualitative interviews were people living with dementia and/or their informal carers who consented to interview after completion of the vCST intervention.

The majority of participants were recruited on an opt-in basis via advertisement (Appendix 3) at relevant third-sector services across the UK (e.g. charities, societies, and local carers groups), as well as by including the study on the 'Join

Dementia Research' online database (www.joindementiaresearch.nihr.ac.uk). Recruitment took place between August – December 2020. As local services were closed during the COVID-19 pandemic, the third-sector organisations advertised the study predominantly via their email mailing lists, websites, postal newsletters, or at support/social groups being held via videoconferencing apps online. A small number of participants were also recruited via a clinical dementia care service in Ireland. These participants were approached from the service's waiting list by clinicians who would run the groups as part of their usual service provision. No incentives were provided to participants who took part in this research.

The aim was to recruit 24 participants, 12 to the vCST group and an equally sized control group. This sample-sizing decision was guided by careful consideration of the following:

- In consultation with stakeholders at several focus-groups, four participants per vCST group was judged as an appropriate group-size for online CST.
- Within feasibility trials generally, 12 participants per condition is a recommended 'rule of thumb' sample-size (Julious, 2005).
- The delivery of three full cohorts of vCST was judged to be a realistic aim within the allocated timeframe.

A post-hoc sensitivity analysis completed using G*Power 3.1 (Faul et. al., 2007; power set at 0.80 and using a 5% significance value), revealed that a sample size of 24 would enable detection of large effects of 1.05 or above.

2.3 Procedures and design

This research was a controlled, pre-post, proof-of-concept study, mixed in design by incorporating quantitative cognitive measures and qualitative interview data. Pre and post measures relating to mood and quality of life were also collected and reported in a separate doctoral thesis by the joint-researcher and fellow clinical psychology trainee, Luke Perkins.

Participants who expressed interest in the study were met online via 'Zoom' for an initial information-providing session in which details about the project were provided and any questions answered. Participants were provided with written information (see Appendix 4) about the study via email prior to this meeting. Carers, where involved with participant consent, were provided with a 'carers' agreement' document (see Appendix 5) which outlined the expectations of their role. Participants' capacity to consent to participation was assessed on an individual basis at the initial meeting in line with the Mental Capacity Act (Department of health, 2005) legislation routinely used within clinical practice. Consent was obtained verbally at this meeting and then confirmed more formally via email (see Appendix 6). Participants provided demographic details at this meeting if they wished to take part in the study.

2.3.1 Randomisation and blinding

Participants were randomly allocated to either the vCST or TAU groups by a researcher who would not be facilitator for that cohort. Randomisation was completed by initially assigning participant-codes with a random six-decimal number from 0-1 using the 'RAND' function in Microsoft Excel. These numbers were then ranked from highest to lowest, with rankings 1st-4th being automatically allocated to the vCST condition and 5th-8th to the TAU condition. With suboptimal recruitment, the Irish cohort was randomised with a four:two (vCST:TAU) blocking ratio.

Participants were blind to their group allocation at the pre-measures stage. They completed these measures during a 'Zoom' meeting in the week prior to group commencing and post-measures in the week after the final group session. Assessors were also blinded to the participant group allocation and were independent researchers.

2.3.2 Intervention

CST was delivered across 14 sessions, twice weekly over seven weeks to groups of four people living with dementia. The researchers aimed to deliver the programme adhering as closely as possible to the original protocol outlined in the 'Making a Difference 1 – Second Edition' manual (Spector, et al. 2020) with some minimal adaptations for online delivery. The group sessions lasted one hour and were facilitated by two trainee clinical psychologists, or in the case of the Irish cohort two occupational therapists with extensive experience of delivering CST. The facilitators used the 'waiting-room' function to admit participants at the start of the sessions. Participants were supported by the group facilitators during the call to switch on their cameras and microphones and to change their display to 'gallery'-view. Group members were also supported to change their display names to accurately reflect who was present.

Following consultation with various stakeholders including professionals with experience of CST, people living with dementia, carers, and service managers, the CST manual was adapted for online delivery. Manual development and adaptations are described in more detail in Luke Perkins' thesis. 'PowerPoint' slides were developed to guide the facilitators on how to run each individual session and maintain consistency between cohorts (See Appendix 7 for a sample). The main themes for each session remained identical to the original manual: physical games, sounds, childhood, food, current affairs, faces/scenes, word association, being creative, categorising objects, orientation, using money,

number games, word games, and team quiz. Sessions also followed the pre-prescribed structure: starting with introductions, a short 'warm-up' activity, the group-song, orientation, discussion of a current news story, main activity, summary, and farewells. Most activities were easily adapted for facilitation online using the functionality of the 'Zoom' platform. For example, famous faces photographs were displayed using the shared-screen function, as opposed to having printed copies. Other activities required some reworking or required participants to bring along items from their household environments. For example, participants were asked to bring along a food for tasting, or the group followed a video-guided chair exercise in the 'physical games' session. A more detailed list of how activities were adapted can be found in Table 1.

The control group continued 'treatment-as-usual' which, based on participant/carer accounts, consisted of no additional treatment during the COVID-19 pandemic.

2.3.3 Feedback interviews

After the post-measures appointments participants in the vCST condition were asked for their consent to participate in the qualitative feedback interviews, to which all agreed. Interviews were completed at a separate 'Zoom' meeting within two weeks of the group ending.

Table 1
vCST adaptations

Session	Original main activity	vCST main activity	Participants to source and bring
1. Physical games	A) Throw a ball whilst asking questions about group members. B) Play a game such as skittles.	A) Pretend to throw a ball to each other on screen whilst asking questions. B) Choose a 'coloured-card' on screen, behind which is a question about exercise, health, sports etc. C) Follow along to a chair exercise video.	-
2. Sounds	A) Play sound effects and match sounds to pictures. Play songs and ask for singer / song name. B) Play percussion instruments.	A) Play sound effects and match to everyday objects using shared-screen. B) Play musical instrument sounds and name the instrument. C) 'Remember the song?' – play familiar songs and name/sing along.	Any object that makes a sound.
3. Childhood	A) Complete personal details sheet or draw childhood home. B) Demonstrate use of childhood toys or try and discuss childhood sweets.	A) Complete the childhood memory page and introduce family members to the group. B) Draw childhood homes. C) Show pictures of childhood toys on shared-screen. D) Show pictures of childhood sweets/foods on shared-screen.	Any object from childhood e.g. food, photo, toy etc. Pens/pencils, paper.
4. Food	A) Budget and plan a dinner using priced groceries and fresh foods. Categorise foods, discuss foods from different cultures. B) Taste foods and discuss memories. Brainstorm food categories or food naming.	A) Show foods on shared-screen and prices, ask participants to plan a shop based on a theme. B) Show foods and prices on shared-screen and price-match. C) Show cookery videos on shared-screen. D) Try and discuss foods which participants bring along.	A baked good (e.g. cake), or favourite snack.

vCST adaptations cont.

5. Current affairs	A) Discuss issues from a selection of newspapers. B) Use questions on cue cards to stimulate conversations about specific topics.	A) Watch news clips via shared-screen and discuss. B) Vote and discuss various current affairs topics.	-
6. Faces/scenes	A) Discuss printed copies of famous faces or scenes. B) Discuss non-famous faces, take photographs of group members.	A) Present 'now and then' photos of famous places using shared-screen and discuss. B) Present famous faces using shared screen and discuss.	A photograph of someone / somewhere special.
7. Word association	A) Supply the missing word in common phrases. B) Present the first few words of a song and ask participants to sing.	A) Display the start of common phrases on shared-screen and ask participants to complete. B) Start some songs using shared-screen audio and ask participants to continue.	-
8. Being creative	Do a creative activity such as cookery, collage, clay modelling, gardening, or drawing.	A) Follow a video on shared-screen on how to make a paper aeroplane or jumping frog. Support participants to follow along. B) Lead the group in creating a paper snowflake. C) Ask members to draw pictures of one another.	Paper, pens, pencils.
9. Categorising objects	A) Come up with words beginning with a certain letter or fitting to a category. B) Present objects or pictures of objects and group into categories.	A) Name items that come under specific categories or start with a letter. B) Display pictures of everyday objects and put into categories using shared-screen.	-
10. Orientation	A) Show a map, draw an outline, discuss places, transport etc. B) Discuss whether people have moved, travelled etc.	A) Show a map on shared-screen, discuss places travelled, lived etc. Use annotate function to draw on the map. B) Ask members to recommend places to others.	A printed map if participants have access to a printer.

vCST adaptations cont.

11. Using money	A) Prepare pictures of common objects and guess the prices. B) Supply examples of old and new money to stimulate discussion.	A) Display pictures of objects using shared-screen and ask members to guess or match the price. B) Discuss how the price of everyday items/food as changed. C) Ask members to bring old/new coins and discuss.	Coins or banknotes, new and old, or foreign currencies.
12. Number games	A) Play games involving numbers e.g. bingo, dominos, darts etc. B) Play 'snap', or 'higher-lower' with playing cards. Or guess how many items are in a container.	A) Add up playing cards together. B) Play 'higher or lower' with one deck of cards. C) Play bingo using an online number generator and printed playing card. D) Play snap using the camera to display cards at once.	A set of playing cards. A bingo card if members have access to a printer.
13. Word games	A) Play word games e.g. 'hangman'. Or enact out words on cards. B) Prepare a large crossword.	A) Enact out words on the camera. B) Display riddles using shared-screen and ask members to guess the answers. C) Play an idioms game from an online resource in which pictures relate to common phrases. D) Play 'hangman' using the whiteboard function. E) Play a crossword using an online resource.	-
14. Team quiz	Play a trivia quiz or another game previously enjoyed. Play 'true or false', or 'fact or myth' Have a special group tea with cakes and treats, discuss people's views of the group.	Play a trivia quiz displaying the questions using shared-screen, or 'true/false' or 'myth-buster' quizzes using online resource. Have some tea and snacks together on camera and discuss people's views of the group.	Tea/coffee, favourite drink and cake or snack.

2.4 Measures

Two outcome measures were used to assess cognition: the Montreal cognitive assessment tool (MoCA: Nasreddine et. al., 2005), and the Alzheimer's disease assessment scale – Cognition (ADAS-Cog: Rosen et. al., 1984). Assessment sessions were conducted by two trainee clinical psychologists who were independent of the vCST sessions and were blinded to participant group allocation. The same blind-assessor conducted the pre, post, and feedback sessions with each participant.

The MoCA was chosen as it is widely used within clinical practice as a dementia diagnostic screening tool and has a validated adapted version for remote use (MoCA-Blind). The ADAS-Cog was selected due to its extensive use within previous CST research where it has demonstrated sensitivity to change (Spector et. al., 2003). Careful consideration was also taken to choose measures which would be easily adapted for remote-use and which would take approximately one hour to administer.

Adaptations were required to allow for the measures to be facilitated online via a 'Zoom' videoconferencing call. Careful thought was given to this process amongst the lead researchers and by consulting with the current limited literature on online administration of cognitive assessments. An electronic assessment toolkit was developed to guide facilitators on administration and promote inter-facilitator consistency, along with a 'PowerPoint' presentation to display stimuli using the 'Zoom' shared-screen function.

2.4.1 MoCA

The MoCA is a cognitive impairment screening tool which in its original format is one-page in length and scores a total of 30-points. It assesses cognitive domains of attention, orientation, executive function, visuospatial ability, language, and

memory. Conventionally, a score of less than 26 is considered indicative of cognitive impairment (Nasreddine, et. al., 2005). The MoCa-Blind (Pendlebury et. al., 2013) was originally developed for administration over telephone and removes all of the visual elements of the assessment. It is scored out of 22-points and then easily converted back to 30. Two recent studies provide preliminary evidence of the MoCA's validity in use via videoconferencing (Chapman et. al., 2019; liboshi et. al., 2020).

2.4.2 ADAS-Cog

The ADAS-Cog is a brief, yet more comprehensive cognitive assessment than the MoCA, which was originally developed to evaluate the severity of symptoms in Alzheimer's Disease. It is purported to be 'the most commonly used' instrument in dementia-related clinical trials (Connor & Sabbagh, 2008). It incorporates subtests relating to word recall, naming, commands, constructional praxis, ideational praxis, orientation, word recognition, and remembering instructions, and scores are based on the number of errors made. The blinded assessors also subjectively rate individuals' spoken language, comprehension, word-finding abilities. Scores range from 0-75 with higher scores indicating greater impairment. The assessment has evidenced test-retest reliability (Rosen, et. al. 1984) and internal consistency (Weyer et. al., 1997). Although further research is warranted, a recent comparison study found good agreement in scores between videoconferencing-administered ADAS-Cog and face-to-face administration (Yoshida et. al., 2020).

