“Anything that’s going to assist in the road we’re on is worth it” - Exploring the experiences of delivering individual cognitive stimulation therapy (iCST) for informal dementia caregivers: A thematic analysis.

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Title of degree programme	**Professional Doctorate in Clinical Psychology**
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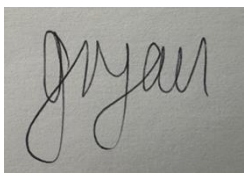
Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed:  Date: 12.08.2024

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Contents

Thesis Abstract

The number of people living with dementia in the UK is expected to continue to rise, as the population continues to age. Dementia has physical, psychological, social, and economic impacts, affecting not only those diagnosed with the disease, but also those who care for them. This thesis aims to gain insight into means of supporting both people living with dementia, and their informal caregivers, with the hope of adding to the evidence base considering how best to meet the needs of this population.

Paper one is a literature review considering if acceptance and commitment therapy (ACT) helps informal dementia caregivers with their wellbeing, namely levels of depression, anxiety, and burden. Ten papers were identified, critically appraised and synthesised. The included articles highlighted that ACT led to reduced levels of depression, anxiety, and burden, with promising results regarding use of virtual delivery and longevity of positive effects. However, the included papers were limited by methodological constraints, primarily use of small, volunteer samples and single-arm designs, making it hard to draw generalisable conclusions. The research area remains small and more large-scale research, making use of more diverse samples, is recommended to strengthen the current evidence base.

Paper two is an empirical research paper which explores informal dementia caregiver's experiences of attempting to implement individual cognitive stimulation therapy (iCST) following their engagement in an iCST 'train the carer' group. Seven participants engaged in a semi-structured interview, which were analysed using reflexive thematic analysis. Three overarching themes were identified: *formal versus informal intervention, perceived benefits of the intervention, and perceived barriers for caregivers.* This empirical study highlights clear benefits of iCST for people living with dementia, informal caregivers,

and the caregiving dyad together. However, there were barriers to implementation of iCST namely the formality and demands of the intervention, as well as competing demands for caregivers, which led to low implementation. Future research exploring how to make implementation of iCST more feasible for dyads, utilising larger and more diverse samples is recommended.

The final paper in this thesis is an executive summary which provides an overview of the completed empirical paper. It has been written in a style which is accessible and has been reviewed by the research participants to ensure that it accurately captures their views.

Paper One: Literature Review

Does acceptance and commitment therapy (ACT) help informal dementia carers with their psychological wellbeing, namely burden, anxiety, and depression?

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(Excluding Title Page, References and Appendices)

This literature review has been written in accordance with author guidelines for Ageing and Mental Health Journal. The author guidelines are in Appendix A.

Abstract

Purpose: Research indicates that dementia caregivers are at risk of poorer psychological wellbeing, hence the importance of providing caregivers with timely, effective interventions. Recently, utilisation of acceptance and commitment therapy (ACT), an emerging evidence-based psychological therapy, has been explored for dementia caregivers. This review aimed to identify and appraise existing literature to understand if ACT helps informal dementia caregivers with their wellbeing.

Methods: A systematic search of six databases for papers published up to February 2023 was conducted. A total of 10 studies were identified, critically reviewed, and synthesised.

Results: The included articles illustrated that ACT helps informal caregiver wellbeing, with reduced levels of depression, anxiety and burden noted. Studies appear to indicate that reductions are clinically significant and highlight promising results with regards to longevity of improvements.

Conclusions: ACT appears a promising psychological intervention for dementia caregivers. However, there were significant methodological limitations across the included studies, as well as review limitations, which impact on the ability to draw firm conclusions. Ultimately, more large-scale studies are needed to strengthen the evidence base.

Keywords: Dementia, informal caregivers, acceptance and commitment therapy, ACT, wellbeing

Introduction

In the United Kingdom, there are currently around 900,000 people living with dementia (PWLD) whilst the current estimated cost to support them is at 34.7 billion (attributed to healthcare, social care, and unpaid care). Both figures are expected to rise as the population continues to age (Wittenberg et al, 2019). Currently, up to 94% of people with dementia are cared for by informal caregivers (Prince et al, 2015); taken to mean someone who provides unpaid help to a friend or family member needing support (Brodaty & Donkin, 2009). Unfortunately, informal caregiver's own needs, as well as means to support them, are often overlooked in the research with research tending to focus on direct support for PWLD.

Caring for someone living with dementia impacts on the wellbeing of caregivers, with the potential to lead to physical, psychosocial, and financial stress (Lindeza et al, 2020). This may include cardiovascular problems, lower immunity, chronic conditions (Schulz et al, 1995), alongside potential social isolation; sacrificing carer's own hobbies and restricting time with loved ones, to provide care (Brodaty & Hadzi-Palovic, 1990). Financial stress may include provision of direct care, as well as loss of earnings due to reduced employment (Brodaty & Donkin, 2009). It is unsurprising, therefore, that informal dementia caregivers often experience reduced psychological wellbeing themselves. Systematic reviews demonstrate high rates of depression and anxiety (Cooper et al, 2007; Sallim et al, 2015), with prevalence rates of 31.2% and 32.1% respectively (Kaddour & Kishita, 2019).

Furthermore, reduced caregiver wellbeing has shown to impact on the person living with dementia, linked with increased behavioural and psychological symptoms including agitation and disinhibition (George et al, 2020). This suggests a bidirectional relationship in the caregiving dyad, whereby both parties' distress appears to increase in response to the

other. Further, caregivers with greater psychological distress are more likely to admit person living with dementia to residential care (Gaugler et al, 2009). This has implications not just for PLWD, but also financial implications for health and social care, especially as unpaid care accounts for 40% of dementia costs in the UK, saving the UK economy 13.9 billion per year (Wittenberg et al, 2019).

Given the personal, health and social costs of dementia caregiving, it is important that caregivers receive timely interventions to support and enhance their own wellbeing. Though there is no clear consensus on definition (Lindert et al, 2015), the research into caregiver wellbeing most commonly defines wellbeing utilising a loss-deficit model. In this model, caregiver wellbeing is understood in relation to moderating or diminishing levels of negative mental attributes including burden, depression and/or anxiety (Stansfeld et al, 2017). Presence of these 'negative' factors is indicative therefore of poorer wellbeing.

In terms of therapeutic interventions for caregivers, most have been based on cognitive behavioural therapy (CBT). CBT broadly includes training individuals to develop cognitive and behavioural skills which equip them to provide care to PLWD, and reduce caregiver's own distress (Kwon et al, 2017). CBT aims to reduce distress by challenging caregivers' unhelpful cognitions, such as 'I should set aside my interests and dedicate myself to care' (Marquez-Gonzalez et al, 2007), and change these into adaptive thoughts, alongside increasing pleasant activities and/or help seeking (Gallagher-Thompson & Coon, 2007).

There is a sizeable literature base demonstrating CBT leads to improved outcomes including reduced depression, anxiety, stress, as well as improved quality of life, perceived self-efficacy and improved caregiving skills, all with large effect sizes (Kwon et al, 2017).

CBT has been shown to be particularly effective for depression in dementia caregivers, whilst research has tended to focus less on anxiety as an outcome, highlighting a gap in the research (Li et al, 2013).

More recently, acceptance and commitment therapy (ACT) (Hayes, 2004), has been considered for dementia caregivers. Whereas CBT attempts to change unhelpful thoughts and emotions, acceptance (a key concept in ACT) has been defined as the tendency to remain in contact with one's thoughts and emotions, without altering them (Hayes, 2004). It is normalised for caregivers, to have negative thoughts and feelings towards the care recipient, given caregivers experience numerous stressors and are required to adapt to many adverse experiences. ACT aims to train caregivers in acceptance of or openness to experiencing these aversive emotions, to allow themselves to have and express them (Marquez-Gonzalez et al, 2010). Recent research has recognised the importance of acceptance skills in successfully adapting to the caregiver role (Losada et al, 2014).

However, many caregivers struggle to accept difficult internal events, and as such may feel guilt for having negative thoughts and emotions. Caregivers who experience such may be prone to avoiding the discomfort by engaging in 'experiential avoidance' which entails use of escape-avoidance coping strategies such as attempting to avoid or suppress difficult thoughts. Experiential avoidance has been linked to increased distress in dementia caregivers, acting as a significant predictor of caregiver anxiety, depression, and burden (Flaxman et al, 2011).

In contrast, psychological flexibility, focuses on connecting with the present moment rather than avoiding unwanted internal experiences (Wicksell et al, 2010). Psychological

flexibility, the target for ACT interventions, has been linked to improvements in anxiety (Bluett et al, 2014), depressive symptoms and wellbeing (Kohtala et al, 2015). This suggests ACT, which works to simultaneously increase psychological flexibility and reduce experiential avoidance may therefore be helpful for dementia caregivers (Hayes, 2004).

The goal of ACT is to enhance psychological flexibility through practice of six core skills—acceptance, cognitive defusion (stepping back from unhelpful thoughts and emotions), mindful awareness of the present moment, self-as-context (perspective taking), and finally: clarifying and acting on what is most important for caregivers so that they can move towards values-based living (Hayes et al, 2013). In the caregiver context, ACT aims to promote acceptance of aversive events relating to caregiving and increase the caregiver's commitment and action towards their values.

Rationale for literature review

ACT has been shown to be effective in improving wellbeing in a variety of populations including people with depression and anxiety (A-Tjak et al, 2015; Gloster et al, 2020), as well as caregivers of people living with other conditions (Han et al, 2020), including chronic pain (Weiss et al, 2019) and cancer (Burke et al, 2014).

Whilst the research relating to use of ACT with dementia caregivers is in its infancy, there has been a growth in research in recent years. The current literature review, therefore, focuses on understanding if ACT helps informal dementia carers with their psychological wellbeing. In line with the aforementioned definition, wellbeing will be understood in relation to mental health challenges (Stansfeld et al, 2017), with attention paid to depression, anxiety, and burden. The review will focus specifically on these mental health challenges, as

they are most considered in the literature. The review has the potential to provide valuable learning with regards to the evidence base considering psychological interventions and their role in supporting dementia caregivers.

Method

Search Strategy

A systematic search strategy was completed in February 2023. The databases searched were Google Scholar, Web of Science, PsycArticles, EBSCO Host, Scopus and Cochrane Library. Given the high volume of results yielded from Google Scholar, Haddaway and colleagues (2015) recommended only the first 200-300 results are examined in literature reviews. As such, only the first 200 results were reviewed. Completion of searches on databases detailed above aimed to minimise possibility that eligible papers were missed. Hand searches were also conducted to review reference lists and identify additional relevant articles.

Unpublished literature was searched using OpenGrey and Ethos to mitigate publication bias. Publication bias refers to the phenomenon, whereby studies reporting significant findings are more likely to be published than studies which report no significant findings (Fanelli, 2012). No additional studies were identified for inclusion in this way.

The following search terms were used, alongside Boolean operators: (Dementia Caregiver* OR Family Caregiver* OR Dementia Carer*) AND (Acceptance and Commitment Therapy* OR ACT* OR Acceptance-based Approaches). The databases were searched electronically, with no date limiter applied.

Paper Selection and Data Extraction

The initial search yielded 302 results. Eighty-two were recognised as duplicates and removed. Titles and abstracts were screened and, if deemed appropriate, the full text was retrieved and subjected to the inclusion and exclusion criteria. Ten studies were identified to be included within this review. An outline of the studies is provided in Table 1, with Figure 1 detailing the literature search process (Liberati et al., 2009).

Inclusion and Exclusion Criteria

To be included in the current literature review, studies were required to:

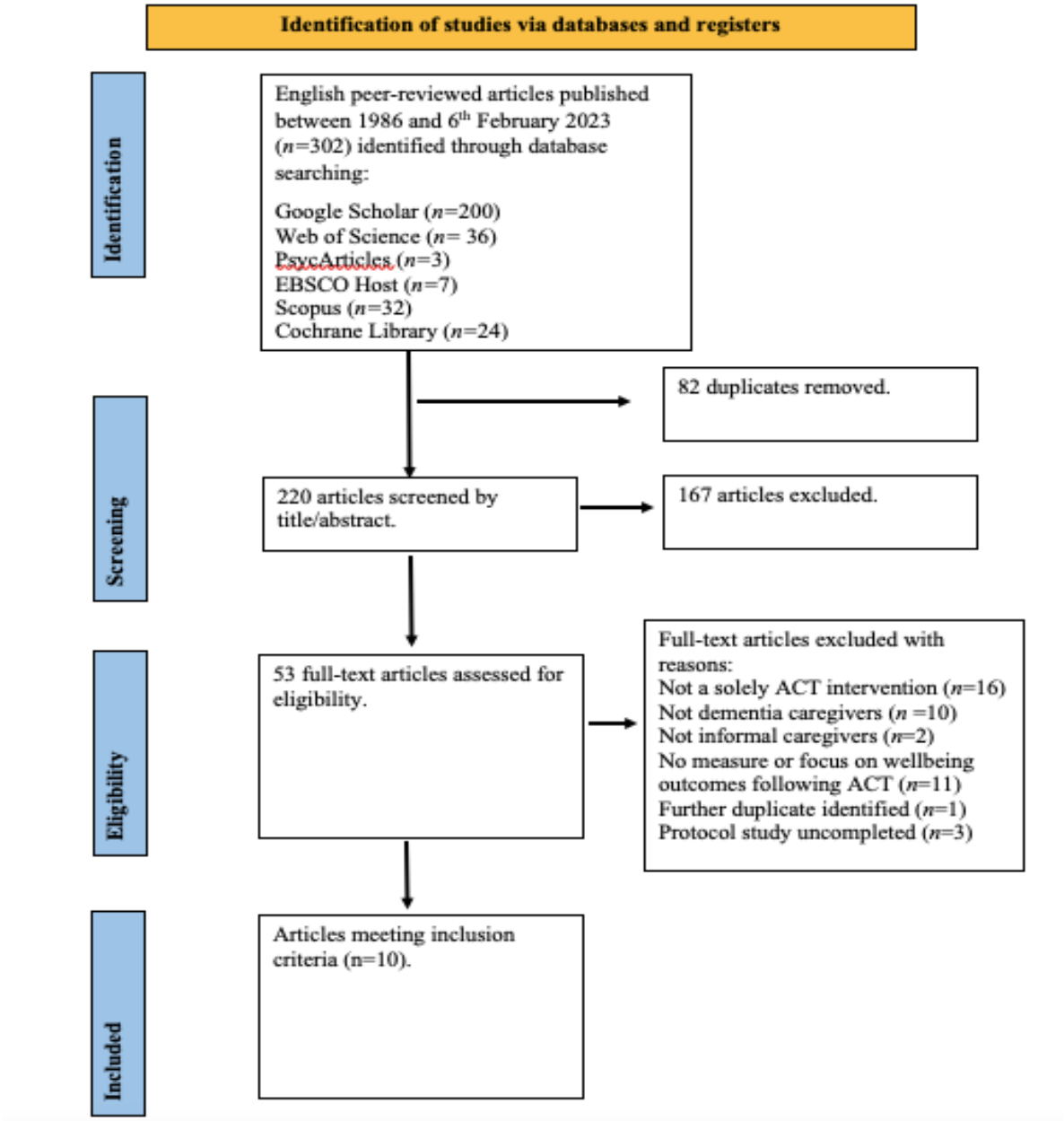
- Be published in a peer-reviewed journal
- Be published in English due to a lack of translation resources
- Specifically focus on acceptance and commitment therapy with informal caregivers of PLWD
- Report either a measure of, or discussion exploring concepts related to psychological wellbeing (namely anxiety, depression, and burden), following engagement in an ACT intervention.

Studies which met the following criteria were excluded:

- Studies which consider the effectiveness of ACT interventions from the perspective of professionals
- Studies which utilised other therapeutic models in conjunction with ACT as part of the intervention.

Figure 1.

Flow chart demonstrating literature review search strategy.



Critical Appraisal

The Downs & Black Checklist (1998) was utilised to evaluate the methodological quality of quantitative studies. The checklist was chosen as it allows for appraisal of randomised controlled trials alongside quasi-experimental intervention studies, making it appropriate for all quantitative papers included in this review. The checklist has adequate

psychometric properties and has been shown to be helpful for informing decisions concerning overall quality as well as detecting potential sources of bias (O'Connor et al, 2015).

Each item on the checklist is scored out of one. Articles were awarded 1 point if a criterion was fully met or 0 points if a criterion was not met or 'can't tell' (necessary details were not included in the paper). In the current review, the checklist was modified, specifically scoring of item 27. This item considers whether a study performed a power calculation and whether it was sufficiently powered, with a usual maximum score of 5. The checklist was altered so that the maximum score for item 27 was 1 in the current review, which means a power analysis was conducted *and* the study was sufficiently powered, thus, the highest possible score for the checklist overall was 28 (instead of 32).

Due to the heterogeneity in design across studies, questions not relevant to the specific study, for example those referring to randomisation in a single-arm study, were rated as not applicable and not calculated in overall totals. As such, a percentage score was given to each study to allow for comparison across studies and illustrate quality in line with quality levels previously reported: excellent (93%+); good (71%+); fair (54%+); and poor (>53%) (Hooper et al, 2008).

The critical appraisal skills programme (CASP) qualitative checklist was used to appraise the qualitative studies (CASP, 2018), advocated by the National Institute for Health and Care Excellence (NICE) review protocol guidelines (2018). Each item on the CASP is scored out of 2, with a maximum score of 20. Articles were rewarded 2 points if the criterion is fully met, 1 point if criterion is partially met, and 0 points if the criterion is not met or 'can't tell'.

The mixed methods studies were assessed using both checklists. Quality scores for each paper, are illustrated in Tables 2 and 3 (appendices B & C), whilst key strengths and limitations for the studies are highlighted in Table 1. A summary of the quality of studies has been synthesised within the results.

Results

Overview of included studies

Though the paper provides limited details on methodology, Marquez-Gonzalez et al (2010) recruited 16 family caregivers to compare the effectiveness of ACT-based group intervention, and an unspecified control group, with regards to levels of depression and anxiety pre and post intervention.

In Madrid, Losada et al (2015) conducted a randomised control trial (RCT), utilising 135 family caregivers who met clinical threshold for anxiety and depression, recruited through Health Care Centres and internet advertisement. They compared the effectiveness of individual ACT to both CBT and a 'minimal support' wait-list group, with regards to changes in depression and anxiety.

Similarly, Marquez-Gonzalez et al (2020) utilised a RCT to compare individual ACT to CBT, a wait-list control group, and a functional analysis-guided modular intervention (FAMI), with regards to changes in depression and anxiety. They recruited 92 family caregivers, who met clinical threshold for depression, through Health Care Centres in Madrid.

In a single-arm intervention study in America, Fowler et al (2021) assessed changes in depression, anxiety, and burden pre and post intervention, following engagement in telephone-based ACT. They utilised a sample of 15 family caregivers, who met clinical threshold for anxiety, recruited through primary care clinics, as well as community groups.

Utilising a mixed methods approach in the United Kingdom, George et al (2021) conducted a single-arm study to assess the impact of group-based ACT on burden. They recruited 23 caregivers, who had previously expressed an interest in research participation. They utilised a qualitative feedback form following the intervention, though it is not clear how this was analysed.

Kishita et al (2021) conducted a single-arm study focused on feasibility of an online self-guided ACT intervention, whilst also assessing levels of depression and anxiety. They recruited 33 family caregivers, who met clinical threshold for anxiety and/or depression, recruited either via clinician referral from healthcare services in the UK, or via self-referral following advertisement.

Contreras et al (2022) invited all participants from Kishita et al's (2021) study to participate in a semi-structured interview, to share their experiences and provide feedback, after completion of the intervention. Twenty-three caregivers volunteered to take part, and interviews were analysed using thematic analysis.

Fauth et al (2021) conducted a single-arm intervention study to assess the impact of a guided online self-help ACT intervention on caregivers' levels of depression and burden.

Fifty-one family caregivers volunteered to participate, following recruitment via community agencies in America.

Utilising a mixed methods approach in America, Han et al (2022) conducted a single-arm intervention study to assess the impact of online ACT on depression, anxiety, and burden. Seven family caregivers who met clinical threshold for depression and/or anxiety volunteered, following advertisement through care agencies and community-based programs for PLWD. They utilised semi-structured interviews to gain insight into caregiver's experience, analysed using interpretative phenomenological analysis.

Han et al (2023) completed a pilot randomised control trial to compare the effectiveness of an online ACT-group with a control group, provided with psychoeducation. Nineteen family caregivers who met clinical threshold for depression and/or anxiety volunteered to participate, following advertisement through local community groups. Changes in levels of depression, anxiety and burden were assessed.

Table 1.

Data extracted for the 10 studies included in the literature review.

Author, Date and Country	**Sample**	**Methodology**	**Key Findings**	**Strengths**	**Limitations**
Marquez-Gonzalez et al. (2010) Spain	16 female dementia family caregivers. Clinical sample.	Quantitative. Pre-post study to compare ACT intervention (N=8) to a control group (N=8). ACT-based group intervention (8 x 2-hour weekly sessions). Outcome measures: - Center for Epidemiological Studies Depression Scale (Short version; Andresen et al, 1994) - Profile of Mood States – Tension Anxiety Subscale (POMS;) McNair et al, 1971)	Non-significant decrease in anxiety and depression in ACT group.	Clear aims and value of research. Detailed summary of intervention. Results clearly presented. Validated measures used.	No details regarding sampling, allocation to groups and experience of control group. Minimal details regarding statistical test. Limitations not discussed. No power analysis reported. Small sample.
Losada et al. (2015) Spain	135 dementia family caregivers. Clinical sample.	Quantitative. RCT to compare effectiveness of ACT (N=45), CBT (N=42) and control group (N=48). ACT intervention: 8 x 90-minute weekly individual sessions. Outcome measures:	At post-intervention, ACT participants showed significantly lower anxiety and depression. Similar results obtained for CBT and ACT.	Clear aims and appropriate design. Methods sufficiently described. Participants randomised to groups,	Voluntary sample. Control group condition found to be significantly different with regards to social contact.

		- Center for Epidemiological Studies Depression Scale (Short version) - Profile of Mood States – Tension Anxiety Subscale (POMS) Carers assessed pre, post-intervention and follow-up (6 months).	The effect on anxiety was greater than the CBT group. Effect of ACT intervention was maintained but diluted at follow-up.	and assessors blinded. Validated measures used. Discussion of potential confounders. Results clearly presented and conclusions justified. Limitations discussed. Effect sizes reported. Completed power analysis.	
Marquez-Gozalez et al. (2020) Spain	92 dementia family caregivers. Clinical sample.	Quantitative. RCT to compare effectiveness of ACT (N=21), CBT (N=23), functional analysis-guided modular intervention (FAMI, N=24) and control group (N=21). ACT intervention: 8 x 90-minute weekly individual sessions.	At post-intervention, ACT intervention group showed statistically significantly reduced anxiety and depression with large effect sizes. Effect of ACT was maintained but diluted for anxiety at follow-up.	Clear aims and appropriate design. Methods sufficiently described. Participants randomised to groups, and assessors blinded.	High attrition rate, particularly at follow-up. Did not report results for all outcome measures assessed. Small sample sizes in intervention groups. Control group condition significantly different

		All intervention groups engaged in 3 booster sessions at 1-, 2.5- and 5-month post-intervention. Outcome measures: - Center for Epidemiological Studies Depression Scale (Short version) - Profile of Mood States – Tension Anxiety Subscale (POMS) Carers assessed pre, post intervention and follow up (6 months).		Validated measures used. Discussion of potential confounders. Results presented and conclusions justified. Limitations discussed. Effect sizes reported. Completed power analysis.	with regards to social contact. Voluntary sample.
Fowler et al. (2021) USA	15 dementia family caregivers. Clinical sample.	Quantitative. Single-arm ACT intervention study. Telephone-based ACT intervention (TACTICS) = 6 weekly hour-long individual sessions. Outcome measures: - Patient Health Questionnaire-9 (PHQ-9; Lowe et al, 2004) - Generalised Anxiety Disorder Scale (GAD-7; Spitzer et al, 2006).	Participants showed significant reductions in anxiety at post-intervention and follow up. Medium reduction in burden observed, but only statistically significant at 6-month follow-up. Reduction in depression noted at post-test and follow-up, but not significant.	Clear value. Detailed description of intervention. Some acknowledgements of pilot study limitations.	Small, volunteer sample. No control group, or power analysis. Sample unrepresentative. Some participants accessing alternative support services alongside ACT.

		- Zarit Burden Interview (Zarit et al, 1985). Carers assessed pre, post and two follow-up points (3 months/6 months).			
George et al (2021). United Kingdom	23 family dementia caregivers. Non-clinical sample.	Mixed methods research design. Single-arm intervention study. ACT-based group intervention (5-hour long sessions) Outcome measures: - Zarit Burden Interview Assessed pre, post and three-month follow-up. Qualitative feedback gathered via post-intervention evaluation form.	Limited changes in burden. Qualitative feedback indicates the group was considered helpful and had an impact on carers' lives.	Clear justification. Some acknowledgements of limitations. Some discussion of potential confounders.	Lack of detail in methodology, including how qualitative data was assessed. Included psycho-educational component - Potential confounder. Small, voluntary sample. No power analysis.
KIshita et al. (2021) United Kingdom	33 family dementia caregivers. Clinical sample.	Quantitative. Single-arm intervention study. ACT intervention: 8 online self-guided sessions (with telephone feedback from therapists). Optional peer support group. Outcomes assessed: - Patient Health Questionnaire-9 (PHQ-9)	At post-test, 40% of those presenting with mild-moderate anxiety showed a reliable improvement in GAD7 scores. At post-test, 26% of those with mild-moderate depression showed a reliable improvement in PHQ9 scores.	Clear aims. Acknowledged limitations of feasibility study. Considered treatment fidelity. Some discussion of confounders.	Primarily self-referred, female sample. No control group, or follow-up. Potential impact of peer support group. Study found to be underpowered.