2.4.3 Qualitative interviews

The semi-structured feedback interview asked group-members about their experiences of accessing and attending vCST. The interviews were conducted via video-call on 'Zoom' with the same blinded assessors who had completed the

pre-post measures with that individual. Some participants chose to attend the interview alone, while others attended jointly with their carers who had supported them in accessing the sessions (e.g. with computer set-up). Interviews lasted approximately 30 minutes with questions and prompts relating to three main areas: general experiences of the group; specific questions about CST as delivered *online*; and barriers and facilitators to accessing the intervention. An interview schedule was developed based on previous literature on qualitative experiences of CST (Orfanos, 2019), and in consultation with experienced members of the research team (Appendix 8). Specific prompts to aid memory of the groups (e.g. activities, group-name, names of members etc.) were provided to optimise the recall of the participants with dementia.

2.5 Analysis

2.5.1 Cognitive measures

Only preliminary effects were investigated within this initial proof-of-concept study. The data will also contribute to a larger RCT analysis which is currently underway and will be appropriately powered to apply inferential statistics. To consider initial effects, descriptive statistics were calculated for pre-post cognition scores across treatment conditions (TAU vs. vCST). Effect sizes of the difference between groups (Cohen's *d*) were calculated by dividing the difference in mean change scores by the pooled standard deviation. A Two-Way Mixed ANOVA was also conducted to tentatively explore significance testing..

2.5.2 Qualitative interviews

The feedback interviews were recorded with participant consent and then later transcribed verbatim and anonymised. As the aims of the research were to answer very specific questions about the acceptability, barriers and facilitators of the intervention, as opposed to being theoretically driven, a thematic framework

analysis was deemed most appropriate for analysis. The thematic framework analysis allows for a recursive process of extracting patterns across the data set. The data were analysed following the guidance outlined by Braun and Clarke (2006). This method is not rigidly aligned to any epistemological tradition and hence can be applied flexibly (Braun et. al. 2016). The researcher's epistemological stance can best be described as interpretivist, in that objective/value-free enquiring is not considered possible for the investigation of social phenomena. Hence the researcher's social context and understanding were important to consider throughout the analysis and a 'bracketing' exercise was completed as described in more detail within the critical appraisal section of this thesis. A bottom-up 'inductive' approach to data analysis was adopted to identify themes. Themes were identified from transcripts at a 'semantic' level, based on the surface-level meaning of participants' spoken contributions and without attempting to look beyond the participants' words.

Familiarisation of the data was gained through the transcription process and by re-reading all interviews after complete transcription. Initial ideas of interest were transformed into broad-brush codes, organising the data into meaningful groups. At this stage visual tables and mind-maps were used to gain a sense of how coded extracts might be sorted into potential overarching and sub-themes (see Appendix 9 for an example of initial coding, clustered into themes). An iterative process of reviewing and refining the coded data into themes commenced in consultation with the researcher's supervisor (Dr Joshua Stott), until a thematic framework was finalised. Any disagreements were resolved through discussion and consensus. All stages of the analysis were completed using NVivo software. A fellow trainee clinical psychologist provided credibility checks on a random sample of the transcripts by reviewing and providing feedback on the initial codes. Any discrepancies or disagreements were resolved through discussion. As the aims

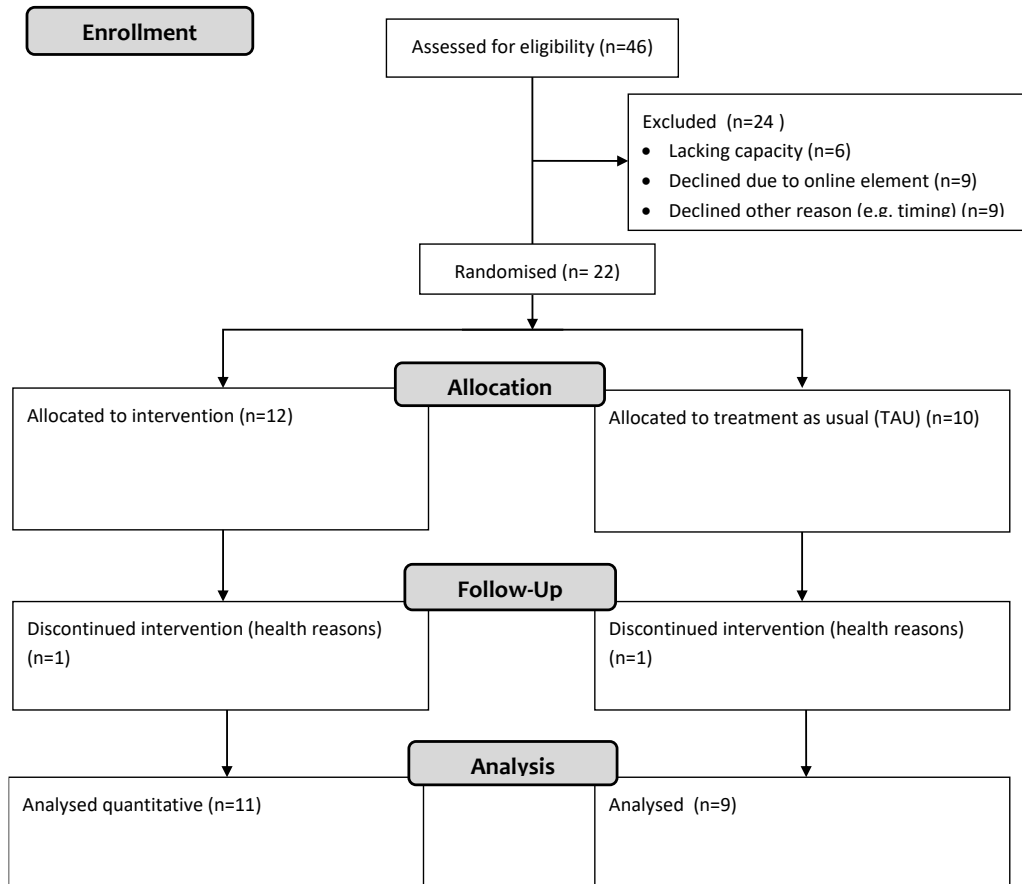
of this study were to explore specific details with regards to applying the intervention to real-life clinical settings it was deemed important to include even 'minor' themes within the dataset which may only have been contributed by one or two individuals but may still hold important value. A descriptive approach was therefore applied which categorised the themes into those best described as 'very prevalent', 'majority', 'minority' or 'rare' (see Table 5 for details). It is understood that there are differing stances on the use of such 'quantitative' descriptors when applied to qualitative methods, however this approach was based on similar literature within the dementia field (McKechnie, et.al., 2014). This approach was considered helpful within this context to enable readers to judge the breadth of each theme, allowing clinicians to make informed judgements when applying the intervention in practice where previously no research or guidance has been available.

3. Results:

3.1 Sample

In total 22 participants were recruited; 12 formed an intervention group (vCST); 10 formed a treatment-as-usual control (TAU) (See Figure 1).

Figure 1
Participant flow through the study



Two participants dropped-out due to worsening illness, one from each the experimental and control group. Having approached all individuals on their service waitlist, the cohort in Ireland did not reach full capacity due to several individuals declining the intervention and preferring instead to wait for traditional CST to resume within their service. Participant demographics can be found in Table 2. The majority of participants were female (64%) and white British (64%), with an average age of 73 years. The most common dementia type was Alzheimer’s Disease (46%), however 23% of participants did not specify their diagnosis. Attendance amongst the vCST participants was high and averaged 95% across the 14-sessions offered.

Table 1*Participant demographics*

		TAU		vCST	
		M (SD)		M (SD)	
Age (years)		69.9 (10.4)		73 (7.6)	
Baseline MoCA		19.1 (7.0)		19.3 (7.2)	
Baseline ADAS-Cog		16.3 (11.7)		18.2 (13.4)	
		TAU		vCST	
		<i>n</i>	%	<i>n</i>	%
Sex					
	Female	6	66.6	7	63.6
	Male	3	33.3	4	36.4
Ethnicity					
	White British	6	66.6	7	63.6
	White other	0	-	1	9.1
	White Irish	2	22.2	3	27.3
	Mixed white & black Caribbean	1	11.1	0	-
Dementia Type					
	Alzheimer's Disease	2	22.2	7	63.6
	Posterior Cortical Atrophy	1	11.1	0	-
	Korsakoff's Syndrome	1	11.1	0	-
	Frontotemporal Dementia	1	11.1	0	-
	Mixed	1	11.1	3	27.3
	Unspecified	3	33.3	1	9.1

Note: Figures rounded to one decimal place

3.2 Quantitative results

Analyses were conducted only for participants who completed both pre and post measures.

On the MoCA, lower scores indicate greater impairments. There was no significant main effect of treatment condition (vCST vs. TAU) [$F(1,18)=0.12$, $p=0.73$, $\eta_p^2=0.007$], or of time (pre vs. post) [$F(1,18)=0.890$, $p=0.358$, $\eta_p^2=0.047$] on participants' MoCA scores. There was also no significant interaction effect [$F(1,18)=0.682$, $p=0.420$, $\eta_p^2=0.037$]

On the ADAS-Cog increased scores indicate greater impairment. There was no significant main effect of treatment condition (vCST vs. TAU) [$F(1,18)=0.156$, $p=0.697$, $\eta_p^2=0.009$], or of time (pre vs. post) [$F(1,18)=0.022$, $p=0.885$, $\eta_p^2=0.001$] on participants' ADAS-Cog scores. There was also no significant interaction effect [$F(1,18)=0.250$, $p=0.623$, $\eta_p^2=0.014$]. See Table 3 for detailed descriptive results.

Table 3
Descriptive statistics

Measure	vCST ($n=11$)			TAU ($n=9$)			ES(d)
	Pre <i>M</i> (<i>SD</i>)	Post <i>M</i> (<i>SD</i>)	Change Score <i>M</i> (<i>SD</i>)	Pre <i>M</i> (<i>SD</i>)	Post <i>M</i> (<i>SD</i>)	Change Score <i>M</i> (<i>SD</i>)	
MOCA	19.3 (7.2)	19.2 (6.7)	-0.1 (4.8)	19.1 (7.0)	17.4 (6.5)	-1.6 (3.2)	0.37
ADAS-Cog	18.2 (13.4)	18.5 (15.6)	0.3 (4.5)	16.3 (11.7)	15.7 (13.8)	-0.6 (3.6)	0.23

M mean, *SD* Standard deviation, ES effect size (Cohen's d), MOCA Montreal Cognitive Assessment, ADAS-Cog The Alzheimer's Disease Assessment Scale–Cognitive Subscale, TAU Treatment as usual control, vCST virtual cognitive stimulation group.

3.3 Qualitative results

All 11 participants who completed vCST consented to taking part in feedback interviews about their experiences. Participants chose independently whether they preferred to be interviewed alone or with their carer present. Generally, in all instances when carers contributed feedback, the group-participants (people living with dementia) communicated agreement. Hence, data from people living with dementia and carers were not distinguished and coded separately and instead all data from individual interviews were coded as a 'unit', relating to that particular participants' experience. Interviewee information can be found in Table 4.

Table 4
Interviewee details

Participant	Cohort	Attendance	Demographics Gender, Age, Dx.	At interview
1	1	100%	Female, 80, AD	PLWD & carer (husband)
2	1	93%	Female, 66, AD	PLWD only
3	1	100%	Male, 71, AD	PLWD only
4	1	86%	Male, 71, AD	PLWD & carer (wife)
5	2	93%	Female, 79, Mixed (AD & VD)	PLWD only
6	2	100%	Female, 80, Mixed (AD & VD)	PLWD only
7	2	93%	Female, 60, Mixed (AD & PCA)	PLWD only
8	2	100%	Female, 66, AD	PLWD & carer (husband)
9	3	86%	Male, 67, AD	PLWD & carer (wife)
10	3	100%	Female, 84, AD	PLWD & carer (daughter)
11	3	100%	Male, 77, Unspecified	PLWD only
		Average	95%	

Dx. diagnosis, AD Alzheimer's Disease, VD Vascular Dementia, PCA Posterior Cortical Atrophy, PLWD person living with dementia.

3.3.1 Description of Thematic Framework

The final analysis generated 13 sub-themes which were relevant to the research aims. These sub-themes were organised into four over-arching main themes; 'being online'; 'connections with others in vCST'; 'feelings about vCST'; and 'transfer of CST processes and outcomes to a virtual modality'. Table 5 outlines the main thematic structure and includes prevalence descriptors for each theme.

See Appendix 9 for an example of how transcript quotes were coded, and then sorted into, sub-themes, and main themes. Each main theme and sub-theme is presented in more detail below, with illustrative quotations. The same prevalence descriptors as outlined in Table 5 are used throughout the following text.

Table 5
Thematic Framework and Prevalence

Main Theme	Sub-theme	Prevalence*
1. BEING ONLINE	1a: The technology, positives	Very prevalent
	1b: Benefits of online compared to face-to-face	Majority
	1c: The technology, negatives	Majority
	1d: Communication challenges	Minority
2. CONNECTIONS WITH OTHERS IN VCST	2a: Positives	Very prevalent
	2b: Negatives	Majority
3. FEELINGS ABOUT VCST	3a: Positive feelings	Very prevalent
	3b: Negative feelings	Very prevalent
4. TRANSFER OF CST PROCESS AND OUTCOMES TO VIRTUAL MODALITY	4a: Group set-up	Majority
	4b: Group dynamics	Majority
	4c: Mental stimulation	Very prevalent
	4d: Group content	Minority
	4e: Perceived positive outcomes	Majority

*Very prevalent = theme was discussed by all, or all but one of interviews (10-11); Majority = theme applies to more than half of the interviews (6-9); Minority = theme applies at up to half of interviews (3-5); Rare = theme discussed at only one or two interviews (1-2).

3.3.2 Main Theme 1: Being online

This main theme related to practical experiences of the technology, as well as tangible benefits and difficulties related to being online. The 'being online' theme was subcategorised into four sub-themes; 'positives about the technology', 'benefits of online compared to face-to-face'; 'negatives about the technology'; and 'communication challenges'. Overall, there were almost double the number of coded references related to positives about 'being online' as compared to negatives.

1a: Positives about the technology

No, or very minimal technical issues formed a very prevalent subtheme.

"We didn't have any difficulties logging in, no difficulties on that at all. We logged in and it was fine." [P8_Carer]

Some attributed this to the 'good fortune' [P1] or the privilege of having a good internet connection, others explained that they relied on family members for advice should any technological issues arise. Generally, when participants *did* report issues, they were most often 'one-off' occurrences, with quick resolution, and participants dismissed the issues as 'minor'.

"No, only once when I didn't know how to do the video chat on it, that's it. But as I said my son was here on holiday the first week, so it was grand, so we didn't get stuck." [P9_Carer]

A minority of interviewees, both people living with dementia and their carers, commented on how quickly they were able to learn new skills to use 'Zoom' with ease.

A majority of participants reported that the 'Zoom' functions worked well during the groups, including showing images/videos on shared-screen, using the

whiteboard, and using the PowerPoint resources. Several participants commented on appreciating the multi-modal nature of visual and auditory stimuli. All those asked also reported no concerns with being on camera.

“...on every session there was a thing on the screen with ... different coloured squares and then you could pick a colour and behind the colour would then be a question ... And I thought, for like for ‘Zoom’ purposes ... that is really good. And the hangman, you know the word game, it actually worked via ‘Zoom’ the way [facilitator] did it on the screen.” [P7]

1b: Benefits of online compared to face-to-face

Comments on the benefits of accessing the intervention online, compared to the usual face-to-face groups were very prevalent. Some focussed on direct benefits which they had experienced themselves, with reduced travel being the most common.

“It can be easier doing it on ‘Zoom’, than having to go somewhere, unless it’s near. I mean ...[it] can be quite a busy road. So that’s the positive thing about doing it on ‘Zoom’, you haven’t got that to worry about. Or if the weather’s bad or anything like that.” [P4_Carer]

Others, offered more hypothetical benefits beyond their own experience, commenting on the potential scope of vCST to reach more people.

“If I took it this way, it’s only 10-15minutes drive down to [local service], it wouldn’t bother me in the slightest, but if I was a huge distance away from it, I would, that’d be a different answer, so there is an advantage.” [P11]

“Some people live quite remote, some people have mobility problems, or some people aren’t able to use public transport or can’t drive, you know, they can’t get there. So at least it’s more inclusive than the face-to-face.” [P7]

Interviewees commented on the benefits of meeting people from a wide geographical area. Some described meeting a diverse range of people as more ‘enjoyable’ [P4] or ‘fascinating’ [P5], whilst others hypothesised about the potential benefits this could have on waiting-list times, or the logistical benefits for services offering groups.

“Whereas doing it online you could have anybody from anywhere, you don’t even need to keep it in Britain, it could be, you know, talking to an Australian ... I think the advantage could well outweigh... of being able to link up anywhere in the world. So, for example the first 12 people who say ‘I’m interested’ you just link them up, you don’t have to wait to get to 12 people who are all within a 12 mile radius of each other.” [P1_Carer]

Some interviewees enjoyed the comforts of home being close to hand, for example being able to ‘get a coffee’ [P11], ‘put the washing on’ [P3], or ‘not having to dress up’ [P3]. Whilst some explained that online CST was easier to access when feeling unwell.

“If I had have been having to travel 10 or 15miles somewhere and I was feeling under the weather, you know I might have ‘ummed and ahhed’ and not gone. But because it was online and I was warm and comfortable at home, even though I didn’t feel particularly wonderful, I could still attend. So, in that respect... it’s great.” [P2]

Two carers commented on their surprise that the on-screen groups were able to sustain their loved-ones' attention.

"...but it held mum's interest, I didn't think that she would actually sit here for an hour, but it did hold her interest, which was to me a surprise actually." [P10_Carer]

1c: Negatives about the technology

A majority mentioned that attendance at the groups was reliant on having a strong internet connection. A majority also noted that they were reliant on others to be able to access the groups, due to a lack of technical knowledge, at least in the initial stages. However, this was not often framed as a 'negative', but more as a potential barrier for others.

"So, if someone lived on their own and didn't have that support at home, that would be a problem." [P7]

Two participants noted that their screen-view may have been obscured, due to the wrong 'gallery-view' settings, or use of particular hardware (e.g. tablet vs. computer).

"I've been using an iPad, and I'm guessing that I missed out on certain things because I couldn't always see ... everybody on the full screen."
[P2]

One participant described an attentional difficulty when the facilitator switched from one 'Zoom' function to another.

"... you know when the facilitator shares their screen?... I think there's some work necessary for that to become more seamless ... but kind of in that moment my attention wanders, while I'm waiting for something."
[P2]

1d: Communication challenges

A minority of interviewees made comment about how it was generally more difficult to speak online compared to face-to-face groups. Participants with communication difficulties found this particularly difficult.

“It’s made a little bit worse now because she can’t find the language as quickly. And then you get a problem with the difference between what she’s saying and what you’re hearing through ‘Zoom’ anyway. And it tended to pull you back from fully participating, didn’t it?”
[P8_Carer]

A contributing factor was the time-lag that is experienced when communicating via video-conferencing applications.

“I was talking and then you came along, and we both ended speaking at the same time. If you were here in my house that would not happen. So, it makes it more strange and difficult.” [P8]

One participant noted how this was not conducive to a dementia diagnosis in which memory difficulties make it harder to hold on to thoughts for lengthy periods.

“There’s a disconnect isn’t there...a slight time lapse? And one of my problems with Alzheimer’s, if I don’t say it when I think it, more often than not it’s gone, gone forever. So sometimes ... I feel really bad ... I feel as though I’m interrupting what someone’s saying, and it’s not rudeness, it’s just a desire to express what’s in my head before it’s gone.” [P2]

A rare theme was how this was different to face-to-face communication, in which body-language would be easier to notice and interpret.

“When you’re in a real-life situation you can see, you can read people and you know by their movements and their expressions when they want to speak. And that’s quite difficult to do ... online.” [P2]

3.3.3 Main Theme 2: Connections with others in vCST

This main theme relates to participants’ perceived ability to connect with others during vCST. Comments on building connections with others or how this might compare to face-to-face groups were very prevalent. The theme was subcategorised into ‘positive’ and ‘negative’ sub-themes. Overall, there were almost double the number of coded references related to positives about connecting with others in vCST, compared to negatives.

2a: Positives

Statements expressing that participants were able to connect with others in some way via the online modality were very prevalent. This was communicated with the use of words such as ‘attachment’, ‘friendship’, ‘warmth’ and ‘empathy’.

“I felt quite attached to the people in the group.” [P5]

“There were people that I warmed to immediately.” [P3]

“I felt a breadth of humanity, warmth from the facilitators and from the other participants, and oh my goodness when you feel as isolated as I do right now, that warmth and compassion can’t be measured, it’s just immeasurable, it was first class.” [P2]

Some participants noted that the online groups offered a unique antidote to isolation during the global COVID-19 pandemic.

“Well, it was probably the only people I’ve talked to during the whole of lockdown, because I live on my own..., so it was quite nice to have it, to talk to people.” [P5]

A majority commented that it was positive meeting people who were different to themselves. A minority also expressed appreciating meeting others who had similar experiences to themselves, through the shared diagnosis of dementia.

2b: Negatives

One participant noted that they were *not* able to form relationships with others during vCST.

“I don’t think anybody did, because of the distance.” [P8]

A minority commented on missing the ‘intimacy’ of face-to-face interactions, including tactile aspects, and being ‘physically’ present with others.

“Well for one thing we probably would have shook hands when we first met, it’s that sort of thing.” [P6]

“I just think, ack, you know it’s nice to have a real person there isn’t it, a three-dimensional person literally.” [P2]

A minority of interviewees also noted that they missed the ‘unstructured’ time which generally comes with attending face-to-face groups. Particularly in relation to how this allows for more social interactions and opportunities to ‘get to know one another’ better.

“At the end of each [face-to-face] session there tends to be a cup of tea, and a chat, and a biscuit and [name] missed the biscuit, didn’t you? (laughs).” [P1_Carer]

“... Once the group’s finished you’re sat here by yourself. Whereas if you’re out with the group ... you might walk to the bus-stop together or you may have arrived together or leave together, and sort of talk through what you have done that morning. Whereas when you’re online there is no one else really you can talk to about it, because there is just you.” [P7]

3.3.4 Main Theme 3: Feelings about vCST

Many ‘feelings’ were expressed at interview by both people living with dementia and their carers in relation to their experiences of the vCST groups. This main theme was subcategorised into ‘positive’ and ‘negative’ emotions. Overall, almost 60% of coded references in this theme related to positive feelings, compared to 40% related to negative feelings.

3a: Positives

The most commonly expressed positive emotion was one of ‘enjoyment’ which was very prevalent and mentioned in some form at all 11 interviews.

“I enjoyed the exercise and it was well worth doing it.” [P11]

“He would always come in saying ‘now that was very enjoyable’ when it finished.” [P9_Carer]

Other positive emotions related to a sense of ‘inclusion’ and ‘interest’ which were mentioned by the majority.

“Everybody was included, and I think there was one person that had difficulty speaking and he [facilitator] gave [them] time to speak and... tried to encourage [them] to speak ...” [P5]

“The topics were interesting, the topics we discussed. It was a good variety of activities.” [P7]

A minority expressed feeling comfortable, safe, respected, and looking forward to the groups.

“I felt just globally comfortable with the people who were facilitating, and a growing relationship with the ... participants.” [P2]

“It wasn’t patronising ... and sometimes quite serious topics regarding headlines in the newspapers but we always had three choices... so we did feel quite in charge.” [P7]

“We all had respect for one another.” [P9]

Less frequent, but also expressed by a minority, were feelings of happiness, novelty, general positivity, and a boost in confidence.

“But it was very interesting, and it was something completely beyond my experience.” [P6]

“I hope I have expressed adequately how positive an experience it was for me.” [P2]

“Yes, I enjoyed knowing, when I knew the answers and when it was given, yes I was right. It was really... I didn’t think of it at the time, but I suppose I was pleased.” [P6]

One carer also expressed positive benefits to *their* own wellbeing, via ‘respite’ time from the caring role, and in learning new skills to use technology for other areas of their social-life.

“Then my brain was able to switch off while I was sitting in the other room (laughs), so both of us gained... even sitting on the phone for an hour, I’d often ring my friends and I’d sit and be able to have a conversation without being interrupted. You know it worked out well.” [P9_Carer]

“...Like I never even used email really. I had an email address like, but I never used it. But now... I’m using it all the time now.” [P9_Carer]

A majority of interviewees felt that vCST was an ideal solution during the COVID-19 pandemic.