		- Revised Center for Epidemiological Studies Depression Scale (Eaton et al, 2004) - Generalised Anxiety Disorder Scale (GAD-7). Assessed pre and post intervention.		Power analysis completed.	
Contreras et al. (2022) United Kingdom	23 family dementia caregivers. Sub-sample taken from Kishita et al (2022).	Qualitative. ACT Intervention: See Kishita et al (2021). Semi-structured interviews analysed using thematic analysis.	2 relevant themes were identified: 1) Usefulness and relevance of the content of sessions 2) Impact of intervention on participants.	Clear justification. Appropriate use of qualitative methodology with adequate sample size. Some consideration of relationship between participants and researchers.	Majority female, voluntary sample.
Fauth et al. (2021) USA	51 family dementia caregivers. Non-clinical sample. .	Quantitative. Single-arm intervention study. ACT intervention: Guided self-help online ACT sessions (x 10), with option of online education library. Outcome measures: - Center for Epidemiological Studies Depression Scale (Short version)	At post-intervention, caregivers showed decreased symptoms of depression and burden. Statistically significant changes were sustained to follow-up.	Clear aims and justification. Acknowledged limitations of feasibility study. Use of validated outcome measures.	Short follow-up period. High levels of drop-out, only 32% completed the study. Sample homogeneity. Potential confounder – Psycho-education element.

		- Zarit Burden Interview -Short Version (Bedard et al, 2001) Carers assessed pre, post and 4-week follow-up.			No power analysis.
Han et al. (2022) USA	Seven family carers. Clinical sample.	Mixed methods research design. Single-arm intervention study. ACT intervention: 10 weekly ACT videoconference group sessions. Outcomes measured: - Depression, Anxiety and Stress Scale (Antony et al, 1998). - Zarit Burden Interview – Short Version. Measured pre and post intervention. Qualitative semi-structured interviews conducted following intervention, analysed using IPA.	At post-test, significant reductions in symptoms of depression, anxiety and burden with medium effect sizes. Qualitative outcomes indicated sessions helped caregivers gain renewed strength and started their journey towards values-based living.	Clear aims and justification. Acknowledged limitations of feasibility study.	Small voluntary, majority female sample. No control group, follow-up, or power analysis.
Han, Yuen & Jenkins (2023) USA	19 dementia family caregivers. Clinical sample.	Quantitative. Pilot RCT to compare effectiveness of ACT group (n=9) and control group (n=10). 8 (x 1 hour) ACT videoconference group sessions.	At post-test, no statistically significant differences were found across groups. Within groups, non-significant improvements	Clear justification. Use of validated outcome measures. Use of blinding to assess outcomes.	Small, voluntary, majority female sample. Study was statistically underpowered. Short follow-up period.

		Outcome measures: - Depression, Anxiety & Stress Scale - 21 (DASS-21) - Zarit Burden Interview -Short Version. Outcomes assessed at pre, post intervention and one-month follow-up.	were noted in symptoms of depression, anxiety, and caregiver burden for ACT intervention. Effects were not maintained at follow-up.	Power analysis completed.	

Study Quality

The quality assessment process identified a variety of strengths and weaknesses across studies. Some common strengths included clear rationale and justification for the studies, given the infancy of the research, as well as utilisation of validated outcome measures. Despite variation in measures, all were standardised and reported to have good validity and reliability (Gibson, 1997; Martin et al, 2006; Lowe et al, 2008; Osman et al, 2012; Ying et al, 2019). All studies accessibly and clearly reported their findings and demonstrated the clinical value of their research.

Only two studies included (Marquez-Gonzalez et al, 2010; George et al, 2021) received a 'poor' quality score rating. Both studies provided limited details of methodology, which led to numerous "can't tell" ratings, leaving it unclear whether means of quality assurance were not included or not reported in write-up. Limited details impact on validity and reliability of findings.

Sample

All studies made use of non-randomised convenience sampling, primarily recruiting through advertisements targeted at health care centres, day-care or community groups. Studies also utilised voluntary sampling, which is susceptible to bias. Research indicates volunteer samples can display the 'Hawthorne effect' whereby participants show changes simply because they are being studied (Fox et al, 2008). This could mean that caregiver well-being improved, in part, due to their awareness of the research study and aims, leading participants to alter their responses accordingly.

Further, volunteer carer samples have been shown to have different characteristics compared to those who do not volunteer to participate in dementia research. Caregivers who

do not volunteer have family members who are more impaired and experiencing more behavioural and psychological symptoms of dementia (Dura & Kiecolt-Glaser, 1990). Within the current review, samples also tended to be primarily white, female participants. Collectively, these sample constraints limit how representative the reviewed studies are of the entire dementia caregiving population, and thus limit generalisability.

Apart from Losada et al (2015) and Marquez-Gonzalez et al (2020) who had sample sizes of 135 and 92 dementia caregivers respectively, the remaining eight studies had small sample sizes ranging from 7 to 51 participants. In line with guidelines for qualitative research (Vasileiou et al., 2018), the sample sizes in qualitative studies were deemed adequate.

For quantitative studies, small samples may be understandable in the context of the infancy of this research area (with some studies still focused on feasibility and acceptability), however they ultimately reduce the statistical power of a study to detect an effect of an intervention. Further, small samples can impact on statistical test chosen by researchers, with some studies utilising non-parametric tests as a result which are less sensitive (Han et al, 2022; 2023). As a result, included studies with smaller samples, have a reduced chance of detecting a true effect of ACT, even when there is one, with a higher potential for results to be distorted by error.

Five of the quantitative studies did not complete a power analysis (Marquez-Gonzalez et al, 2010; Fowler et al, 2021; George et al, 2021; Fauth et al, 2021; Han et al, 2022), which means it is unclear whether the studies were able to detect true effects of an ACT intervention, or whether these may have been missed. Two studies completed a power calculation, however, results indicated they were statistically underpowered (Kishita et al, 2022; Han et al, 2023). Only two studies (Losada et al, 2015; Marquez-Gonzalez et al, 2020) were found to be sufficiently powered.

Only five studies reported standardised effect sizes (Losada et al, 2015; Marquez-Gonzalez, 2020; Fauth et al, 2021; Han et al, 2022; Han et al, 2023), with no studies including confidence intervals. An absence of effect sizes and/or confidence intervals limits interpretation of significant results as it is unclear exactly *how much* of an impact the intervention had on wellbeing, and what relevance findings have to real-world contexts (Du Prel et al, 2009).

Collectively, these limitations restrict the extent to which generalisable conclusions can be drawn from most of the studies. It is important to note, though, that most studies reflected on the limitations of their sample and any potential impact it had on findings.

Research Design

Five of the studies were single-arm pre-post intervention studies meaning any results regarding the impact of ACT must be approached with caution. Single-arm pre-post intervention studies do not enable researchers to conclude with certainty that effects are a result of the intervention, as it is possible that outcomes may be related to other non-controlled factors. For example, four of the studies offered additional skills and/or supplemented their ACT intervention with other means including peer support group (Kishita et al, 2022), psychoeducation materials (George et al, 2021; Han et al, 2022; 2023) and behavioural activation techniques (Han et al, 2022; 2023).

Furthermore, three studies utilised group delivery of intervention, whereby group delivery itself may have been a confounding variable. Group delivery may allow caregivers to overcome feelings of social isolation, which may in turn improve well-being (Cattan et al, 2005). Participants in George et al's (2021) study reported valuing the peer support group as it led to increased connectedness, suggesting a potential confounding role. In the absence of

comparison groups, it is difficult to conclude whether outcomes are a result of ACT or potential confounding factors.

Marquez-Gonzalez et al (2010) utilised a control group, however it is not clear how participants were allocated to conditions. Only three studies were randomised controlled trials (Losada et al, 2015; Marquez-Gonzalez et al, 2020; Han et al, 2023), commonly recognised as the gold standard for intervention studies. The same three studies also blinded researchers who were assessing outcome measures, to reduce bias. This is important because outcome assessors who are aware of the intervention condition may unconsciously or intentionally alter their assessment (Probst et al, 2016) so that results reflect favourably on an intervention.

Similarly in qualitative studies, the relationship between researcher and participant can impact on findings. The relationship can lead to demand characteristics whereby participants respond in a way in which they think researchers would like, to appease them (Orne, 1962). Whilst Contreras et al (2022) did acknowledge that participants had a relationship with interviewers through the quantitative arm of the study (Kishita et al, 2022), all three qualitative studies did not reflect sufficiently on the potential impact of the relationship between researchers and participants. This lack of interpersonal reflexivity reduces the rigour of studies as researchers have not sufficiently considered how subjectivity may have impacted on findings.

Finally, three studies also did not include a follow-up assessment of outcomes into their design (Marquez-Gonzalez et al, 2010; Kishita et al, 2022; Han et al, 2022), impacting on the ability to draw conclusions regarding the maintenance of any intervention effects. Of those which did include a follow-up, which aids in analysis of longevity of findings, Fauth et al (2021) and Han et al (2023) utilised a short four-week follow-up period whilst others utilised a 3-month (Fowler et al, 2021; George et al, 2021) or 6-month follow-up (Losada et al, 2015;

Marquez-Gonzalez et al, 2020; Fowler et al, 2021). Utilisation of a 6-month follow-up is preferable as it allows for stronger conclusions regarding whether effects are maintained.

Findings

Depression

Seven studies which included a measure of depression, indicated a reduction in depression following engagement in ACT, though this was only found to be statistically significant in four of the studies (Losada et al, 2015; Marquez-Gonzalez et al, 2020; Fauth et al, 2021; Han et al, 2022). The remaining three studies noted a non-significant reduction in symptoms of depression (Marquez-Gonzalez et al, 2010; Fowler et al, 2021; Han et al, 2023). Effect sizes reported varied across the studies from medium (Han et al, 2023) to large effects (Losada et al, 2015; Marquez-Gonzalez et al, 2020; Fauth et al, 2021) (Cohen, 1988; Miles & Shevlin, 2014), suggesting that the ACT intervention was of real value for the dementia caregivers.

Qualitative studies showed similar positive effects. Han et al (2022) identified a theme of "renewed strength". Within this theme, participants recognised that acceptance of feelings and situations outside of their control, helped them to "not feel down", whilst carers reported ACT exercises which could be used when feeling distress helped with the "urge to get upset with care", appearing to highlight reduced low mood associated with caring responsibilities.

When considering whether reductions in depression are maintained for caregivers following intervention, positive effects were only maintained in three of the studies reporting statistically significant effects on depression (Losada et al, 2015; Marquez-Gonzalez et al, 2020; Fauth et al, 2021). However, Fauth et al (2021) only utilised a short four-week follow-up period, compared to six months for others (Losada et al, 2015; Marquez-Gonzalez et al,

2020). Effect sizes for depression were found to be largest at follow-up, for both ACT and CBT, in Marquez-Gonzalez et al's (2020) study.

Anxiety

All seven studies, which included a measure of anxiety, reported a reduction in symptoms of anxiety following engagement with ACT (Marquez-Gonzalez et al, 2010; Losada et al, 2015; Marquez-Gonzalez et al, 2020; Fowler et al, 2021; Kishita et al, 2022; Han et al, 2022; Han et al, 2023). Three studies, however, did not reach statistical significance (Marquez-Gonzalez et al, 2010; Han et al, 2022; Han et al, 2023). Of those studies which considered effect sizes, all reported large effects on anxiety from pre to post intervention (Losada et al, 2015; Marquez-Gonzalez et al, 2020; Fowler et al, 2021) (Cohen, 1988; Miles & Shevlin, 2014), again suggesting ACT interventions had a meaningful impact on dementia caregivers' levels of anxiety.

This appears consistent with qualitative findings. Han et al (2022) identified a theme "journey to acceptance" in which participants reported ACT helped with their worries about the future, as exercises helped them to "anchor more in the present moment". Participants reported that being able to acknowledge, observe and accept their thoughts, feelings and situations allowed them to stop avoiding difficult emotions and/or ruminating over them, appearing to suggest reduced anxiety.

Regarding long-term effects of ACT on anxiety, the results were mixed. Two studies found that positive effects on anxiety were maintained, however stronger effect sizes were noted immediately post-intervention than at follow-up points suggesting the positive effect of ACT diminished with time (Losada et al, 2015; Marquez-Gonzalez et al, 2020). On the contrary, Fowler et al (2021) noted the already large effect size post intervention increased at

6-month follow-up point to a larger effect size, suggesting effects of the ACT intervention were sustained.

Caregiver burden

Two studies reported statistically significantly reduced caregiver burden (Han et al, 2022; Fauth et al, 2021), whilst George et al (2021), Fowler et al (2021) and Han et al (2023) noted a non-significant reduction in burden. Fauth et al (2021) noted effects on caregiver burden were maintained at four-week follow-up whilst Fowler et al (2021) noted a significant effect at six-month follow-up, which was not present immediately post-intervention, though the potential reasons for this were not explored by the researchers.