“Particularly with the pandemic we’re all living through at the moment... it’s wonderful to be able to have that on the screen without a doubt.” [P7]

“I think these times more than ever before, it’s so important for this, some kind of treatment like this, and if it can be only done online... it’s very necessary I think whichever way it’s done. So, if this is the best that can offered ... certainly.” [P10_Carer]

Constituting a very prevalent sub-theme, every participant stated that they would be willing to participate in online vCST again.

3b: Negatives

A minority expressed that the participants missed the group once it was over.

“It’s a shame that it had to finish as we have nothing to focus on now, because there’s nothing happening now.” [P9_Carer]

Missing the ‘journey’ aspect of travelling to face-to-face groups was also a minority sub-theme.

“It’s the journey there and back to wherever the meeting is. It’s because well, I don’t go work anymore because of dementia, so it’s something to do isn’t it. So rather than having one hour just on screen, it would be a total of three hours taken care of.” [P7]

“I think, he would prefer to go out because ... he’s looking to go places all the time.” [P9_Carer]

Two carers reported early negative feelings regarding accepting something online, due to initial reservations or doubts. However, in both instances these remarks were followed-up with positive comments about how it had in fact exceeded expectations.

“At first, at the beginning when they were saying do it online, I was nearly objecting to be honest with you, because lazy-brained I wouldn’t be that well up with the computer, but then when I started to get going, I was so happy that I chose to do it.” [P9_Carer]

“It surprised me, I didn’t think it would be as successful as it was to be honest with you.” [P10_Carer]

Two participants reported feeling anxious regarding the technological aspect of getting into the ‘Zoom’ meetings.

“I was always anxious about whether or not I was going to get the compu[ter]... the whole thing working each time.” [P5]

Two participants also reported feeling as though the groups highlighted their cognitive difficulties when for instance, they felt unable to do a task.

“I have always succeeded at whatever I’ve set my mind to doing ... So, when I can’t do those things, or I feel a little bit out of my depth because I can’t do them it sets off that spiral in my brain of ‘I’m not succeeding, I’m not succeeding’.” [P2]

Although most often followed-up with a comment about the ‘potential of vCST’, a majority of interviewees were clear on their preference for face-to-face groups over online, if provided with the choice.

“Well, I definitely prefer face-to-face if that were a choice. But due to COVID, or generally speaking for some people who might be unable to leave their home or can’t access group-settings ... I think it’s a perfect solution.” [P7]

3.3.5 Main Theme 4: Transfer of CST process and outcomes to a virtual modality

Finally, comments relating to aspects of the groups which were related to how CST might compare or be adapted to a virtual format were very prevalent. This main theme includes comments which directly related to the key processes of CST or the intervention outcomes, and how these might have been experienced in vCST. This theme was subcategorised into five sub-themes; ‘group set-up’; ‘group dynamics’; ‘mental stimulation’; ‘group-content’; and ‘perceived positive outcomes’.

4a: Group set-up

A minority of interviewees reported finding facilitator email-contact helpful. This most often related to the regular email reminders which facilitators sent prior to each session, but also to one-off contacts made when participants required support.

“I only had to email him [facilitator] once because I got mixed up ... So, you know, with that in the background you don’t feel so isolated because you know there’s someone even when you’re not on screen, someone that you can contact via email who will then respond.” [P7]

Positive comments on the overall structure of the groups were also expressed by a minority of interviewees.

“I very much liked the structure of the meetings.” [P2]

A minority reported finding it enjoyable and acceptable bringing pre-prepared stimuli to the groups (e.g. photographs). However, one carer noted that some more direct facilitator-carer communication may have aided this process.

“Sometimes they’d be saying, could you pull something together for next week. If I’d happened to hear it, it would be fine, but it wasn’t always then reminded on the invitations. [Participant] would end up coming to some of the sessions without some of the stimulus ready.”

[P8_Carer]

A minority of interviewees commented on group-size, mostly finding the ‘smaller’ size ideal for vCST. However, one participant who had attended face-to-face CST previously, commented that one or two extra participants may be beneficial in some instances.

“It was lovely that it was a small group ... and it was, very inclusive ... they got to know each other as time went on, which I kind of think also helped as well.” [P10_Carer]

“I think we could have done with two more [participants], it would have been equally good. But because the four of us we all had something to say, so it was ok, but if you had a group of four where nobody wanted to talk, that would be a bit awkward.” [P7]

Although rare, some participants remarked that the start time of 9:00am was too early.

“I would have liked it to have been perhaps a little later in the morning at times. I mean nine o’clock in the morning, because I have problems getting dressed it could make it a little difficult to make timing.” [P3]

An additional rare sub-theme related to the time (one hour) passing very fast and limiting what could be explored in the groups.

“I mean you know the hour that we have in each session, you can only cover so much.” [P3]

4b: Group dynamics

A majority of those interviewed made positive remarks about another group member, highlighting a particular bond they had formed or noting specific attributes they admired.

“Yes, I thought she was very interesting and quite brave because ... she is about to buy a new house ... and she’s about to take a lot on, and I don’t know if I could do it, but I admire her.” [P1]

A minority of participants commented on the compatibility of group members with one another. For instance, that some group members were more vocal than others, and that group-dynamics were impacted by factors such as age-differences and cognitive ability/impairment.

“...now you’re dealing with people with different levels of issue aren’t you... but you know when you’ve got a group of people with different skill sets.” [P8_Carer]

4c: Mental stimulation

The majority of participants reported finding the group sessions mentally stimulating, whilst only one participant reported otherwise.

“Oh yeah I did [find it stimulating], well it was quite interesting, when something would come up and they were talking about it and I would make my own comments on it.” [P11]

4d: Group-content

Only a minority commented on the individual activities or content of the group sessions, many reporting that it was difficult to remember specifics. Enjoyment of the singing component of the groups constituted a rare sub-theme.

“I have enjoyed, well, we both have enjoyed, the singing.” [P1]

One interviewee explained that activities which involved turn-taking seemed to work best.

“You know the ones where it worked better, was the ones where different people were being asked to do specific different things and contribute without other people interrupting, but when they were general conversations, it was more difficult.” [P8]

Whilst another participant remarked that they would have appreciated more time dedicated to discussing various aspects of living with dementia.

“I mean one of the things I really want to develop, is to find out how other people find that the public treat them, with dementia you know?”

[P3]

4e: Perceived positive outcomes

A majority of interviewees spoke about changes they noticed in themselves or in their loved ones as a result of attending the groups. These were conceptualised as a subtheme of ‘perceived outcomes’, with the most common being related to overall wellbeing or mood. A majority of participants noted a change in mood.

“I think she used to come out in good form after it. You know... the way when you’ve been somewhere and you’ve enjoyed yourself, even out of a good movie or something like that, like you feel uplifted slightly.” [P10_Carer]

“It has been an absolute life-enhancing experience for me, the whole thing.” [P2]

“After that ... if he was in low mood in the morning, after that session he’d be happy.” [P9_Carer]

A minority of interviewees commented on how the groups had provided much needed structure or routine to their week.

“It gave me a focus to my week and my days.” [P5]

“It was something for him to focus on you know ... And he’d be up and ready washed and dressed and just sitting there waiting for them to join.” [P9_Carer]

“It’s been hard for mum ... because dad passed away ... and since then it’s been coronavirus, and there’s been no structure at all there for her... It was a nice structure to the week every Tuesday and Thursday.” [P10_Carer]

A minority also noticed changes in cognition. This included increased engagement/initiation with others, for example talking about topics from the group, and also more coherent expressive language skills.

“After some sessions [participant] was more, like lively, motivated and energised.” [P8_Carer]

Interviewer: *“So it sounds as though you noticed some improvements in what we call cognition, thinking skills?”*

“Absolutely, absolutely ... because he was able to make sense in the conversation when he came of it.” [P9_Carer]

4. Discussion:

4.1 Summary

This mixed-methods study sought to explore the acceptability, and preliminary effects of online-delivered cognitive stimulation therapy; 'virtual CST' (vCST). Beyond a noteworthy recent case-study (Cheung, et. al., 2020), this is the first study of its kind to the researchers' knowledge, which examines vCST.

Overall quantitative measures of cognition did not support the hypothesis that vCST contributes to improved cognitive functions comparably with previous face-to-face CST research. On the MoCA, change scores demonstrated a stabilisation effect in the vCST condition of small effect size which was not statistically significant. Qualitative findings suggest that it *is* possible for people living with dementia to engage in CST via an online modality and that vCST is an acceptable intervention for some people living with dementia. To contribute to a more in-depth understanding of the acceptability, facilitators and barriers of vCST 13 sub-themes within four main themes were conceptualised through a thematic analysis; 'being online'; 'connections with others in vCST'; 'feelings about vCST'; and 'transfer of CST process and outcomes to a virtual modality. Further details are discussed below.

4.2 Insights into vCST

4.2.1 Acceptability of the online format?

Overall, the attrition rate within the recruited group-members was low, with only one participant leaving the vCST groups sadly due to worsening health. Week-on-week attendance of individual sessions was also high with the majority of participants attending all 14 sessions. Those who missed a session, did so most often due to a competing medical appointment and sent apologies in advance.

This is consistent with a recent pilot study exploring online therapeutic groups which found that the convenience of the online modality significantly improved attendance rates (Lopez et. al., 2020).

Generally, with regards to 'being online', 'feelings about vCST' and 'connections with others' there were more positive reflections in relation to participation than negative. All of those interviewed, including those with more critical reflections, reported that they would accept an invitation to vCST again in the future, indicative of a high degree of 'acceptability'. There was a general consensus that the provision of vCST was an ideal solution for the particular challenges posed by the COVID-19 pandemic and that vCST 'filled a gap' at an unprecedented time. People living with dementia and their carers also noticed positive outcomes which are comparable to those documented in CST (Lobbia, et. al., 2018). For example, some described improvements in mood, wellbeing, confidence, language-skills, and more active engagement with others.

Despite this, the majority of participants on weighing up their preferences, reported that they would ultimately prefer face-to-face groups if they were afforded a choice. The reasons for this may be varied, including a well-considered cost-benefit analysis which for many would place higher priority on meeting people 'in real-life' than the convenience of attending online. The 'familiarity principle': a preference for things, or systems that we know, may also be a factor at play here. Instilled in UK society during the COVID-19 pandemic was a pervasive, hopeful narrative about 'getting back to life as normal'. Hence, now more than ever participants with a reduced capacity for 'yet more' change may be inclined to yearn for familiar interventions/services, and a closeness to others which is currently missing in other areas of their lives. Many participants remarked on the potential scope and benefits of vCST for '*others*', separate from themselves, for example people with mobility issues, those unable to drive, or those with

worsening physical illness. Hence, it may be hypothesised that the generally high-functioning, mild-staged sample within this study prefer face-to-face as they consider the benefits of vCST not currently relevant to *their* needs or circumstances. Another pattern which arose from analysis related to a *changing* appraisal of acceptability across the course of the intervention. Several participants and/or their carers noted initial reservations, doubts or worries about accepting an intervention based online. Through the course of the intervention perceptions appeared to shift through direct experience, as misconceptions were undermined. In clinical practice this may contribute an initial barrier in recruitment for such groups, and the use of prior-participant testimonials may be important in instilling confidence during recruitment.

4.2.2 Transfer of key CST Principles to vCST

Fostering an environment in which connections and relationships can be built is a key component of CST, and well documented within the research literature (Bertrand et. al., 2019; Dickinson et. al., 2017; Orfanos et. al., 2020; Morrish et. al., 2021).

Participants noted the omission of unstructured social-space within vCST as a drawback of online groups, and noted 'missing' the physical presence of others. Despite this, it is clear that relationship-building was possible within vCST where the majority of participants described developing friendships, closeness, and connection with others. This is consistent with early research findings in the field of online-intimacy which suggest that online relationships can be formed, comparable to face-to-face relationships in their meaning and intimacy (Lomanowska & Guitton, 2016). Some participants described forming bonds very quickly, whereas others felt an increasing connectivity over time. It appears that the small group size of four participants and two facilitators helped to foster safety, and enabled participants to develop inter-personal bonds. Rogers and Lea (2004)

apply social identity theory to argue that group cohesion is not necessarily determined by individual inter-personal bonds, but instead by the development of a social 'group identity'. They maintain that the information-exchanges needed to form group identity are minimal, and hence easily transferable to online modalities. This theory accounts for the development of a group-cohesion in vCST, in which the structure and activities promote a shared group-identity (e.g. shared diagnosis, selection of a group name and song) in spite of the omission of unstructured social opportunities.

Other key principles of CST related to respect, involvement, inclusion, and choice were all present in vCST, mirroring the outcomes documented in recent CST qualitative studies (Orfanos, et. al., 2020; Morrish, et. al., 2021). Enjoyment and a sense of fun was also prominent, with a majority of participants describing the sessions as such.

All but one participant described the vCST sessions as mentally stimulating. Regrettably, in the one instance where this was not the case, it was not elaborated on within the feedback interviews and hence we have little additional information about any potential barriers to this. There is a central assumption that increased mental stimulation in CST mediates cognitive maintenance and enhancement (Hall et. al., 2013). It is also through the promotion of *new* ideas, thoughts and associations that the mechanisms of change likely occur. Several participants noted that the discussions were 'new', 'different', and 'interesting' consistent with this key principle. In addition to the content of the sessions, some participants described the *approach* itself as such, with the experience of 'being online' and learning new ways of being with others as 'novel' and 'outside of their experience'.

Implicit learning rather than explicit teaching is an additional key feature of CST in which participants ideally will not feel as though they are 'being tested', obviously learning, or being overtly stimulated, but instead will experience a sense

of fun and enjoyment and regard the intervention as a 'fun activity group' (Spector et. al., 2020). It is proposed that this dynamic encourages positive self-evaluation and de-stigmatisation which directly impacts on communication and cognitive skills (Spector et. al. 2003). For some, this was paralleled in vCST for example some participants described the intervention as their 'club', noted a confidence-boost, and described feeling safe to express their opinions in ways which they no longer felt able to do in day-to-day interactions. There is evidence that an 'online disinhibition effect' promotes more readily open discussions and sharing of opinions than face-to-face interactions (Suler, 2004).

In contrast, a minority of participants reported experiencing that vCST confronted them with their diagnosis by highlighting their difficulties. As with any group, a balance must be carefully struck as members will have differing skill-sets and activities will challenge some more than others. In in-person CST it is advisable that groups are not formed with a wide-range of abilities and that compatibility within-groups is carefully considered. Several participants in this study commented on the importance of group-compatibility. This may arguably be even more crucial in vCST where facilitators are less able to scaffold cognitive difficulties due to the challenges of communication over videocall. It is also possible however that the novelty of vCST, and specifically the technical aspects, undermines participant confidence and self-evaluation more so than attending face-to-face groups, especially for those who feel less skilled technologically and reported anxiety in relation to the technology. Finally, it is feasible that the research component of this study formed a confounder, in that participants' recall of the sessions may have merged with their experiences of the inherently much less supportive, pre-post measures assessment sessions.

4.2.3 *Facilitators and barriers to accessing vCST*

It is evident that *some* technological knowledge is necessary to access vCST which is not required in face-to-face groups. The support of a knowledgeable carer facilitated access to vCST for some and may pose as a barrier for others who are isolated. Several participants in this study were reliant on family members to set up the 'Zoom' meetings, and some people living with dementia and carers reported anticipatory anxiety in relation to the technology malfunctioning. Generally, group members valued the regular facilitator contact emails, which served as an aid-memoir for attendance but also provided reassurance and support when needed regarding the technology. Several participants also noted that having a reliable and strong internet connection was important, and while not a 'deal-breaker' in terms of acceptability, that on a handful of occasions buffering impacted their experience of the group. Evidence suggests that digital inclusion is generally improving in the UK, however there are still particular excluded groups, including most notably those over age 75, and those with disabilities (Office for National Statistics, 2019). Age UK (2021) reported that while there has been a slight increased uptake of technological use in older adults since the start of the pandemic, this was not substantially greater than previous years and that more support is needed to reduce digital exclusion. Nine individuals within this study opted out of receiving vCST due to the online nature of the intervention, preferring instead to wait for face-to-face CST to return. Over time however, as wider society's make-up changes, a greater proportion of the older adult population will have grown up with the day-to-day use of technology. Hence, modalities such as vCST may become increasingly appealing over time.

Language and communication impairment can form part of the dementia symptomology profile. This is particularly the case in some rarer forms of the disease such as frontotemporal dementia, but also common in the later stages of

Alzheimer's. One barrier to accessing vCST may be where an individual's language skills are particularly impaired and where additional communication support is essential. For example, participants in this study who had communication difficulties reported that the time-lag and reduced visibility of body language over video-conferencing made it even harder to communicate in vCST than in face-to-face interactions. Some participants reported that not enough quiet-space was afforded to allow time for word-finding or sentence formation. This contributed to one participant in particular feeling somewhat excluded from the group and unable to participate as much as they would have liked. Inclusion was enhanced by careful facilitation and the addition of turn-taking activities, as opposed to open dialogue discussions.

4.3 Study limitations

4.3.2 Blinding and confounding treatments

Participants at the stage of post-measures were unavoidably unblinded to their treatment condition due to the nature of the intervention. Participants were asked not to inform the blinded-assessors of their group allocations, however adherence to this policy was not recorded. The integrity of the assessor-blinding could have been measured by asking assessors to rate their knowledge or confidence in participant allocation.

It was deemed highly unethical by the researchers to deny participants alternative forms of social-contact and treatment during a particularly isolating time. It is possible therefore that participants accessed additional interventions, or other online groups without the researchers' knowledge which is a limitation of the design. Participants were advised to inform the researchers if they were concurrently accessing face-to-face CST, however we cannot be sure if this was adhered to. No participants declared accessing concurrent interventions

throughout the course of the study. Medication prescriptions were also not recorded during this research which could contribute a potential confound for the outcomes. However, during the COVID-19 pandemic it is unlikely that participants would have undergone any medication changes during the pre-post research period as the majority of clinical services and psychiatric reviews were suspended unless strictly deemed essential. Similarly, it is unlikely that any participants were accessing alternative face-to-face treatments due to nation-wide service closures. In passing, some participants mentioned attending other online groups such as 'Singing for the Brain' (Alzheimer's Society, 2021) or non-specific social 'coffee-groups' which may have enhanced stimulation and contributed to wellbeing beyond the vCST treatment. However, this only enriches the study's ecological validity as it is comparable to real-life clinical scenarios whereby people living with dementia experience varying degrees of day-to-day stimulation, and access concurrent treatments whilst participating in CST.

4.3.3 Sample-size and sampling

The small sample size in this study is likely to have been underpowered to detect smaller effects which could exist, and inferential analyses should therefore be interpreted with caution.

The research aimed to capture a sample of participants representative of older adults accessing memory-services across the UK and Ireland after receiving a diagnosis of dementia. This is the population who would ordinarily be offered face-to-face CST as part of their post-diagnostic care. As such, the inclusion criteria for this study were set relatively broadly with no lower or upper age limits, no stipulations regarding the type of dementia diagnosis, and no exclusions based on comorbidities. Despite having broad inclusion-criteria the study sample may have been somewhat biased by the recruitment procedures. Initially, attempts were made to recruit solely from advertisement at third-sector organisations

however it became apparent that such organisations were naturally not reaching as many people living with dementia within the community during the pandemic. Hence, the 'Join the Dementia Research (JDR)' online database was added as a recruitment source. People living with dementia accessing this online database were more likely technologically competent and confident and thereby not fully representative of the wider people living with dementia population. This was counteracted however by the inclusion of the 'Irish' cohort who, as a service-accessing cohort were much more representative of a clinical population.

Consistent with this, those who expressed interest via JDR but did not take part, were excluded mostly due to autonomous decision-making. For example, one person felt that they were too young to 'fit' within the group dynamic. In contrast, the majority of those excluded from the Irish cohort were due to capacity concerns and with more severely impaired cognition. Average baseline cognitive scores on the MoCA were lower in the Irish cohort (13), than the other two cohorts (both 21).

It is important therefore to consider the study sampling when generalising the findings from this vCST research. A majority of the participants may represent a 'best-case' sample who are already reasonably high functioning, with pre-existing technological skills and more readily able to learn new skills. In contrast, the sample may exclude a proportion of the clinical population who would experience increased barriers to accessing a resource delivered online. A limitation of this study is the omission of qualitative interviews from those who did not participate in the study and those who outright declined to partake in vCST.

4.3.5 Adapting the measures for 'Zoom' administration

Online facilitation of cognitive measures which were originally designed and standardised for face-to-face administration could undermine the study's data. The validity of assessment tools relies on their standardised administration across

settings. However, in this research some deviations were inevitable and unavoidable; for instance, in the ADAS-Cog the blinded-assessors were unable to present 'real-life', tangible objects in the room and alternatively presented full, colour photographs of objects. Careful thought was given to the adaptation of the tools through exploration of the literature and multiple discussions within the research team. A detailed step-by-step instructional protocol was developed to promote consistent between-assessor administration, and the same blinded-assessors were used for individual participants at pre and post assessments.

The BPS division of neuropsychology published helpful, timely interim-guidelines on best practice in administering neuropsychological testing via video-call during the COVID-19 pandemic (The British Psychological Society (BPS), 2020). The guidelines noted that although no tools existed which had been clinically normed across this 'online' modality, assessment tools generally are widely used across varied face-to-face settings worldwide, for which they have similarly not been normed (BPS, 2020). In the present study participant scores were examined for change over time and were not used for clinical applications or diagnoses. Hence, a lack of 'online'-specific norms was not deemed problematic for the purpose of this 'pre-post' research. Promising evidence from two recent meta-analyses suggests that psychometric tests did not demonstrate inferior performance when administered by videoconferencing (Brearly et. al., 2017) and are not less effective compared to face-to-face assessments facilitated by clinical health professionals (Speyer et. al., 2018).

A further limitation is that the adapted assessment protocols and the qualitative interview schedule were not piloted prior to use within this study.

4.3.6 Adapting CST for 'Zoom'

CST is adaptable by design and promotes creativity and flexibility in facilitation to suit the needs and interests of the participating group members. Whilst retaining the structural format of the groups and maintaining the key principles, CST can vary in *content* from group-to-group. Hence, comparably, this study was not concerned with *some* degree of variation between-groups in vCST sessions. A clear protocol was developed, adhering closely to the original group manual (Spector et. al, 2020). This protocol was utilised by all three vCST groups with the aim of enhancing inter-group consistency. All group facilitators had prior experience of facilitating or attending face-to-face CST sessions and extensive experience of working clinically with adults with dementia. Facilitators were also offered supervision sessions from the principal researcher Prof. Aimee Spector on a needs-basis. In addition to these measures, it may have been useful to complete adherence to the treatment fidelity checks in order to quantify any variability, however this was not considered.

4.4 Implications

This research demonstrates that many of the key CST principles are readily transferable to an online format. Many people may still prefer face-to-face groups, however all things considered, participants could appreciate the potential and benefits of a vCST provision. The value that vCST offered to participants specifically during the COVID-19 pandemic was evident in their spoken feedback. However, participants were also forthcoming about the potential for vCST beyond the pandemic in increasing accessibility for marginalised groups, and in reducing waiting times. Considering that some individuals chose not to take part in this study due to the online element, vCST may not constitute a 'new-norm' for all. However, many participants clearly valued the *option* of an alternative modality

and hence in future clinical practice a mixed-model approach or choice of modality may be important. A mixed-approach could increase service-reach and meet specific service-level and service-user needs. More rigorous research into vCST is needed to establish the efficacy of this treatment, and to contribute to this emerging field.

4.5 Conclusion

This research did not find conclusive benefits of vCST on cognitive measures; however, some descriptive trends indicated cognitive stabilisation in the vCST condition, compared to treatment as usual. Attrition rates and qualitative feedback demonstrated that vCST is a feasible and acceptable intervention for some people living with dementia, with potential benefits to wellbeing and cognition similar to those seen within the extensive CST literature.

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Part 3: Critical Appraisal

Introduction

This critical appraisal outlines my reflections on conducting an empirical research project as part of the doctorate in clinical psychology. The appraisal begins by considering the evolution of the project. Specifically, it focusses on how the project aims changed over time in response to the challenges presented by COVID-19, and on how a final decision about the research topic was made. The early challenges of recruitment are then also discussed within this context. The appraisal finally considers bracketing procedures which sought to reflexively distance the qualitative data analysis from the researchers' personal background, interests, and assumptions, which are overtly outlined.

COVID-19: Closing doors, whilst opening others

Originally, I had intended to conduct my empirical research project on developing a communication training programme for family carers of people living with dementia. My interest in this area was grounded in my previous experiences of working as a speech and language therapy assistant (SLTA) in various clinical settings over several years. In these roles I had the privilege of learning about the importance of communication and developed a toolkit of techniques and best-practice strategies for optimising communication amongst those with cognitive impairments and aphasia. For people living with dementia, difficulties in sustaining conversation can impact negatively on social wellbeing, sense of isolation and societal exclusion (Ablitt, et. al., 2009). Communication breakdown also contributes to behavioural challenges and psychological distress (Downs & Collins, 2015). Despite current National Institute for Health and Care Excellence (NICE) guidelines recommending that all carers of people living with dementia are offered *“training to help them adapt their communication styles to improve interactions with the person living with dementia”*

(NICE, 2019), no such structured, evidence-based training programme currently exists.