All qualitative studies found that participants reported an increased ability to talk about, and less guilt pertaining to, negative emotions in relation to caregiving following engagement with ACT. This enabled them to ask for help from family members or utilise respite care (Han et al, 2022), which appeared to reduce burden by allowing carers to have some time away from caregiving and recognise the importance of their own needs too (George et al, 2021; Han et al, 2022). In line with this, one of the most frequently reported benefits of ACT in qualitative studies was value-based living, whereby carers were supported to identify what truly mattered to them and begin engaging more in activities which they enjoyed, which carers reported improved their wellbeing (Contreras et al, 2022).

Discussion

This literature review examined 10 articles considering if ACT helps informal dementia caregivers with their wellbeing. Overall, the studies indicate that ACT can support informal caregiver wellbeing, particularly caregiver anxiety, however there were inconsistencies in findings reported across studies, likely owing to methodological constraints.

Anxiety was found to reduce in all studies, with large effect sizes. These findings add to wider literature supporting the efficacy of ACT for reducing generalised anxiety (Wetherell et al, 2011), even when delivered remotely (Dahlin et al, 2016), as well as anxiety in family caregivers. Han et al (2020) conducted a meta-analysis considering ACT for family caregivers (not specific to dementia), noting small effects on anxiety. Interestingly, both the Losada et al (2015) and Marquez-Gonzalez et al (2020) studies were included in this meta-analysis, with both studies contributing the largest effect on anxiety compared to caregivers of other conditions. Given ACT had smaller effect sizes for caregivers of other conditions, this could suggest that dementia caregivers are potentially distinct in their needs compared to other caregivers, suggesting a need to tailor interventions to this group.

A positive impact on anxiety is noteworthy given that most intervention studies for dementia caregivers have historically focused on depression, with less consideration given to anxiety (Cooper et al, 2007). A recent meta-analysis has indicated anxiety is as common as depression in dementia caregivers (Kaddour & Kishita, 2019). As such it is important that attention is given to early identification and support for anxiety in dementia caregivers, as with depression.

Further, an improvement in caregiver anxiety is clinically important. The literature base indicates that typically utilised CBT has a limited effect on caregiver anxiety, both for informal caregivers of PLWD (Hopkinson et al, 2019) and older people generally (Kishita & Laidlaw, 2017). This is important given dementia caregivers often tend to be older themselves. Interestingly, and in line with the findings of Losada et al (2015), research comparing ACT and CBT has indicated that ACT may produce stronger effects on anxiety outcomes (Brown et al, 2011).

It is possible that ACT reduces anxiety through training caregivers in cognitive defusion skills, which are taught with the goal of reducing experiential avoidance. These skills expose caregivers to their difficult sensations, feelings, and thoughts. This repeated exposure to internal events is hypothesised to lead to habituation, whereby anxiety reduces following repeated contact with difficult emotions without caregivers utilising avoidance-escape strategies (Arch & Craske, 2008).

Furthermore, given that dementia caregivers often feel guilty for experiencing negative emotions (Gallego-Alberto et al, 2021), accepting instead of repressing negative emotions might help caregivers to normalise their distress, and decrease their worry regarding distress, which over time reduces their general anxiety (Losada et al, 2015). This was noted in Han et al's (2022) qualitative findings and supports broader literature indicating that guilt pertaining to negative emotions is predictive of caregiver distress (Spillers et al, 2008), whilst increased use of psychological acceptance strategies can improve outcomes (Forman et al, 2012).

The results regarding whether effects on anxiety were maintained were mixed, with Fowler et al (2021) noting a more significant effect at follow-up periods, perhaps indicating a delayed impact of ACT. Alternatively, both Losada et al (2015) and Marquez-Gonzalez et al (2020) noted the effect was maintained but smaller compared to immediately after intervention. Despite diluting, the effect sizes at follow-up were still largest for Marquez-Gonzalez et al (2020) compared to other studies. This was the only study to utilise booster sessions after completion of ACT, indicating that booster sessions may have facilitated greater maintenance of effects.

The studies which directly compared ACT to other interventions, including CBT and a functional-analysis modular intervention (a bespoke intervention for caregivers), highlighted that whilst ACT produced promising effects on anxiety, it was also as effective as CBT for

depression (Losada et al, 2015; Marquez-Gonzalez et al, 2020). All seven studies included in the review which measured depression reported a reduction in symptoms, with medium to large effect sizes, however only four studies reached statistical significance, perhaps due to limitations regarding sample and methodology.

These findings are in line with broader literature indicating the efficacy of ACT for symptoms of depression (Zettle, 2015; Zhenggang et al, 2020). Han et al's (2020) meta-analysis considering ACT for family caregivers (not specific to dementia) also revealed moderate effects of ACT on symptoms of depression. Alongside the results of the current review, this suggests ACT could be a helpful alternative to CBT for distressed dementia caregivers.

ACT is thought to reduce depression, by increasing overall psychological flexibility (Hayes et al, 2013). Psychological flexibility is known to act as a protective factor for informal caregivers against psychological distress (Jansen et al, 2017), whilst low levels of psychological flexibility have been related to increased symptoms of depression among caregivers (Sairanen et al, 2018).

Furthermore, a recent study indicated that caregivers' levels of cognitive fusion have a moderator effect in the relationship between an intervention and change in depression whereby ACT was found to have the greatest effect on wellbeing for those with highest levels of cognitive fusion. This highlights the role of cognitive fusion both on levels of depression, but also on whether ACT is likely to be effective for caregivers (Barrera-Caballero et al, 2022). Importantly, qualitative studies included appear to concur, with caregivers reporting that they valued learning to notice and allow painful emotions, as doing so allowed them to step back from these feelings (cognitive defusion) and connect more with the PLWD (Contreras et al, 2022).

Ultimately, results from the current review highlight that ACT can support with *both* anxiety and depression which is promising, as dementia caregivers commonly experience both (Barrera-Cabellero et al, 2021). As such, an intervention which can act on both prevalent difficulties could offer an efficient and cost-effective means of intervention.

Results regarding caregiver burden were promising with all studies which considered burden noting a reduction following engagement with ACT, though not all reached statistical significance. Only two studies which considered burden included a follow-up period. Whilst both papers suggest effects were maintained, this is not sufficient to draw conclusions regarding long-term effects. Nonetheless, the impact on caregiver burden is important given the high prevalence of burden in dementia caregivers (van der Lee et al, 2014), as well as research indicating burden is a significant risk factor for symptoms of depression (Moreno-Camara et al, 2019) in this population.

Qualitative studies included in the current review help to make sense of how ACT reduces burden, as caregivers consistently reported an increased ability to talk about their negative emotions, as well as reduced guilt which enabled them to seek help, thus giving space for the caregiver to look after their own wellbeing and protect against burden (George et al, 2021; Han et al, 2022).

It is important to reflect on whether the mode of intervention delivery had an impact on outcomes, as this may inform clinical practice. All studies in the review utilising virtual delivery obtained positive results, though these were smaller than those reported in large-scale RCTs which utilised face-to-face delivery (Losada et al, 2015; Marquez-Gonzalez et al, 2020). It is difficult to conclude whether smaller effects are due to a lack of power to detect significant effects (as these studies utilised smaller samples), or a reality that there is less of an effect of ACT when delivered remotely.

Whilst the literature into virtual delivery of interventions is relatively new, a recent meta-analysis highlighted no significant differences in outcomes between human-guided virtual interventions and face-to-face psychotherapy for depression, suggesting virtual interventions can be an effective alternative (Moshe et al, 2021). This tentatively suggests that effect sizes in relation to virtually-delivered ACT in the current review may have been limited, due to small samples. Nonetheless, the results from the six studies included in this review utilising virtual delivery are promising and support broader research indicating web-based ACT interventions can be effective (Lappalainen et al, 2022).

Limitations

The limitations of the included papers, which have been previously discussed, should be considered when interpreting results, namely the small, volunteer samples utilised and single-arm designs. Nonetheless, the current review also has limitations that need to be considered. Firstly, the review only considered studies from three countries: America, Spain, and the United Kingdom, whilst limits generalisability regarding the effectiveness of ACT for caregivers in other countries and cultures.

Furthermore, only three outcomes: depression, anxiety, and burden were considered. It is important to note that wellbeing as a concept encapsulates more than just these components (Huber et al, 2019). Whilst most research continues to focus on the wellbeing of dementia caregivers through the loss-deficit model, this has been criticised as a narrow interpretation which misses other important elements of wellbeing (Cunningham et al, 2019). It has been argued that wellbeing should reflect not only the absence of undesirable outcomes but also the presence of positive aspects (Cunningham et al, 2019), with evidence indicating that both positive and negative feelings can co-exist for informal caregivers of PLWD

(Farhadi et al, 2016). Without assessing other elements of wellbeing, conclusions regarding wellbeing more generally cannot be definitively drawn.

Although the Down's and Black tool has been deemed an appropriate and reliable measure of assessing study quality, the process of critical appraisal for the review was carried out by the author, with no second reviewer, which limits the reliability of the results. To mitigate this, the process of reviewing was clearly outlined, and scoring of papers included in appendices, to increase transparency and allow for replication. Nonetheless, some changes to the tool were made including altered scoring of one item, and utility of percentage scores to allow for comparison. The tool was not intended to be used in this way and any deviations from the standardised tool could reduce previously reported psychometric properties.

Finally, studies not reported in English were excluded, due to lack of translation resources, which could mean important findings have been missed.

Considerations for Clinical Practice and Future Directions for Research

Overall, the review highlights that ACT could be a promising intervention for dementia caregivers, when delivered either face-to-face or via virtual means, though the evidence base is small.

The evidence that ACT can be effective when delivered remotely is important as research suggests that many dementia caregivers may receive limited support for their own wellbeing, owing to several barriers accessing support including reduced mobility, limited availability of therapists and a reality that caregivers often cannot leave PLWD alone. Remote delivery of ACT has the potential to eradicate some potential barriers. Future research should consider large scale trials, with sufficient sample sizes, to fully understand the impact of virtual delivery, with potential to compare virtual and in-person delivery.

Furthermore, ACT appears to show promising results regarding long-term effects, however these were best maintained in the study which made use of booster sessions at 1, 2.5 and 5 months after post-intervention (Marquez-Gonzalez et al, 2020). Clinicians utilising ACT with dementia caregivers could consider incorporating 'booster sessions' into ACT delivery, to support greater maintenance of effects. Nonetheless, the longest follow-up period considered in the current review was 6-months. Future research should consider how well these effects are maintained over longer periods of time, especially as caregiving for a person living with dementia may last for years.

Future studies in this area should aim to strengthen their methodological design in other ways too. Use of comparison groups in future studies as a minimum, would improve validity of the evidence base as well as use of larger, more diverse samples, to enhance generalisability. Diverse samples may include non-female caregivers, as evidence has suggested a presence of sex and gender differences in caregiving burden (Xiong et al, 2020). Diverse samples may also include exploration of the efficacy of ACT in non-Western countries, as research suggests the experience of caregiving for PLWD can be different (Wang et al, 2023).

Future research could continue to explore possible mechanisms of ACT for producing positive outcomes in caregivers (Losada et al, 2015). Understanding mechanisms has the potential to support the development of screening tools which could inform clinician decisions regarding which intervention might be helpful for each caregiver. This would allow caregivers to receive interventions most likely to meet their needs, in a more timely and cost-effective way.

Whilst other outcomes were considered by studies included in the current literature review, for example positive aspects of caregiving (Fauth et al, 2022; George et al, 2021), this has not yet been consistently considered. It would be desirable for future research to

consider other outcome measures, such as ambivalence, guilt, and positive aspects of caregiving (Losada et al, 2018; Romero-Moreno et al, 2021), especially as carers who report higher levels of positive aspects of caregiving report lower levels of depression and anxiety (Mausbach et al., 2006). Gaining an understanding of the impact on wellbeing more broadly could further inform allocation of interventions to effectively meet caregiver needs.

Conclusion

This review is believed to be the first to systematically explore whether ACT can help informal dementia caregivers with their wellbeing. The findings provide evidence indicating ACT could be a beneficial intervention for dementia caregivers in terms of improving symptoms of anxiety, depression, and burden. The limitations of the included studies and the review need to be considered when interpreting these findings, and conclusions must be drawn with caution. The research area is ultimately in its infancy, and as such, more large-scale research is needed to replicate positive findings of small-scale, methodologically limited, studies.

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Appendices

Appendix A. *Ageing and Mental Health Instructions for Authors*

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=camh20#checklist-what-to-include

Appendix B. The *quality scores for the included quantitative studies table.*

Table 2. Quality scores for the included quantitative studies.