As clinical psychologists we tend to appreciate working *directly* with clinical populations and I had previously enjoyed working with people living with dementia as a carer in residential homes. Initially I had hoped therefore, that my research might involve working with people living with dementia directly. However, on considering the above literature the project developed based on the observed need: a direct response to the lack of theoretically-grounded communication interventions *for carers*. Hence a project formed whereby we would develop a theoretically-driven training package for carers and pilot that intervention for feasibility and acceptability amongst informal carer groups.

During the COVID-19 pandemic there were widespread service closures for people living with dementia and their carers, across the UK, practically overnight. Only care deemed most clinically essential was provided and face-to-face interactions were put on pause in order to keep this vulnerable population as safe as possible at an unprecedented time. I received anecdotal, yet consistent, feedback from service-providers, that informal carers of people living with dementia in particular were struggling at this time with increased care-demands, little respite, worsening disease symptomology, and the sudden collapse of previous support systems. The Alzheimer's Society also published a striking report consistent with these accounts, in which 95% of informal carers reported worsening physical and mental health, and substantially increased hours providing unpaid care (Alzheimer's Society, 2020). We were advised that carers generally did not have the time, energy, or emotional resources within that early COVID-19 climate to engage in additional training, even if that training were offered remotely. I felt a keen sense of unease at the prospect of adding to carers' sense of burden, contributing more to a 'problem', rather than being 'part of a solution'. Within this unique context the research team acknowledged that

by providing a service, we could unintentionally add to an acute problem for informal carers, and we therefore made the difficult decision to suspend the original project plan.

This decision felt difficult for me personally on numerous fronts; 1) I was saddened and disappointed that by 'abandoning' our project we were also essentially 'abandoning' informal carers who noticeably needed *something* at this difficult time, our project just did not seem to fit this acute and unique remit of need; 2) I had put a lot of time and work into developing the project up to this point, including securing ethical approval for the research to take place. As a trainee, the prospect of starting from scratch, felt mammoth at a time when a lot of anxiety and uncertainty was already prevalent in relation to the unknown impact of COVID-19 on training and future qualification; 3) At a time when many trainee placements were put on hold, and a national narrative of 'rallying round', 'doing ones' part', and 'supporting our NHS heroes' was prevalent, I felt a sense of powerlessness and uselessness when abiding by government guidance and 'staying home'. It felt as though our skills as clinical psychologists were valuable at such a time of need and that there must be more I could, and should, be doing.

My current project, 'Virtual Cognitive Stimulation Therapy (vCST) – A 'new-norm' for supporting people with dementia during a global pandemic and beyond?' grew from this context. I wanted to contribute something which was meaningful for people living with dementia and their carers during the pandemic but which was possible from the safety of home; both for the researchers, and participants. I wanted it to meet a current need, as well as to have lasting impact upon the research literature and future clinical practice. I am proud now, looking back, to consider this project as achieving those initial aims.

I was surprised to learn that Cognitive Stimulation Therapy (CST) had not yet been adapted for online use, considering the wealth of research into other variations of

CST such as 1:1 delivery (Yates, et. al., 2015), maintenance CST (Orrell, et. al., 2014), and diverse adaptations to deliver culturally-sensitive CST worldwide (Bertrand, et. al., 2019; Wong, et. al., 2018; Alvares Pereira, et. al., 2020; Mkenda, et. al., 2018). I knew that supporting older adults online would require *some* contribution from already burdened carers. However, I also recognised the carer-respite benefits that may arise from engaging directly with people living with dementia, independently, for two hours per week. Once the research team delved deeper we received widespread interest from services across the UK who were considering the prospect of delivering virtual CST (vCST) but who had no guidance, previous experience, or evidence to draw upon. People living with dementia were no longer receiving the treatments which we know are evidenced to slow disease progression and improve wellbeing, at a time when wellbeing and quality of life were acutely impacted by isolation and loneliness (Hwang, et. al., 2020; Wickens, et. al., 2021). I also had first-hand experience from my recent older-adult placement of the access barriers for many people living with dementia in getting to services for conventional CST groups, even prior COVID-19, and so I swiftly recognised the potential of this project in meeting not only current needs, but also those beyond the pandemic. It felt as though with one door unexpectedly closing, another extremely meaningful door opened from which this project arose.

Reflections on recruitment

Conducting research with clinical populations is challenging at the best of times. Some challenges were exacerbated during the COVID-19 pandemic and unique challenges also arose especially in relation to conducting research remotely. I found the process difficult and isolating at times but also recognised that the broad clinical psychologists' skills-set lends itself well to overcoming such challenges.

A key area of difficulty was in recruitment, where uptake was initially slow. Working remotely contributed to my feeling somewhat helpless in this process with no 'active', tangible action I could take from the comfort of my home. People living with dementia have historically been underrepresented and excluded from research (Dewing, 2002), most likely due to the challenges that participants with cognitive impairments pose to researchers, and the assumptions made about people living with dementia's abilities to contribute meaningfully to research (Lloyd, et al., 2006). However, the National Institute for Health Research (NIHR) promotes the involvement of service-users in research which directly relates to the health and social care they receive in public provision (NIHR, 2021). As clinical psychologists we are taught about the importance of person-centred care, service-user empowerment, and stakeholder involvement in research, it was therefore of paramount importance to me that we included people living with dementia in the study, not only in accessing the treatment, but in helping to shape the developing vCST protocol and in directly contributing to the outcome measures data, rather than opting for informant-based measures. I also recognised that my personal skills and experience in working with adults with cognitive impairments and communication difficulties, placed me at an advantage in promoting the inclusion of people living with dementia in research.

In the absence of traditional in-person recruitment channels, such as poster/newsletter distribution, face-to-face third-sector and charity liaison, and attendance at service-user groups, alternative recruitment sources were required. I had to flexibly adapt the recruitment approach part-way through the project but also consider the impact this might have on the sampling pool and interpretation of results during the analysis and write-up. In response to slow uptake, we set up additional recruitment via a large online dementia research advertising platform. This had the benefit of attracting recruits who were already keenly, proactively seeking to take part in research. However, it also inadvertently privileged the recruitment of a sub-set of

the population who had pre-existing skills and confidence in using technology to access internet-based resources. It was hoped that balancing this with the clinical service-cohort in Ireland would allow for a more representative sample overall.

Some participants who I met via video-call for information-giving were initially unsure about their stance on participation in an online intervention, often fearful of the technical aspects or hoping to wait for the provision of face-to-face groups to return. Listening, offering an empathic response whilst concurrently providing reassurance, and clear information were all key skills in rapport building which I believe helped build confidence in potential recruits. This was often enough for them to take a leap of faith in the project without feeling overwhelmed by it. Overall, I was struck by participants' willingness to take part, not so much for the benefits to themselves but more to contribute something which they judged to benefit others. Many participants communicated to me a willingness to feel 'useful', to contribute to science in the 'fight against this horrible disease [dementia]', and to play an active role within society which they felt they had lost since diagnosis. Many also asked me to share the results of the study with them on publication and offered their assistance with any further research opportunities I might link them with. Participants' willingness to take part helped me to feel confident that what we were doing was meaningful and worthwhile, and promoted my personal motivation for the work even at times when the research felt challenging.

Participants' expressions as outlined above, are consistent with research that suggests that people living with dementia *do want* to take part in research where they have historically been excluded (Abbato, 2015; de Boer, et. al., 2007), and that infantilising notions of 'protecting' people living with dementia from research on ethical grounds may in fact be detrimental (Hellström, et. al. 2007). There are potential wellbeing and self-esteem benefits for people living with dementia in taking part in research. Literature suggests that people living with dementia who have taken part in

research have voiced surprise that anyone should take an interest them (Keady & Gilliard, 1999), and have expressed feelings of value, worth (Barnett, 2000), and being taken seriously as a 'capable person' (Dewing, 2002). Hence, participation in research itself contributes to people living with dementias' sense of self-worth and positive self-concept. It has been proposed that one possible mechanism of change underpinning CST, is as a result of the intervention's core ethos and style which promotes positive self-evaluation and de-stigmatisation in people living with dementia (Spector et. al. 2003). The programme's key principles promote participation, inclusivity, and respect. The research component of this study may therefore unintentionally form a confound variable on measures of wellbeing and cognition. This, however would be consistent across studies involving the active participation in CST and thereby still allows for reasonable comparisons to be made across the CST-literature.

Personal perspective: Bracketing

Within qualitative research and phenomenological inquiry, efforts should be made to minimise the impact of the researchers' pre-existing knowledge, beliefs and assumptions in order to optimally attain valid analyses and conclusions from participant accounts (Chan et. al., 2013). 'Bracketing' is an exercise which involves the researcher reflexively identifying and putting aside personal experiences, views, and preconceptions which could influence the data interpretation (Fischer, 2009). It is however naturally acknowledged that pre-understandings can never be *fully* 'bracketed' or eliminated from the research process (Koch, 1995). However, bracketing is a technique which as part of best-practice should be applied throughout the research process, from the initial study conception through to dissemination, in order to minimise 'as much as possible' the influence of such factors.

It is with regret, that I did not actively engage in a bracketing exercise at the study conception phase of this research project and hence it is important to concede that my background, preconceptions, and personal views may have appreciably influenced the formation of this study. Without wanting to justify this lack of adherence to best-practice principles, I wonder in hindsight whether the unique COVID-19 context, and a rapid reactive response to the emerging situation inadvertently contributed to my neglecting this vital part of the early research process.

I began my mindful engagement with reflexivity and bracketing during the qualitative semi-structured interview proforma development. At this point I became increasingly confronted by the prospect that my phrasing of questions would influence data collection. From this point, and through data analysis and interpretation I aimed therefore to examine my attitudes and potential influence on meanings drawn from the data. It is by outlining my background, interests, and personal assumptions here that I hope to make explicit *what* was self-consciously attempted in bracketing throughout the data analysis.

As previously outlined above, I came to this project with a sincere optimism about the potential of vCST to meet an acute need for people living with dementia during the COVID-19 pandemic. The unique pandemic context, the wartime 'we can do it' attitude, and media accounts of increased isolation amongst older adults, fostered an inherent vested interest within me in wanting the intervention to be effective or useful to people living with dementia and their carers. I attempted to keep this bias in mind as much as possible, specifically during the coding and thematic analysis phase. I repeatedly asked myself to question the origin of my interpretations of the data and attempted to code at a semantic-level based on the *surface* meaning of participants' expressions.

My preconceptions about technological access and skills in older adults initially made me question whether this study would be appropriate at all for this population. My

background within a working-class family in which computers and the internet were very slowly introduced to the home environment, and where my grandparents never learnt to use the internet, I believe influenced my assumptions about the older adult demographic and their willingness to engage with technology. I initially came into the project worried about the amount of extra support participants might need in order to set-up the technology and a concern about how much additional labour and time this might require from a researcher perspective. I was, however, curious to learn how my assumed-barriers might impact the uptake of the intervention and hence became interested in the facilitators and barriers of access to vCST which were incorporated as key research questions within the project design. I was pleasantly surprised to discover from the analysis that the majority of participants had very few technological issues and required minimal support. Even at times when participants were themselves anxious about technology or pre-empted challenges, generally they reported experiencing the issues as minor and acceptable.

Early on in recruitment I was also aware of the visible age difference between myself and participants. As a younger adult in my 30s I had preconceptions about how my involvement might be misinterpreted by older adults. My assumption that older adults may prefer 'traditional' forms of intervention predisposed me to assume that they might judge me negatively for imposing upon them a digitalisation of traditional healthcare. My worry was that this would be misjudged as an attempt to cost-effectively replace in-person care, a 'dehumanisation' of healthcare which would ultimately eliminate traditional face-to-face provision. I noticed during analysis that part of my assumption was supported by the data, in that 100% of participants reported preferring to opt for traditional in-person CST over an online equivalent. However, generally participants also acknowledged the wide-reaching potential and benefits of an online provision in conjunction with traditional forms of care. They did not appear to consider research into vCST as contrary or harmful to traditional forms

of care, but instead as a supplementary provision which could enhance patient choice.

The absence of explicit bracketing processes amongst the wider research team may be a limitation of the study methodology. For instance, it would have been useful for the independent researchers who conducted the feedback interviews with participants to have undergone their own individual bracketing exercise prior to commencing interviews. On transcription of the interviews, I became aware that despite my semi-structured interview protocol, some degree of influence from the interviewers is inevitable. On-the-spot judgements about 'where to take' the interview may have impacted on what was and was not expressed by participants. This was despite efforts to minimise the instances of closed or leading questions in the interview protocol and debriefing the interviewers on best-practice principles. Additionally, the interviewers' conscious avoidance of 'leading the interview' may also have adversely affected the depth and complexity of data collected. Fischer (2009) highlights the tendency for some interviewers to prioritise a 'putting aside' of their own assumptions, then unintentionally failing to encourage participant elaboration. In some instances, this was a source of frustration for me when I was transcribing, as I became aware of interesting themes emerging from the data which were quickly dismissed by the interviewers without expansion or follow-up enquiry. A key example is in the 'outlier' of one participant who stated that he 'did not find the sessions cognitive stimulating'. Follow-up enquiry here, may have enabled a deeper understanding of this participants' experience. I believe also that an early reflexive bracketing exercise with the interviewers may have positively affected their confidence or willingness to proceed with richer follow-up enquiry.

Conclusion

The COVID-19 pandemic impacted this research in a variety of ways. In practical terms it affected my ability to conduct the work in the traditional ways, for instance in meeting for face-to-face supervision, participant recruitment, and in obtaining participant informed consent. However, it also shaped the fundamental research questions being asked. It initiated an opportunity to involve people living with dementia directly in my work and inspired the adaptation of CST in a way which had not yet been explored. The COVID-19 pandemic amongst all its devastation, has accelerated innovation across many domains of life and I believe that this research adds a meaningful contribution to the CST literature. I feel proud that this project sets the foundation for future research into online CST and in its future application to clinical practice.

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Appendices

Appendix 1: Literature review search scripts

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to March 26, 2020>
Search Strategy:

-
- 1 exp Alzheimer Disease/ (91854)
 - 2 exp Dementia/ (162442)
 - 3 exp Dementia, Vascular/ (6553)
 - 4 dement*.tw. (110158)
 - 5 alzhem*.tw. (141564)
 - 6 vascular.tw. (561865)
 - 7 1 or 2 or 3 or 4 or 5 or 6 (797722)
 - 8 exp Caregivers/ (35469)
 - 9 (carer* or caregiver* or care-giver*).tw. (76367)
 - 10 8 or 9 (85777)
 - 11 (family or informal or in-formal).tw. (789772)
 - 12 10 and 11 (26723)
 - 13 exp Health Education/ (240489)
 - 14 exp Patient Education as Topic/ (84523)
 - 15 (group* or train* or education* or learn* or teach* or psychoeducation).tw. (4691518)
 - 16 13 or 14 or 15 (4823233)
 - 17 exp Behavioral Symptoms/ (361539)
 - 18 exp Depression/ (115922)
 - 19 exp Anxiety/ (83072)
 - 20 (behavio?r* problem* or psycholog* symptom* or psychiatric symptom* or agitat* or aggression or depress* or anxiet* or challeng* behavio?r*).tw. (608214)
 - 21 17 or 18 or 19 or 20 (839811)
 - 22 7 and 12 and 16 and 21 (875)
 - 23 limit 22 to (english language and yr="2000 -Current") (728)
- *****

Database: Embase <1980 to 2020 Week 13>
Search Strategy:

-
- 1 exp Alzheimer Disease/ (196399)
 - 2 exp Dementia/ (350313)
 - 3 exp Dementia, Vascular/ (12109)
 - 4 dement*.tw. (159573)
 - 5 alzhem*.tw. (195538)
 - 6 vascular.tw. (742690)
 - 7 1 or 2 or 3 or 4 or 5 or 6 (1122946)
 - 8 exp Caregivers/ (78576)
 - 9 (carer* or caregiver* or care-giver*).tw. (108947)
 - 10 8 or 9 (124418)
 - 11 (family or informal or in-formal).tw. (976112)
 - 12 10 and 11 (36284)
 - 13 exp Health Education/ (308768)
 - 14 exp Patient Education as Topic/ (110086)
 - 15 (group* or train* or education* or learn* or teach* or psychoeducation).tw. (6193380)
 - 16 13 or 14 or 15 (6349332)
 - 17 exp Behavioral Symptoms/ (3829210)
 - 18 exp Depression/ (453387)
 - 19 exp Anxiety/ (196885)
 - 20 (behavio?r* problem* or psycholog* symptom* or psychiatric symptom* or agitat* or aggression or depress* or anxiet* or challeng* behavio?r*).tw. (781072)
 - 21 17 or 18 or 19 or 20 (4277652)
 - 22 7 and 12 and 16 and 21 (2433)
 - 23 limit 22 to (english language and yr="2000 -Current") (2127)
- *****

Database: APA PsycInfo <1806 to March Week 4 2020>
Search Strategy:

-
- 1 exp Alzheimer Disease/ (45914)
 - 2 exp Dementia/ (75763)
 - 3 exp Dementia, Vascular/ (0)

4 dement*.tw. (67393)
 5 alzhem*.tw. (60825)
 6 vascular.tw. (18651)
 7 1 or 2 or 3 or 4 or 5 or 6 (114632)
 8 exp Caregivers/ (27974)
 9 (carer* or caregiver* or care-giver*).tw. (58082)
 10 8 or 9 (61742)
 11 (family or informal or in-formal).tw. (333062)
 12 10 and 11 (23863)
 13 exp Health Education/ (18298)
 14 exp Patient Education as Topic/ (0)
 15 (group* or train* or education* or learn* or teach* or psychoeducation).tw. (1783373)
 16 13 or 14 or 15 (1785480)
 17 exp Behavioral Symptoms/ (0)
 18 exp Depression/ (25405)
 19 exp Anxiety/ (70171)
 20 (behavio?r* problem* or psycholog* symptom* or psychiatric symptom* or agitat* or aggression
 or depress* or anxiet* or challeng* behavio?r*).tw. (508373)
 21 17 or 18 or 19 or 20 (512440)
 22 7 and 12 and 16 and 21 (637)
 23 limit 22 to (english language and yr="2000 -Current") (493)

EBSCO CINALH Search	
S16	S14 AND S15
S15	Limiters - Publication Year: 2000-2020; English Language
S14	S5 AND S8 AND S9 AND S13
S13	S10 OR S11 OR S12
S12	TI (behavio#r* problem* or psycholog* symptom* or psychiatric symptom* or agitat* or aggression or depress* or anxiet* or challeng* behavio#r*) OR AB (behavio#r* problem* or psycholog* symptom* or psychiatric symptom* or agitat* or aggression or depress* or anxiet* or challeng* behavio#r*)
S11	(MM "Depression+")
S10	(MM "Behavioral Symptoms+")
S9	TI (group* or train* or education* or learn* or teach* or psychoeducation) OR AB (group* or train* or education* or learn* or teach* or psychoeducation)
S8	S6 AND S7
S7	TI (family or informal or non-professional) OR AB (family or informal or non-professional)
S6	TI (carer or caregiver) OR AB (carer or caregiver)
S5	S1 OR S2 OR S3 OR S4
S4	TI vascular dementia OR AB vascular dementia
S3	TI alzhem* OR AB alzhem*
S2	TI dement* OR AB dement*
S1	(MM "Alzheimer's Disease")

Appendix 2: Ethical approval confirmation letter

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

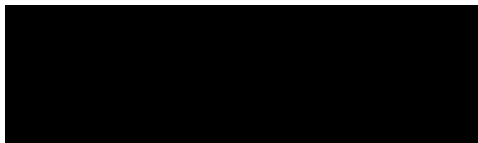
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, 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 3: 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 4: People living with dementia information sheet

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 regrettably 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

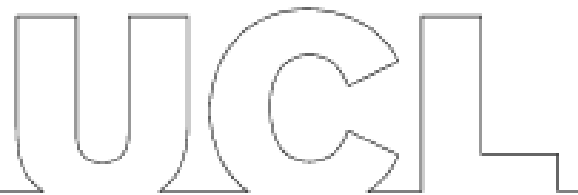
Address: Clinical, Education & Health Psychology, Division of Psychology & Language Sciences, 1-19 Torrington Place, London, WC1E 7HB

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.

Appendix 5: Carer agreement



CARER'S/SUPPORTER'S AGREEMENT FOR VIRTUAL CST GROUP

Cognitive stimulation therapy (CST) is a brief treatment for people with dementia. The groups are usually run outside of the person's home, at local daycentres or memory services. We want to work together to find the best way of facilitating these groups over the internet, so that people can stay in their own homes if they want to.

We know that homes are often busy places, and that the environment will be quite different to the one we usually run these groups in. We would like to ask for your help to assist the person you care for/support in participating in the group.

What we will do:

We will aim to create a safe online environment where people feel comfortable attending a group. The group will consist of the same members each week so that participants will get know one another. The groups will be facilitated by two trained facilitators who are clinical psychologists in training.

What we would like to ask you (the carer/supporter) to do:

Below is a list of things you can do to help ensure the smooth running of the group:

1	A quiet space: Try to find a quiet space for the group participant to access the group uninterrupted for approximately 1 hour; preferably in a room alone.
2	Participants should attend alone as, much as possible: Your support, as carer/supporter, in setting-up the meeting is greatly appreciated, however usually CST groups run without carers/supporters attending. Please do not attend the group yourself. Make sure that the person you care for/support knows where you will be (e.g. in a nearby room), if they need you for any reason.

3	<p>Get connected early: Please support the person you care for/support, if they need it, to get set up on the computer and enter the Zoom meeting. Get connected 10-15minutes before the session start time.</p>
4	<p>Optimise your internet speed: To avoid internet connectivity issues, try to make sure that no one else in the house is using the internet at the same time as the group.</p>
5	<p>Ensure minimal distractions: Make sure there are no distracting noises or sights when the group is happening, e.g. television, radio etc.</p>
6	<p>Check that the participant can hear and be heard: Make sure that the person you care for/support is sitting close enough to hear everyone taking part. Increase the volume on your device if needed. Support the person you care for/support to bring their glasses, hearing aid etc. to the meeting, if they need it.</p>
7	<p>Put your device on something stable: Put your laptop, computer, tablet or iPad on something stable rather than holding it in your hand. For example, on a table or desk so that the participant is at the centre of the screen. You may need to adjust the camera angle slightly.</p>
8	<p>Take your time: 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.</p>
9	<p>Have your phone nearby: Please keep your phone near you so that if we need your assistance with anything, we can call you during the session.</p>

Frequently Asked Questions:

What if the person I care for/support will struggle to attend without my support? When we meet with you and the person you care for/support initially, we will ask some questions to check whether we feel they are suitable for our groups or not. Although we want as many people to benefit from virtual Cognitive Stimulation Therapy (CST) as possible, we recognise that it might not be right for everyone because of communication, sensory, memory or concentration difficulties. However, if we feel that the person you care for/support *would* benefit from the group, you can be assured that the facilitators are trained practitioners who have specialist skills and experience in engaging with people with dementia. If, for any reason, we feel that the person you care for/support needs some extra support during the group, or that they are becoming distressed in any way we will call you straight away - this is why we ask that you keep your phone nearby.

In our experience, and in line with the research evidence; people get more from the groups when they attend alone. This is because with dementia symptomology, people often lose confidence and look to carers/supporters to answer questions for them, or to check if they've answered 'correctly'.

CST is all about using parts of the brain that do not get exercised day to day. When we exercise these parts of the brain, we create new neural connections which stimulate brain growth and brain maintenance. As part of the group we might ask the person you care for/support to talk about topics they have not thought about in a long time. CST aims to do this in a supportive way which enables the person to feel successful, not in a way that makes it too hard. It is not about getting the 'right answers', but more about the process of encouraging thought, communication, word-finding and using the 'imagination' when memory is not accessible.

What should I do when the person I care for/support is attending the group? This may be a rare opportunity, especially in the current Covid-19 situation, for you to have some time alone. Although we would ask that you are available nearby if needed, we would also encourage you to do something for yourself during this time.

If you consent to the above please email cerne.felstead.18@ucl.ac.uk or luke.perkins.15@ucl.ac.uk with the following statement:

"We / I consent to:

- Trying to support the groups as outlined above.*
- The researchers holding my personal information (e.g. name and telephone number) in case they need to call me.*
- The sessions being video-recorded as outlined in the research information sheet."*

Acknowledgments:

This document is an edited version of the Memory Matters South West CIC 'Online Workshop Agreement' 2020 and we thank them for their contribution.