DOWNS AND BLACK CHECKLIST FOR CLINICAL TRIAL QUALITY ASSESSMENT	Marquez-Gonzalez, Romero-Moreno & Losada (2010)	Losada et al. (2015)	Marquez-Gozalez et al. (2020).	Fowler et al. (2021)	George, Boyce, Evans and Ferreira (2021).	KIshita et al. (2022)	Fauth et al. (2021)	Han et al. (2022)	Han, Yuen & Jenkins (2023)
Q1. Is the objective of the study clear?	1	1	1	1	1	1	1	1	1
Q2. Are the main outcomes clearly described in the Introduction or Methods?	1	1	1	1	1	1	1	1	1
Q3. Are characteristics of the patients included in the study clearly described?	1	1	1	1	1	1	1	1	1
Q4. Are the interventions clearly described?	1	1	1	1	1	1	1	1	1
Q5. Are the distributions of principal confounders in each group of subjects clearly described?	0	2	2	N/A	N/A	N/A	N/A	N/A	1
Q6. Are the main findings of the study clearly described?	1	1	1	1	1	1	1	1	1
Q7. Does the study estimate random variability in data for main outcomes?	1	1	1	1	1	1	1	1	1
Q8. Have all the important adverse events consequential to the intervention been reported?	0	0	0	1	0	0	1	1	0
Q9. Have characteristics of patients lost to follow-up been described?	N/A	1	1	1	0	N/A	0	N/A	1
Q10. Have actual probability values been reported for the main outcomes except probability < 0.001?	0	1	1	1	1	0	1	1	1

Q11. Were subjects who were asked to participate in the study representative of the entire population recruited?	0	0	0	0	0	0	0	0	0
Q12. Were those subjects who were prepared to participate representative of the recruited population?	0	0	0	0	0	0	0	0	0
Q13. Were staff, places, and facilities where patients were treated representative of treatment most received?	0	1	1	0	0	1	0	0	0
Q14. Was an attempt made to blind study subjects to the intervention?	0	0	0	0	0	0	0	0	0
Q15. Was an attempt made to blind those measuring the main outcomes??	0	1	1	0	0	0	0	0	1
Q16. If any of the results of the study were based on data dredging was this made clear?	1	1	1	1	1	1	1	1	1
Q17. Was the time period between intervention and outcome the same for intervention and control groups or adjusted for?	0	1	1	N/A	N/A	N/A	N/A	N/A	1
Q18. Were the statistical tests used to assess main outcomes appropriate?	0	1	1	1	1	1	1	1	1
Q19. Was compliance with the interventions reliable?	0	1	1	1	1	1	1	1	1
Q20. Were main outcome measures used accurate? (valid and reliable)	1	1	1	1	1	1	1	1	1
Q21. Were patients in different intervention groups recruited from the same population?	0	1	1	N/A	N/A	N/A	N/A	N/A	1
Q22. Were study subjects in different intervention groups recruited over the same period of time?	0	1	1	N/A	N/A	N/A	N/A	N/A	1

Q23. Were study subjects randomized to intervention groups?	0	1	1	N/A	N/A	N/A	N/A	N/A	1
Q24. Was the randomized intervention assignment concealed from patients and staff until recruitment was complete?	0	0	0	N/A	N/A	N/A	N/A	N/A	1
Q25. Was there adequate adjustment for confounding in the analyses from which main findings were drawn?	0	0	1	0	0	0	0	1	1
Q26. Were losses of patients to follow-up taken into account?	N/A	1	1	1	1	0	0	N/A	1
Q27. Was the study sufficiently powered to detect clinically important effects?	0	1	1	0	0	0.5	0	0	0.5
Total percentage score:	**31%**	**79%**	**79%**	**66%**	**47%**	**57.5%**	**57%**	**65%**	**76%**
Quality score rating (in line with Hooper et al, 2008)	**Poor**	**Good**	**Good**	**Fair**	**Poor**	**Fair**	**Fair**	**Fair**	**Good**

Note. Question 27 scoring modified. 1 point rewarded if power analysis was conducted and study was deemed sufficiently powered, 0.5 if power analysis was completed but study was not sufficiently powered and 0 points if a power analysis was not conducted or 'can't tell'. All other items were awarded 1 point if a criterion was fully met or 0 points if a criterion was not met or 'can't tell'. If a question was not applicable to a research study, N/A is indicated.

Appendix C. *The quality scores for the included qualitative studies.*
Table 3. Quality scores for the included qualitative studies.

Critical Appraisal Skills Programme questions (Critical Appraisal Skills Programme, 2018)	George et al (2021)	Contreras et al (2022)	Han et al (2022)
Q1. Clear aims?	2	2	2
Q2. Qualitative methodology appropriate?	2	2	2
Q3. Research design appropriate?	2	2	2
Q4. Recruitment strategy appropriate?	2	2	1
Q5. Data collection appropriate?	0	2	2
Q6. Relationship between researcher and participants considered?	0	1	1
Q7. Ethical issues considered?	2	2	2
Q8. Data analysis rigorous?	0	2	2
Q9. Clear statement of findings?	2	2	2
Q10. Value of research?	2	2	2
Total score out of 20	**14**	**19**	**18**

Note. Articles were awarded 2 points if a criterion was fully met, 1 point if a criterion was partially met, or 0 points if a criterion was not met or "can't tell".

Paper Two: Empirical Paper

"Anything that's going to assist in the road we're on is worth it" - Exploring the experiences of delivering individual cognitive stimulation therapy (iCST) for informal dementia caregivers: A thematic analysis.

Gemma Helen Ryan

Student ID: 21026388

Supervised by Dr Helen Scott

Word Count: 7988

(Excluding Title Page, References and Appendices)

This empirical paper has been written in accordance *with author guidelines for Ageing and Mental Health Journal. The author guidelines are in Appendix A.*

Abstract

Background: In response to the need to improve access to interventions and home care for people living with dementia, an individual version of Cognitive Stimulation Therapy (iCST) was developed. This research aimed to qualitatively explore informal caregivers' experience of delivering iCST to a person living with dementia, building on limitations of previous research.

Method: Seven participants were recruited following their engagement in a 'train the carer' iCST intervention group. Semi-structured interviews were completed and analysed using reflexive thematic analysis.

Results: Three overarching themes and eight subthemes were identified including*: Motivations to engage with iCST, "It's just that it helps you to make the most of the day you've got",* and *Challenges of implementing iCST into real life.*

Conclusion: This research indicates iCST benefits caregivers, the person living with dementia, and the dyad collectively. There were however significant barriers to implementation, including the formality of the intervention, and caregivers' competing demands. Further research exploring how to support caregivers in their implementation of caregiver-delivered interventions, with more diverse samples, is needed.

Keywords: Dementia, informal caregivers, individual cognitive stimulation therapy, experiences

Introduction

There are currently around 900,000 people living with dementia in the United Kingdom (Wittenberg et al., 2019). As the population continues to age, the risk of dementia increases and, therefore, the number of people living with dementia is expected to continue to rise (Livingston et al., 2017), up to as high as 1.7 million people by 2040 (Chen et al., 2023).

Dementia is an umbrella term used to describe a decline in cognitive functioning, activities of daily living and social participation (NICE, 2018). Dementia is characterised by a progressive global deterioration in cognitive functions, most commonly: memory, language, visuospatial, and attentional abilities (WHO, 1992; Hugo & Ganguli, 2014). To be diagnosed with dementia, the loss of abilities must be present in several domains, be progressive and impair functional abilities in day-to-day life (McKhann et al., 2011).

Unsurprisingly given the widespread impairment, caregiving for someone with dementia is complex. Research indicates dementia caregivers have higher levels of stress, depression, social isolation and physical health concerns than non-caregivers (Gilliam & Steffen, 2006), as well as higher rates of burden compared to caregivers of other conditions (Teahan et al., 2020). Understandably, the far-reaching impacts of providing care can compromise an individual's ability to continue to support someone living with dementia.

There are currently approximately 700,000 informal caregivers of people living with dementia in the UK (Carers UK, 2021), most commonly a spouse or child. Informal caregiver is taken to mean someone who provides unpaid help to someone needing support. Help may entail personal care, housekeeping, medication administration, financial and wellbeing support (Brodaty & Donkin., 2009).

With this, comes financial implications. The total cost to the UK economy of care for people with dementia is at 34.7 billion pounds, though this is expected to nearly triple by 2040 (Wittenberg et al., 2019). These costs are split between healthcare systems, social care, and costs of unpaid care (provided by informal caregivers) with the latter contributing significantly to overall cost (Knapp et al., 2006). As such, any intervention for people living with dementia must consider the well-being of caregivers to support the continuation of their caring roles, to make use of society's limited resources.

There is currently no cure for dementia. Whilst pharmacological interventions can lead to modest improvements in cognitive functioning (NICE, 2018), they have limited effectiveness on certain types of dementia, adverse side-effects, and mortality risks (Maust et al., 2015). A range of psychosocial interventions have therefore been developed as an alternative, including creative (art/music therapy), sensory, and psychological (reminiscence/validation therapy/cognitive training) interventions (Patel et al., 2014). They aim to promote cognition, independence, and wellbeing via safe and cost-effective means of intervention (McDermott et al., 2018).

Currently, cognitive stimulation therapy (CST) is the best-established psychosocial intervention (Cafferata et al., 2021), recommended by the National Institute for Health and Social Care Excellence as the first-line psychosocial intervention for dementia in the UK (NICE, 2018). CST is a brief yet structured approach, aiming to enhance cognitive and social functioning through stimulating activities such as discussion of past and present events, word games, puzzles, or music (Spector et al., 2003). CST consists of fourteen twice-weekly group sessions delivered by a healthcare professional over the course of seven weeks. Recent reviews (Cafferata et al., 2021; Chen, 2022; Saragih et al., 2022) have highlighted the

effectiveness of CST in maintaining cognition and improving quality of life, as well as its enjoyment factor and cost-effectiveness (Knapp et al., 2006).

Approximately two-thirds of memory services in the UK offer CST (Royal College of Psychiatrists, 2022). However, access to this resource can be challenging for some individuals with dementia due to lack of local availability or transport, mobility difficulties, or not wanting to engage in group interventions. Improvements in access to interventions and home care for people living with dementia are therefore needed (Yates et al., 2014).

In response to this need, an individual version of cognitive stimulation therapy (iCST) was developed (Yates et al., 2014). iCST follows the same principles as CST however in iCST, caregivers are trained to deliver CST to a person living with dementia in their home environment. Each iCST session lasts around 20 to 30 minutes and can be done thrice weekly (Yates et al., 2014). iCST has the potential to yield several distinct benefits compared to CST, primarily home delivery, catering for the needs of those unable or unwilling to access groups. Further, home-based iCST offers better integration with existing routines and possible longer-term delivery with one consistent, familiar person (i.e. informal caregiver).

Currently, iCST is not readily accessible within the NHS (Orrell et al., 2017), primarily because there has been relatively little research into iCST, given its infancy. In a randomised controlled trial (RCT; Orrell et al., 2017); three-hundred-and-fifty-six pairs of people with dementia and their caregivers were randomly assigned to receive either iCST or treatment as usual. The study found no evidence that iCST improved cognition or quality of life for people with dementia. Participating in iCST, however, did enhance the quality of the caregiving relationship, the caregivers' quality of life and reduced caregiver depressive symptoms. In a more recent RCT with two-hundred-and-forty-one caregiving dyads, Kor et

al. (2024) reported a positive effect of iCST on cognition, behavioural and psychological symptoms, and quality of life for people living with dementia, as well as improved positive aspects of caregiving for caregivers. Crucially, both studies uncovered positive outcomes for caregivers. This is important because this may prolong their ability to provide care (Yang et al., 2014) therefore contributing to the cost-effectiveness of dementia care (Yaffe, 2002), as dyads are less likely to require support and resources from healthcare services (Orrell & Bebbington, 1995).

With regards to the contradicting effects on cognition, Orrell et al. (2017) highlighted low levels of implementation, with only 40% of dyads completing two sessions a week, which likely contributed to the limited effectiveness of iCST on cognition. In contrast, Kor et al (2024) achieved adherence rates of 93% and reported a greater effect on cognition.

Attention must be paid to the acceptability of interventions considered for people living with dementia, as increased acceptability supports greater intervention implementation, alongside improved clinical outcomes (Hommel et al., 2013). Sekhon et al (2017) define acceptability as a multi-faceted construct, reflecting the extent to which people receiving an intervention consider it to be appropriate, based on experiential cognitive and emotional responses. They identified seven components to acceptability: affective attitude, burden, ethicality, intervention coherence, opportunity costs, perceived effectiveness and self-efficacy. They propose these components help assess the acceptability of any intervention within the development, evaluation and implementation phases.

Post-intervention interviews with twenty-three of the dyads from Orrell et al's (2017) RCT highlighted whilst dyads found iCST stimulating and enjoyable, they had various difficulties implementing the intervention. The primary difficulty was challenges fitting iCST

into their schedules, alongside feelings of frustration for the person living with dementia when activities were not challenging enough, poor health of the person with dementia, negative outlooks about the progressive nature of dementia, and carers feeling insufficiently skilled to deliver iCST (Leung et al., 2017). These barriers map onto several facets of acceptability as described by Sekhon et al (2017), namely affective attitude (how dyads felt about the intervention), burden (perceived amount of effort required to engage) and self-efficacy (confidence in ability to implement intervention), collectively suggesting that perhaps iCST, as suggested by Orrell et al. (2017) was not deemed acceptable by dyads, likely contributing to low implementation.

Though insightful, Leung et al's (2017) study is not without limitations, including potential sample bias as participants interviewed were those who had engaged well with iCST. As a result, the current study aims to build on this limitation, by including all who engage in iCST, to provide new, qualitative information on the positive and negative aspects underlying informal caregivers' experience of delivering iCST in the hope of furthering an understanding of whether iCST is an acceptable alternative to CST, and ultimately, how best to support those living with dementia and their caregivers.

Research Question

What are the experiences of delivering iCST to a person living with dementia for informal caregivers following their attendance at the 'train the carer' (iCST) group?

Method

Ethics

Ethical approval was obtained from Yorkshire and The Humber - Sheffield NHS Research Ethics Committee (Appendix B), NHS Health Research Authority (Appendix C), and

Staffordshire University Ethics Committee (Appendix D). The local NHS Trust provided capacity and capability approval (Appendix E).

Participants provided written consent for participation. In the single instance of a virtual interview, the participant was encouraged to schedule their interview at a time and location that ensured privacy. During write-up, any identifying information was removed, and pseudonyms were used, to ensure confidentiality.

No psychological or physical harm was anticipated to occur because of participation. No signs of distress were noted during the interviews however, given the potentially emotive nature of the topic, all participants were signposted to sources of support via the participant information sheet and debrief form. Any disclosures or safeguarding concerns were to be communicated to the relevant support team; however, none were reported. Full details on risk management are provided in the risk assessment (Appendix F).

Design

A Cochrane review indicated a lack of in-depth qualitative studies of cognitive stimulation approaches (Woods et al., 2012), with even less research considering iCST. Therefore, a qualitative design with purposive sampling and semi-structured interviews was used to allow for a greater understanding of caregivers' experience of delivering iCST (Lewin et al., 2009).

Data was analysed using Reflexive Thematic Analysis (RTA; Braun & Clarke, 2022). RTA facilitates the identification and analysis of patterns or themes in a given dataset (Braun

& Clarke, 2012), allowing the researcher to organise and distil the data, into accessible and meaningful summaries of participant responses (Braun & Clarke, 2019).

RTA was selected over other qualitative approaches, such as Interpretative Phenomenological Analysis (IPA), because of its nomothetic approach, considering patterns across groups, in this instance, dementia caregivers. Comparatively, IPA's idiographic approach focuses on both meaning across participants and the unique experience of each participant (Smith & Osborn, 2015), which were deemed less relevant for the research question.

Further whilst considered, other means of thematic analysis, including coding reliability and codebook approaches were not used. These approaches make use of a deductive approach to coding, utilising a structured codebook. Resulting themes are often framed as 'domain summaries', whereby themes provide somewhat superficial summaries of what participants said regarding a topic, as opposed to themes as patterns of shared meaning, as in RTA. This type of approach was deemed less helpful, given the paucity of research into iCST and the need to explore dementia caregivers' experiences. Instead, RTA considers coding as an inductive and reflexive process. RTA encourages the researcher to embrace reflexivity as an asset in knowledge production (Braun & Clarke, 2019). Given the researcher's own experiences of dementia caregiving, it was important for this to be considered throughout analysis.

iCST Intervention Group

No existing research has examined the effectiveness of iCST when taught in a group. The iCST intervention group ('train the carers') was developed by a memory service in a

Midlands NHS trust as part of routine offering, not solely for research purposes. The group was therefore developed independently of the researcher, prior to their involvement. The group was based on the iCST programme developed by Yates et al. (2014) and entailed three hour-long weekly face-to-face group sessions, facilitated by a consultant clinical psychologist (one session) and a trainee associate practitioner in clinical psychology (two sessions), both experienced within memory services. The group aimed to equip caregivers with the skills to deliver iCST to the person living with dementia whom they cared for in their home environment, with the recommendation that a 30-minute session should be completed three times a week (Yates et al., 2014).

During session one, caregivers considered what is CST and how iCST is different. They considered their approach to iCST (including exploration of how best to engage a person living with dementia), identified potential activities for sessions and considered how to make sessions person-centred. Session two explored how caregivers could plan iCST sessions at home, including session structure (overarching theme, orientating the person with dementia and main activity). In the final session, caregivers considered how to review an iCST session, including whether the session was enjoyable, what went well and what might be changed in future sessions.

In the current study, the iCST group was offered as a means of maintenance therapy for the person living with dementia. The group was offered to caregivers whilst the person living with dementia whom they cared for was enrolled in typical CST groups, with the hope that once the person living with dementia had completed the seven-week CST course, the cognitive stimulation could be continued at home by their informal caregiver. This meant that whilst the caregivers learnt CST for the first time, the individual who they cared for had

already accessed CST. This is distinct from previous studies exploring iCST (Orrell et al., 2017, Kor et al., 2024), whereby iCST was the sole means of intervention.

Recruitment

The study recruited through the iCST group. As CST for the person living with dementia approached an end, their caregivers were invited to attend the iCST group in October 2023. During the first group session, potential participants were made aware of the research project through use of a study advert (Appendix G). In the second session, they were asked by the group facilitator whether they would like further information on the research project and if so, they were provided with the participant information sheet (Appendix H).

In the final session of the group, the research project was discussed by the group facilitator to allow caregivers an opportunity to ask questions regarding the research. Facilitators suggested that if potential participants were willing to engage in the research, the group facilitator would pass this onto the researcher on their behalf. Following that, telephone contact was made by the researcher one-week following group completion to those who expressed interest, to provide further information about the research, and answer any questions. If participants wanted to proceed, a suitable time and method for interview was then agreed.

Eligibility Criteria

Eligibility criteria were developed with a consultant clinical psychologist experienced working within memory services. Inclusion criteria were as follows:

- Informal caregiver of a person living with dementia
- Person living with dementia must be open to the Trust's memory services
- Person living with dementia must have attended CST group
- Informal caregiver must have attended all sessions of the iCST 'train the carer' group
- English speaking (due to lack of funds available for translation).

Participants

The proposed sample size was ten, across a minimum of two 'train the carer' groups to enhance generalisability of findings. Eight dementia caregivers opted into the group during the recruitment time frame. Seven caregivers attended all group sessions, and all agreed to participate in a research interview (the eighth individual was ineligible due to missed sessions). Participant socio-demographic details can be seen in table one.

Recruitment was concluded both because no further 'train the carer' groups ran during the recruitment time frame, and because information power was identified by the researcher during analysis, noting a repetition of responses across participants. Information power indicates that if a sample holds more information, relevant to the research question, then a lower number of participants can be considered acceptable (Malterud et al., 2016). Braun and Clarke (2013) suggested that for small projects at the professional doctorate level, 4-10 participants are recommended for interviews, as obtained in the current study.

Table 1.

Participant Socio-demographic and support details.

Name	Age	Gender	Ethnicity	Diagnosis of PLWD	Relationship to PLWD	Years spent caring	Time spent caring (hours per week)
Derek	85	Male	White British	Mixed Type	Husband	0.5	28
Howard	75	Male	White British	Vascular	Husband	2.5	10
Sarah	53	Female	White British	Alzheimer's	Daughter	2.5	25
Kate	77	Female	White British	Mixed Type	Wife	2	70
Jayne	72	Female	White British	Mixed Type	Wife	3.5	70
Sylvie	56	Female	White British	Mixed Type	Wife	3	2
Mary	65	Female	White British	Alzheimer's	Wife	1.5	1

Participants were aged 53-85 (*mean*=69) years, residing in the UK and were White British. There were five females and two males. Participants cared for people living with Alzheimer's disease (*n*=2), Vascular dementia (*n*=1), and Mixed Type dementia (diagnosed when different sub-types present for a person i.e. both Alzheimer's and Vascular features) (*n*=4).

Participants' relationship to the person living with dementia included husband (*n*=2), wife (*n*=4) and daughter (*n*=1). Participants had spent between six months to three-and-a-half

years (*mean*=2.1 years) caring, spending between 1-70 hours per week providing care (*mean*=27.28 hours).

Procedure

One-to-one semi-structured interviews were conducted, following an interview schedule (Appendix I), four-weeks after group completion, to allow time to attempt to implement iCST. Prior to the interviews beginning, the researcher obtained informed consent (Appendix J & K). Six interviews took place face-to-face at an NHS base, with one interview taking place via Microsoft Teams due to personal preference. Interviews were conducted in November 2023 and lasted an average of 27 minutes (range: 16 to 38 minutes). Participants received a debrief sheet (Appendix L) at the end of interview. Interviews were audio-recorded using MS Teams and transcribed verbatim by the researcher.

Caregivers were also asked for consent to being contacted after data analysis to review research executive summary and provide feedback on whether results accurately reflected their views. All seven participants consented, and executive summary was sent via email in April 2024.

Analysis

Interview data was analysed using Reflexive Thematic Analysis according to Braun and Clarke (2022) guidelines. RTA allows for the identification, development, and analysis of patterns within and across participant data, culminating in “themes” (Braun & Clarke, 2021).

Braun and Clarke's (2006, 2012, 2013, 2014, 2021) six-step RTA framework was followed (Appendix M) throughout. The six-step process entailed dataset familiarisation, which involved the researcher listening to each interview before transcription, transcription and re-reading each transcript twice whilst noting initial key ideas in a reflective journal. Transcripts were printed, and initial codes (Appendix N) were noted by hand in transcript margins, highlighting data appearing most relevant to the research question. Coding was systematically completed using both semantic and latent coding. Initial codes were then written onto sticky notes and analysed manually by grouping the sticky notes into broader codes, which allowed for generation of patterns across the dataset. At this point, some codes were removed due to there being a minimal depth of data for these. Once grouped, broader codes were then further distilled to generate the subthemes and themes, with use of thematic maps to help organise the pattern of responses (Appendix O). During this process, subthemes and themes were reviewed by revisiting data extracts to ensure connection with the theme and relevance to the research question. Developing themes were subject to review, and then further refined and defined, through discussion with supervisors and academic peers during workshops. Data extracts which best captured the themes were identified by the researcher and included in the write-up.

Rigour

Consistently utilising the six-step approach to RTA (Braun & Clarke, 2006) ensured a consistent approach to analysis throughout. The researcher also utilised the 15-item quality 'checklist' developed by Braun & Clarke (Braun & Clarke, 2021, p.269) during analysis, which encourages researchers to evaluate the transcription process, coding, analysis, and the written report.

Following initial analysis, themes were discussed with the research supervisor and peers during RTA-focused workshops which offered credibility checks. Direct quotations were used during write-up and samples of the data analysis are provided (Appendix P), collectively increasing transparency and trustworthiness of the research (Patton, 2002). Finally, participants were provided with opportunity to feedback on whether results accurately encapsulated their views, acting as a further rigour check.

Reflexivity and Epistemology

In qualitative research, researchers must make their (epistemological and other) assumptions explicit (Holloway & Todres, 2003). In this instance, the analysis was underpinned by a constructivist ontology and an interpretivist epistemology (Rohleder & Lyons, 2017). This, in keeping with RTA, allowed for an inductive approach to analysis, whereby the coding and theme development are driven by the data content (Byrne, 2021). Further, this approach allowed the researcher to consider their personal experience and understanding of the subject.

Constructivism posits that there is no single reality or truth, but rather reality is created by individuals. This ontological position provides opportunities for participants to express their interpretations of their experiences. Given the interpretivist epistemology, reality is interpreted from the data, allowing the researcher to discover the underlying meaning of events for participants.

The researcher utilised a reflexive approach throughout. Subsequently, the researcher considered how their own experience as a dementia caregiver, alongside experience working within memory and dementia services, proved an asset to the research. This likely enabled

the researcher to establish rapport with participants, potentially yielding richer data as a result, as well as providing a helpful framework for making sense of participant responses.

Although the researcher brought rich knowledge of their lived and clinical experience to the research, use of a reflective diary was important to ensure any output remained true to participants' experience of caregiving. Utilisation of a reflective diary and supervision throughout the research process, supported awareness of the researcher's role in the research (Braun & Clarke, 2021), aided transparency and ultimately credibility of the research. Within this diary, the researcher acknowledged their experiences, their interpretations, and how these would impact on their approach to the research.

Results

The RTA resulted in three overarching themes: *Motivations to engage with iCST*, *"It's just that it helps you to make the most of the day you've got"* and *Challenges of implementing iCST into real life.* Eight subthemes were also identified (see Table Two).

Table 2.

Themes and Subthemes.

Theme	Subtheme
1. Motivations to engage with iCST	1.1. Choosing the right time 1.2. Opportunity to meet and share ideas
2. "It's just that it helps you to make the most of the day you've got"	2.1. Feeling empowered, resourced and directed 2.2. Opportunity for connection within dyads 2.3. Increased autonomy reduces carer load: "If it's benefit to him, it's benefit to me" (sic).