Appendix 6: Consent form

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.	<p>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.</p> <p>I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in:</p> <ul style="list-style-type: none"> - <i>an appointment to complete questionnaires prior to my attendance at the online CST group sessions.</i> - <i>14 sessions of an online CST group intervention, if allocated to the 'zoom-CST' group.</i> - <i>an appointment to complete questionnaires after attendance at the online CST group sessions.</i> - <i>an appointment at the end, where I will be asked some questions about my experience of participating in the group.</i>
2.	<p>I understand that my personal information (<i>name, age, gender, ethnicity, address, telephone number, email address, dementia type, questionnaire answers and session recordings</i>) will be used <i>only</i> for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing.</p>

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 7: Sample PowerPoint session guide



Session 1 – Physical Games

 November 2020


1



Greetings and Introductions (5 mins)

- Go around the group and ask group members to introduce their names, their current location and one fact about themselves. Examples include:
 - Their last/favourite job
 - Where they grew up
 - Favourite hobby
 - Favourite TV programme/movie
 - Something interesting/unusual that happened in their life


2



Group Name

- Vote on the group name. Ask the group to come up with 2 or 3 names and then ask to vote


3



Group Song (5 mins)

- Vote on the group song. Ask the group to come up with 2 or 3 songs and then ask to vote on which one they would like to sing at each session.
- Once voted, find song on youtube to play in the session. Agree that the facilitator will email out the song lyrics for next session so they can have a copy to print out.


4



Orientation (5 mins)

- Discuss the following with the group:
 - Day
 - Date
 - Month
 - Year
 - Season
 - Weather
 - Time
 - Their location


5



Current Events (10-15 mins)

- Show the group a short clip of a recent news story and ask them to discuss. Example questions include:
 - What are your thoughts about this news story?
 - Do you agree/disagree with what was discussed?
 - How does it compare to how things were when you were younger?
 - Has anything similar to this happened before?
 - How could things be different/change?


6



Choose Main Activity (15-20 minutes)

- Ask the group to choose which activity they would prefer to do out of the following 3 options:
 - Pretend to throw a ball at each other (say the name of the person you want to pretend to throw the ball too) and say something about yourself (like the introduction task) OR
 - Ask each person to pick a colour square and answer a question about health, exercise and sports (see next page) OR
 - Watch a chair exercise video and follow along as a group - <https://www.youtube.com/watch?v=atv8eJroGLk> (22 mins) or <https://www.youtube.com/watch?v=YGRIeSp5abc> (15-20 mins)


7



Colour/Questions Activity

- Use share screen to show the colour cards on Handout 1. Ask each group member to pick a colour and ask the corresponding question to each group member. Encourage discussion of the answers between group members.

8



Wrap Up (5 mins)

- A note of thanks to group members for participating
- Play group song
- Reminder of next session (Sounds)
 - Ask whether participants would like to bring an instrument or favorite CD/Tape/Record to show and discuss next session
- Goodbyes

9

Appendix 8: Qualitative interview schedule

Research aims:

- 1) **Is the intervention acceptable in this online format?**
- 2) **What are the barriers/facilitators to engagement?**

Remember to record the interview session on Zoom and inform the participant. You do not need to take notes, as the recording is sufficient for data collection.

To the facilitator:

Aim to conduct the interview in approx. 30minutes. Please cover all four 'main' questions in **red bold** below. The prompts are available to promote further discussion and explore topics in more depth. Whilst you should aim to cover as many of the questions and prompts as possible, the most important prompts are highlighted in **blue** to help you to prioritise.

Some quick thoughts and tips on interviewing:

Qualitative interviewing is based on a guided conversation with an emphasis on asking questions and listening to respondents' answers (Rubin & Rubin, 1995). The purpose is to derive interpretations not facts (Warren, 2011).

- Cultivate interest in what the participant is saying e.g. keep quiet, use counselling skills to demonstrate active listening.
- Be empathetic and non-judgemental.
- Allow the interviewee to use their own words.
- Avoid asking 'why' questions instead say "tell me more about X".

Interview schedule:

"Thank you for agreeing to meet with me to talk about your experience of the online Cognitive Stimulation (CST) groups. The interview should take around half an hour or so. There are no right or wrong answers to these questions, I am just interested in how you found the groups. If, for any reason you would rather not answer a question that is absolutely fine and do let me know. I want you to feel as comfortable as possible, so please do let me know if you would like a break or if you want to stop the interview at any point. The interview will be recorded to help us with our research and we will later type up the conversation for analysis. What you say will be anonymised however, and all identifiable information will be removed. Do you have any questions before we begin?"

Interview questions:

- 1) General experience of the groups: **What was the group like for you?**

Prompts:

- *Did you enjoy the sessions? Why/why not? How, tell me more?*
- *Did you interact with others during the sessions? Make friends?*
- *Feel comfortable with others? Did you feel you could be yourself in the group?*
- *Tell me about the activities you did in the group. How did you find them?*

A list of activities as reminder (e.g. *tell me about when you made a paper aeroplane*):

Discussions about current news; singing; sharing objects you brought; naming childhood toys; guessing sounds; planning and costing a food shop; baking at home; then/now landscapes; completing phrases; making a paper aeroplane; using money; playing higher or lower with cards; doing a quiz.

- *Did you feel involved/included?*
- *Did you feel respected? Did you feel like your opinion mattered in the group?*

- *Did you feel mentally stimulated? e.g. did you feel engaged, did you think about new ideas compared to other groups/conversations you have day to day?*
- *Were there any positive changes or benefits you got from taking part? e.g. did it help with your memory skills, or general wellbeing?*
- *Were there any negative changes/aspects to taking part?*

2) Specific to online CST: ***What did you think about attending the groups online, through your computer, rather than face-to-face in real life?***

Prompts re. Positives:

- *Was it similar or different to attending groups or meetings face to face?*
- *What made you decide to take part initially?*
- *Was there anything helpful about doing it online?*
- *Were there any particular aspects you thought worked well online? e.g. using the whiteboard, or showing pictures/videos with shared screen?*

Prompts re. Negatives:

- *Was there anything unhelpful about doing it online?*
- *How did you feel being on camera?*
- *Did you experience any technical issues? What was the impact?*
- *Did you have any concerns about privacy or internet safety?*
- *Was there anything you think was lost by not being face-to-face?*
- *Would you choose to do something similar online again?*

3) Barriers and Facilitators: ***Was there anything that made it difficult to attend the groups online? Was there anything that helped you to attend?***

Prompts:

- *Did you have any technical difficulties setting up to get to the groups?*
- *Did you get any help to attend? e.g from carer / facilitator?*
- *Did the facilitators do anything helpful that made it easier for you to access this group online? (e.g. provide a 'how to use Zoom' guide, sending email reminders)*
- *Would you say it was easier/harder to attend online than in real life?*

4) Open question: ***Is there anything else that we haven't covered that you wanted to add about your experience of online CST?***

End:

Explain that this marks the end of the participants' active involvement with the research project. "How was the interview for you?". Wish the participant the best for the future and thank them greatly for their participation.

After the interview:

Interviewer's subjective notes:

- Was there anything of interest you believe remained 'unsaid'?
- Was there anything of note in the participants' body language?
- Is there anything else you would like to add

Appendix 9: Example of how quotes were initially coded and clustered into themes

Sample Transcript	Codes (in order of prevalence)	Sub-Theme	Sub-Theme	Main Theme
<i>"We didn't have any difficulties logging in, no difficulties on that at all, we logged in and it was fine."</i>	No technical issues	The Technology	Positives	BEING ONLINE
Carer: <i>"When you had visual stimulus that you were able to specifically respond to, like being shown maps or whatever you know, that seemed to work better than the general discussions didn't it?"</i>	Zoom visuals and functions worked			
<i>"I was quick on the uptake, I thought it was going to be very difficult and then I realised it wasn't."</i>	Able to learn the tech skills quickly			
<i>"...It can be easier doing it on 'Zoom', than having to go somewhere, unless it's near... [it] can be quite a busy road. So that's the positive thing about doing it on Zoom, you haven't got that to worry about...or if the weather's bad or anything like that."</i>	Not having to travel	Benefits of online compared to F2F.		
<i>"Whereas doing it online you could have anybody from anywhere, you don't even need to keep it in Britain, it could be... talking to an Australian."</i>	Online not limited to location			
<i>"I mean yeah I suppose, it is nice to be in your own home too... I suppose that would be nice, if everything were back to normal it might be nice to say "oh great I don't have to go anywhere today".</i>	Comforts of home			
<i>"...but it held mum's interest, I didn't think that she would actually sit here for an hour, but it did hold her interest, which was to me was a surprise actually."</i>	Online kept attention			
<i>"Because ... people have mobility problems or some people aren't able to use public transport or can't drive, you know, they can't get there."</i>	Good for people w. mobility issues			
<i>"You know if I had have been having to travel 10 or 15miles somewhere and I was feeling under the weather, you know I might have 'ummed and ahed' and not gone, but because it was online and I was warm and comfortable at home, even though I didn't feel particularly wonderful, I could still attend. So, in that respect, you know in that respect it's great."</i>	Good if feeling unwell			
<i>"...mum was on a waiting list now for two years, so if it meant that it could be compensated or done together with, so that maybe some people go on a Monday somewhere, and then maybe they have something on a Thursday on the computer... you know what I mean, so maybe they could be combined? Because as I understand it, the waiting lists are going to be bigger than ever now."</i>	Shorter WL times			
<i>"... doing it online, we're able to continue with meeting the other people as well, which might not have happened. So that's a real positive isn't it."</i>	Able to keep in touch afterwards	The Technology	Negatives	
<i>"I have problems with the computer yes, if I have problems I shout [husband] and bless him he comes."</i>	Reliant on others for tech skills			
<i>"I mean again so much of it was down to fortune because we happened to have a pretty good broadband."</i>	Needing a good internet connection			
people living with dementia: <i>"Yes, you know you couldn't see them, so you lose the connection."</i> Interviewer: <i>"ah I see, were you only seeing one participant at a time?"</i> Carer: <i>"No 2 or 3, you could see [facilitator] and you could see another lady who was an observer wasn't she?"</i> Interviewer: <i>"ahh I see, but you couldn't see..."</i> Carer: <i>"...all the other people."</i>	Not able to see everyone at once			
<i>"Some refinement, ... you know when the facilitator shares their screen?... I think there's some work necessary for that to become more seamless... I'm thinking of when I was teaching and I used an interactive whiteboard it took me a long time to get used to making things seamless so that students didn't have to wait precious seconds and lose their attention span whilst I was fiddling around."</i>	Visuals need refinement			
<i>"Because I was talking and then you came along, and we both ended speaking at the same time. If you were here in my house that would not happen. So, it makes it more strange and difficult."</i>	Communication harder online	Communication Challenges		
<i>"So, when you're in a real-life situation you can see, you can read people and you know by their movements and their expressions when they want to speak. And that's quite difficult to do that online."</i>	Body language hard			

Appendix 10: Overview of the contributions in this joint thesis project

Cerne Felstead (CF) and Luke Perkins (LP) were jointly and individually responsible for different aspects of this project. Both individual theses were written entirely independently. Additionally, other researchers were involved during this work and their contributions are summarised below.

Task	Contributor
Literature Review search and analysis	CF
Literature Review Quality Checklist	LP and CF
Design of empirical study	CF and LP, 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	CF and LP
Design of intervention	CF and LP LP took a lead on facilitating focus groups and designing vCST session plans and resources. CF took a lead on designing the focus group questions, the analysis of focus group data and development of vCST guidelines with assistance of Carey Fagan (Assistant Psychologist)
Recruitment	CF recruited 9 participants LP recruited 13 participants
Delivery of vCST	LP, CF and Claire Rooney (Occupational Therapist) delivered 14 sessions of vCST to 4 participants each.
Adaptation of measures for online facilitation and creation of assessment packs	CF
Assessments	CF and LP jointly responsible, assisted by Nur Diyanah Abdul Wahab (Trainee Clinical Psychologist) and Wing Gi Leung (Trainee Clinical Psychologist)
Development of semi-structured feedback interview protocol and facilitation of interviews.	Lead by CF. Assisted by LP, Nur Diyanah Abdul Wahab (Trainee Clinical Psychologist) and Wing Gi Leung (Trainee Clinical Psychologist)
Data Entry and storage	CF and LP

Data Analysis	CF completed analysis on cognitive measures and qualitative feedback interviews. LP completed analysis of mood and quality of life measures.
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