3. Challenges of implementing iCST into real life	3.1. Juggling demands: "Everything seems to pile up over us" 3.2. Burdened with the responsibility 3.3. Restricted by formality: "It wouldn't feel natural and organic"

Theme 1: Motivations to engage with iCST

This theme captures caregivers' experiences of deciding whether to use iCST, considering factors which impacted their level of motivation to implement including subthemes of *choosing the right time* and *opportunity to meet and share ideas.*

1.1. Choosing the right time.

Participants reported through learning iCST and considering whether to implement the intervention, they became aware that they were already engaging in several stimulating activities as routine: "We go out a lot, drive out a lot […] he's doing everything he was taught to do… he did that anyway" (Sylvie). Participants therefore perceived they were already engaging in iCST: "I think in a lot of ways we are doing it without realising we're doing it" (Kate).

This led to a reduced motivation to engage with the intervention, as participants reported they wanted their loved ones living with dementia to continue with the activities they already did, in favour of iCST: "At the moment, he's just you know, happy doing what he's doing […] so that's a good thing" (Mary). This appeared closely connected to the stage of dementia

which the person was currently in, with those in the earlier stages of dementia reporting a lesser need for iCST.

1.2. Opportunity to meet and share ideas.

Participants shared that attending the 'train the carer' group boosted their motivation to engage with iCST. Participants reported the group provided opportunity to share "good ideas" (Kate) as to how carers might implement iCST, aiding motivation to implement iCST principles at home, for example:

"One lady wanted something for her husband […] They wanted to know what things to do to stimulate. So, I said I used to work with prisoners. The prisoners used to make matchstick models […] that was useful. So, two or three have said we're going to go and try it now" (Howard).

There was a sense that the knowledge harboured collectively was greater than the knowledge carers would have had individually: "I'd never thought of anything like that alone" (Jayne), which led carers to feel grateful for the opportunity to have learnt from each other, thereby increasing the likelihood of carers choosing to implement iCST.

Theme 2: *"It's just that it helps you to make the most of the day you've got"*

This theme captures the different benefits of iCST caregivers perceived, including subthemes of *Feeling empowered, resourced and directed*, *Opportunity for connection within dyads* and *Increased autonomy reduces carer load:* "*obviously if it's benefit to him, it's benefit to me" (sic).*

2.1. Feeling empowered, resourced and directed.

Participants identified that engaging in iCST offered them something tangible they could utilise to support a person living with dementia. The group provided opportunity to learn something new to support their loved one living with dementia, which appeared to empower caregivers with new tools to use and was seen as a benefit to engagement with iCST: "If we hadn't of gone to the group […] we wouldn't have even thought how puzzles or looking at a photo album could make any difference" (Mary). Further, the intervention appears to have offered a sense of direction day-to-day for carers: "It's just that it helps you to make the most of the day you've got" (Jayne), providing meaningful activities for carers to use with their loved one: "It gets her from sitting staring at the television" (Sarah).

Being able to provide something to do for a loved one living with dementia appears to have led to carers "feeling better" (Derek) about their caregiving role, as it was something they could put into action, despite the progressive nature of dementia: "When the day of reckoning does come, I know I've done everything I can for my mum." (Sarah).

2.2. Opportunity for connection within dyads.

Participants identified that engaging in iCST increased connection between them and the person living with dementia. Increased connection appeared to be fostered by a shift in presentation of their loved ones living with dementia, whilst engaging in iCST sessions. Participants reported noticing people living with dementia were actively engaged in the intervention: "I could see the cogs moving, I could actually see her taking it in" (Sarah). This shift in presentation appeared to allow for connection, despite the dementia diagnosis, as it appears to have reoriented people living with dementia: "It's like my mum again" (Sarah).

Engaging in iCST appears to also evoke connection by inviting carers to engage in reminiscing themselves alongside the person living with dementia, for example reflection on happy times: "you're like oh, god, yeh when we did that when we went there" […] from when we were happy, and we were doing stuff" (Mary).

2.3. Increased autonomy reduces carer load: Obviously if it's benefit to him, it's benefit to me' (sic).

Participants reported that the benefits to their loved ones living with dementia attributed to iCST, also benefitted them. The benefit to caregiver well-being appeared somewhat dependent on the benefits for the person living with dementia, reflecting a symbiotic relationship.

Caregivers expressed that iCST helped to reduce their mental load, by increasing autonomy and motivation in the person living with dementia. For example, Jayne described a shift in interactions with her husband following engagement with iCST: *"And that's you know instead of me saying, you've got to get your shoes on, we're going now […] he'll say now "Oh, yeah, better get sorted. Got to get my shoes on, see what I mean?"*

Engaging in iCST resulted in less pressure on caregivers to persuade their loved ones to engage in activities, as individuals with dementia displayed initiative: "If it improves his attitude to things, I suggest we do, then that's beneficial to me" (Kate). Collectively, it appears these changes reduced caregiver burden by reducing day-to-day stressors in interactions, indicating a mutually beneficial intervention for both the caregiver and the person living with dementia.

Theme 3: Challenges of implementing iCST into real life

This theme captures the challenges reported by caregivers in implementing iCST into their real-world context following engagement with the group, including subthemes of: *Juggling demands: "Everything seems to pile up over us nowadays", Burdened with the responsibility* and *Restricted by formality: "It wouldn't feel natural and organic".*

3.1. Juggling demands: "Everything seems to pile up over us nowadays"

Nearly all participants identified that competing demands acted as a preventative barrier from engaging in iCST. For some carers, this was due to their responsibilities held away from caring, particularly those who still worked. For other participants, the competing demands of other engagements such as hobbies and interests led to a shortage of time: "during the day, we're either going places or he's busy you know in the garage or gardening" (Mary).

Participants also highlighted that engaging in the intervention was difficult due to the time-consuming demands of providing care: "The time is difficult, because everything seems to pile up over us nowadays. Because everything that you've got to do takes a lot longer to do" (Kate). Further, there was a recognition that often caring for someone with dementia entails more generalised time-consuming caring demands, for example, physical health concerns. The apparent pressure of multiple simultaneous demands on caregivers was a barrier to implementation.

3.2. Burdened with the responsibility.

Caregivers recognised that the onus of responsibility to organise and implement iCST was on them, as the person living with dementia is unable. Language used by participants

indicated a strong sense that this is something they "should do" (Derek), despite other pressures. Participants recognised that implementing iCST requires thought and forward planning, such as deciding session topics. The extra work required was therefore a barrier for some caregivers: "I mean, it's more for me to think about" (Sylvie).

Beyond the organisation of sessions, it was apparent sessions required effort from caregivers to adhere to the iCST model, as opposed to passive engagement. For example, in the way they discuss topics: "For me. It's harder work, because I've got to, instead of just saying, oh, it's so and so, I've got to then sort of try and work out paths to go down to get him where he needs to be" (Jayne). Taking the 'leader' role in iCST sessions was a clear barrier to engagement, as it increased responsibility for caregivers already under pressure.

3.3. *Restricted by formality: "It wouldn't feel natural and organic"*

The perceived formal nature of iCST was a barrier to implementation, as caregivers felt the intervention was "too much orientated towards, you've got to do a formal thing. You've got to sit down, and you've got to put this together and you've got to have this and you've got to have that" (Kate). It was reflected that this would reduce engagement with iCST, as constraints on caregivers' time meant stringent requirements of iCST seemed more difficult.

Further, there was an apparent worry that this style of approach, akin to a student-teacher dynamic, might "turn off" (Kate) their loved ones, and participants felt that you would not "get such a good result from people" (Kate) as a result. Instead, participants seemed to be yearning for a more natural means of stimulating their partners, with less formal requirements: "I think it has to be organic. Doesn't it?" (Sylvie).

Discussion

As the number of people living with dementia, and informal caregivers continues to rise, this research aimed to understand caregivers' experiences of delivering iCST, with the hope of understanding whether iCST may be a viable alternative to traditional clinician-delivered CST, adding to existing research considering how best to support those living with dementia. An RTA of seven semi-structured interviews resulted in three themes: *Motivations to engage with iCST, "It's just that it helps you to make the most of the day you've got",* and *Challenges of implementing iCST into real life.* These themes encapsulate both the benefits and challenges encountered by dyads whilst attempting iCST.

The first theme "*Motivations to engage with iCST*" relates to the caregivers' decision-making regarding whether to implement iCST, highlighting factors which affect their motivation to engage. The subtheme: "*Choosing the right time"* indicates this decision was partly informed by caregiver's perception of iCST as something they already did, with caregivers indicating their existing means of stimulation took precedence over iCST, reducing motivation to engage. This may be due to 'opportunity costs' and 'perceived effectiveness' processes described in Sekhon et al's (2017) theory of acceptability. In this instance, it appears caregivers perceived the extent to which personal benefits, such as means of enjoyment from existing stimulation, needed to be given up to engage in iCST as too great. Further, participants appear to perceive iCST as less likely to achieve its purpose than existing means of stimulation. Collectively, these factors likely led to reduced acceptability of iCST for some participants, thereby reducing engagement.

This preference for existing stimulation, whilst understandable, given the importance of routine for people living with dementia (Telenius et al., 2022) is potentially problematic. It

indicates caregivers are waiting to use iCST when their loved one living with dementia has declined further and is no longer able to engage with existing means of stimulation. However, research indicates that the further progressed the dementia, the lower the response to a cognitive intervention (Onder et al., 2005). Further, implementing cognitive interventions with people with more severe cognitive decline is an even more difficult task for caregivers, resulting in demotivation and low adherence (Silva et al., 2021). Findings highlight the need to empathise the perceived benefits of early engagement in interventions with caregivers, to slow down cognitive deterioration in the earlier stages of dementia.

The second subtheme "*Opportunity to meet and share ideas"* suggests the group context was important. To the author's knowledge, this is the first study to examine the effects of learning iCST in a group, with results indicating that group learning motivated dyads to implement the intervention and optimised their engagement. It appears the group increased caregivers' self-efficacy, boosting acceptability and implementation of iCST (Sehkon et al., 2017). Indeed, research indicates peer support established in group training programmes improves caregiver emotional support and engagement with the intervention (Saita et al., 2016; Cheung et al., 2021). Previous research exploring other psychological interventions indicates groups allow attendees to communicate with others in a similar situation, share ways to cope with challenges, and learn from each other (Dal Bello-Haas et al., 2014), as in the current study.

The second theme *"It's just that it helps you to make the most of the day you've got"* captured perceived benefits of the intervention, for both caregivers and people living with dementia, despite iCST not primarily targeting caregivers. The subtheme '*Feeling empowered, resourced and directed'* appears to map onto the body of literature indicating

caregiving can help to make dementia carers feel good about themselves and feel as if they are needed (Lloyd et al., 2016). Benefits to caregivers have also been noted in other studies considering caregiver-delivered interventions for dementia (Poon, 2022; Kor et al., 2024). Findings suggest that involving both people with dementia and their informal caregivers may yield indirect benefits, which would not come with targeting only half of the dyad (Poon, 2022). This is important as carers who report positive aspects of caregiving, including sense of purpose, report lower levels of depression and anxiety as well as increased morale (Quinn & Toms, 2019), which will likely prolong their ability to provide care.

iCST also provided '*Opportunity for connection within dyads'*, with participants appreciating the framework iCST provided to connect with their loved ones. This opportunity for connection appears to have strengthened relationships, with similar results found in previous studies of iCST (Leung et al., 2017), as well as wider evidence that cognitive support provided by carers can help to improve the relationship quality (Genoe & Dupuis, 2014) and enhance carer well-being (Moon & Adams, 2012).

The subtheme '*Increased autonomy reduces carer load: Obviously if it's benefit to him, it's benefit to me' (sic)* may provide further insight into how iCST helped to improve the quality of the caregiving relationship. Participants noticed shifts in loved ones living with dementia which manifested as increased autonomy and motivation. Caregivers reported this benefitting them as it reduced the need for caregivers to direct and make demands of the person living with dementia, likely impacting on levels of burden. Collectively, all positive shifts to the caregiving relationship are important as a positive caregiving relationship is positively related to care-recipient wellbeing (Burgener & Twigg, 2002), caregiver wellbeing (Quinn et al., 2009), and longevity of caregiving abilities. Sekhon et al's (2017) theory

suggests the collective perceived benefits of iCST likely improved caregivers' affective attitude towards the intervention, increasing perceived acceptability of iCST for caregivers.

It is however important to note that whilst in the moment changes were noted in the person living with dementia whilst engaging with the intervention, there were no comments from participants on whether those changes were maintained beyond iCST sessions. The lack of a reported sustained effect on cognition is in line with some existing literature investigating iCST, with other studies reporting no improvement in cognitive function (Orrell et al., 2017). However, it is worth noting that research interviews took place only four weeks following completion of the iCST training programme, which may not have been a sufficient time frame to assess effects on cognition.

Nonetheless, it is difficult to ascertain whether the lack of a reported sustained effect on cognition in the current study was due to iCST itself being ineffective, or whether the difficulty was adherence to the model, especially as implementation of iCST, in its manualised form, was limited. At the time of interview, only one participant was implementing iCST as set out in the manualised approach. It is important to reflect that lack of implementation is not specific to this study (Cheung et al., 2021), with a large-scale RCT (Orrell et al., 2017) also noting challenges implementing the iCST model, with 22% of dyads not completing any sessions.

When considering the barriers to implementation, it is unsurprising that the primary challenge encountered by caregivers was competing demands, as outlined in theme three: *Challenges of implementing iCST into real life*. Previous research into caregiver-delivered interventions noted similar (Cheung et al., 2021), with difficulties adhering to interventions

attributed to caregiving burden, multiple obligations (i.e., work/childcare/hobbies), lack of time and increased workload for carers due to planning and organising interventions. When tasked with competing demands, dementia caregivers often have little time or energy for 'pleasurable' or additional activities (Nichols et al., 2008), and iCST may be seen as an 'add-on' activity in comparison to the tasks which *need* doing (i.e. personal care, administration).

Caregivers also recognised feeling "*Burdened with the responsibility"* to organise iCST sessions, adding to their own demands. Further, caregivers reported feeling "*restricted by formality*" reflecting that the stringent requirements of manualised iCST (Yates et al., 2014) acted as a barrier to their engagement. By formality, participants reported they did not like the 'sit down' nature of the sessions which felt artificial.

Sekhon et al (2017) identified 'Burden' as one facet of acceptability, indicating that the perceived amount of effort required to participate in the intervention impacts whether an intervention is perceived as acceptable. Theme three appears to suggest the existing demands placed on caregivers, alongside the requirements of iCST, led to a reduced sense of acceptability, lowering implementation.

Strengths and Limitations

This study aimed to provide new information in a growing area. The group aspect is to the author's knowledge, novel, and therefore provides new information adding to existing literature considering how best to support people living with dementia and their caregivers. However, the 'train the carer' group explored in the current study was based on the iCST programme developed by Yates et al. (2014), despite it being already established that caregivers found intervention delivery burdensome (Leung et al., 2017). Further, people living with dementia had already engaged in traditional CST groups. As a result, it is difficult

in the current study to isolate the effects of iCST to establish whether iCST is an acceptable alternative to CST.

Nonetheless, to build on the limitations of previous research, the current research included seven of the eight individuals who attended the iCST group. It is hoped that encapsulating all who attempted to iCST reduced bias and yielded greater insight into factors impacting engagement. It is, however, likely that a risk of bias remains as participants eligible for participation in the research had opted to engage in the iCST group, indicating a degree of motivation. Motivation is an important factor in the success of psychological interventions, with positive results most likely to occur when participants are motivated, and personally invested (Ryan & Deci, 2008). Consequently, current findings may not generalise to less motivated caregivers.

There was a degree of heterogeneity in the sample with significant variation in years and hours per week spent caring, which undoubtedly impacted on time available to engage with the intervention for those providing more care. There was further heterogeneity in the ages of participants, with older caregivers often expressing their own difficulties due to age. It therefore felt unethical to probe said caregivers further, which led to shorter interview times, likely impacting the depth of data achieved in some interviews. Finally, the sample was small and specific to only one iCST intervention group, despite intentions to recruit from more groups. Though the sample size was deemed acceptable, above limitations limit transferability of findings.

Further, interviews took place only four weeks following completion of the iCST group. This relatively short timeframe leaves it impossible to ascertain any longer-term

effects. Finally, all participants were White British. As such, it is recommended future research seeks a representative sample with greater diversity (Allmark, 2004), especially as research has highlighted potential differences in the way dementia is viewed (less of a public health problem with vast negative connotations) in non-Western countries (Cipriani & Borin, 2014).

Clinical Implications

The current study, as well as previous research (Orrell et al., 2017, Leung et al., 2017), highlights low implementation of iCST, with few dyads able to implement iCST as suggested, indicating that iCST is not acceptable or feasible for dyads. This suggests caregivers require more support to utilise the intervention, to increase its acceptability. For example, in the current study, no further contact from healthcare services was made with dyads following completion of the 'train the carer' group. Future interventions should consider ongoing monitoring and support for dyads in utilisation of iCST to support engagement (Milders et al., 2013), as this has been found to boost implementation (Kor et al.,2024).

Caregivers in the current study identified factors which could support implementation of iCST, including group learning, establishing peer support, and sharing ideas. Learning iCST in a group appears to have been facilitative, with benefits noted which differed to those harboured when learning iCST individually. This carries potential important clinical implications, suggesting group learning may enhance engagement with iCST, and caregiver-delivered interventions more generally.

Currently, there is ultimately not enough support, both within the current study and wider literature, which favours the implementation of iCST over traditional CST. Nonetheless, iCST clearly has benefits, especially to the caregiving relationship. This is important, as a positive caregiving relationship can prolong caregivers' ability to provide care (Yang et al., 2014), which reduces pressure on social resources (Livingston et al., 2017), contributing to its cost-effectiveness.

There are also clear benefits to iCST for those living with dementia for whom traditional CST is not an option. It is well established that a complete lack of cognitive activity accelerates cognitive decline, particularly in dementia (Salthouse, 2006). As such, there is a clear benefit to offering iCST in instances where traditional CST is not accessible, however, this requires the support of a motivated caregiver, which may not always be a reality for people living with dementia.

The current research was the first to consider iCST as a means of maintenance therapy, with people living with dementia having already completed traditional CST. This is important given reports that any gains in cognitive performance tend to disappear within weeks following cognitive interventions (Reid et al., 2012). Therefore, if iCST can be developed to be more feasible for dyads, it could be a useful offering to maintain any effects gained during CST.

Finally, incorporating caregivers into the delivery of an intervention allowed for a sense of purpose and opportunity for connection, with research indicating it yielded a therapeutic effect for caregivers. This should be considered when developing future

caregiver-delivered interventions for people living with dementia, to enhance caregiver wellbeing, fidelity to any intervention and overall effectiveness.

Future Research

Despite the promising insights, the findings from this study alone are not enough to draw sufficient conclusions due to study limitations, and as such, more research is needed to validate findings. Further research should consider the use of a longer-term follow-up period, as well as a more diverse sample.

Future research could also build on existing studies, particularly the barriers to implementation, to explore potential ways to improve engagement and acceptability of iCST. Research has already started to consider how to adapt iCST to be more feasible, including development of an iCST app with mixed results (Rai et al., 2021). Whilst no one component of a caregiver-delivered intervention can remove other existing competing demands for carers, consideration should be given as to how best to reduce the demands associated with any caregiver-delivered intervention, including iCST, to increase carer's ability to engage. Research has indicated that implementation of interventions can be influenced by the proximity between dyads and health-care professionals, with greater success when close contact is maintained between dyads and professionals (Kor et al., 2024). Further, providing caregivers with a manual with instructions and activities, supporting with ongoing monitoring of the delivery of the intervention, and utility of a short and succinct programme (Milders et al., 2013; Cheung et al., 2021; Silva et al., 2021) have also been shown to increase implementation. Research could draw on these factors, as well as findings from the current research, when considering design and protocol of future caregiver-delivered iCST

interventions. Inclusion of caregivers as well as people living with dementia in this process will be critical, to ascertain feasibility.

Finally, any future research considering iCST could assess iCST as a standalone intervention, with the potential to compare experiences with dyads who receive iCST as an adjunct to traditional CST groups, to understand further whether iCST is acceptable as its own intervention, or best utilised as a means of maintenance, in conjunction with CST, as explored above.

Conclusions

Overall, the themes yielded in the current RTA paint a mixed picture, indicating important factors which both facilitate and act as barriers to engagement with iCST. Clearly, there are benefits for the caregiver, care-recipient and dyads collectively, which likely prolong a caregivers' ability to provide care. However, it is apparent that iCST as currently explored is not feasible for caregivers. There is not enough evidence to support the use of iCST over typically clinician-delivered CST but iCST may offer a helpful alternative for those who cannot attend CST, or as a means of maintenance. Further research is needed to consider how to better support caregivers to implement iCST, whilst addressing methodological limitations of the current research.

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Appendices

Appendix A. *Ageing and Mental Health Instructions for Authors*

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=camh20#checklist-what-to-include

Appendix B. *Ethical approval from Yorkshire and The Humber - Sheffield NHS Research Ethics Committee.*

NHS
Health Research Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee
NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Telephone: 0207 104 8388

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

22 May 2023

Dr Helen Scott
Staffordshire University Doctorate in Clinical Psychology
Science Building, Leek Road
Stoke-on-Trent
ST4 2DF

Dear Dr Scott

Study title:	**Informal carers' experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis**
REC reference:	**23/YH/0098**
Protocol number:	**N/A**
IRAS project ID:	**325146**

Thank you for your letter responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-

committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 325146	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

On Behalf Of
Dr Tim Sprosen
Chair

Health Research Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee

NHS Blood and Transplant Blood Donor Centre
Holland Drive
Newcastle upon Tyne
Tyne and Wear
NE2 4NQ

Tel: 0207 104 8388

21 August 2023

Miss Gemma H Ryan
Staffordshire University Doctorate in Clinical Psychology
Science Building, Leek Road
Stoke-on-Trent
ST4 2DF

Dear Miss Ryan

Study title:	**Informal carers' experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis**
REC reference:	**23/YH/0098**
Protocol number:	**N/A**
Amendment number:	**Amendment 1**
Amendment date:	**09 August 2023**
IRAS project ID:	**325146**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [325146 Amendment 1]	1	09 August 2023
Copies of materials calling attention of potential participants to the research [325146 Research Study Advert V4 09082023]	4	09 August 2023
Research protocol or project proposal [Research Protocol V3 09082023]	3	09 August 2023

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 325146:	**Please quote this number on all correspondence**

Yours sincerely

On Behalf Of
Mrs Yvonne Stephenson
Chair

E-mail: sheffield.rec@hra.nhs.uk

Appendix C. *NHS Health Research Authority.*

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Helen Scott
Staffordshire University Doctorate in Clinical Psychology
Science Building, Leek Road
Stoke-on-Trent
ST4 2DF

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

22 May 2023

Dear Dr Scott

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Informal carers' experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis**
IRAS project ID:	**325146**
Protocol number:	**N/A**
REC reference:	**23/YH/0098**
Sponsor	**Staffordshire University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **325146**. Please quote this on all correspondence.

Yours sincerely,
Libby Williamson
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Professor Nachiappan Chockalingam*

Appendix D. *Staffordshire University Ethics Committee.*

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name	Gemma Ryan
Title of Study	Informal carers' experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis
Status of approval	**Approved**

Thank you for your request to make an amendment to your application to the Independent Peer Review (IPR) panel. Details of the amendment are as follows:

Change to research process: a reduction of available sessions over which participant recruitment takes place.

Your application is now **approved**.

Action now needed:
You must now apply through IRAS for approval. You must not implement the changes to your study before this second approval. Relevant sites might also need to be notified prior to the implementation of the change.

Please forward a copy of any approval letter you receive from the HRA to Edward Tolhurst at e.tolhurst@staffs.ac.uk, copied to ethics@staffs.ac.uk, as soon as possible after you have received approval.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the University ethics committee an end of study report.

Comments for your consideration: *This letter supersedes the letter sent on 23rd January 2023, which incorrectly referred to a reduction of interviews.*

Signed: Dr Edward Tolhurst
University IPR ethics coordinator

Date: 24th January 2023

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name	Gemma Ryan
Title of Study	Informal carers' experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis
Status of approval	**Approved**

Thank you for your request to make an amendment to your application to the Independent Peer Review (IPR) panel. Details of the amendment are as follows:

A reduction in the timescale after their involvement in the intervention group to arrange the interviews (4 weeks rather than 8 to 12 weeks).

Your application is now **approved**.

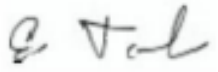
Action now needed:
You must now apply through IRAS for approval to apply these changes. You must not implement the changes to your study without relevant NHS approvals.

Please forward a copy of any approval letter you receive to ethics@staffs.ac.uk, as soon as possible.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send the university ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

Comments for your consideration: None.



Signed: Dr Edward Tolhurst
University IPR ethics coordinator

Date: 4th August 2023

Appendix E. *Local NHS Trust Capacity and Capability Approval*

Gemma Ryan (RRE) MPFT

From:	Christopher Flanagan (RRE) MPFT
Sent:	03 July 2023 14:41
To:	Gemma Ryan (RRE) MPFT
Cc:	Chantel-Lea Grocott (RRE) MPFT; Liz Glaves (RRE) MPFT
Subject:	IRAS 325146 Gemma Ryan Staffordshire University – Confirmation of Capacity and Capability at MPFT
Attachments:	Organisation Information Document V1 13022023.docx

Dear Gemma,

RE: IRAS 325146 – Confirmation of Capacity and Capability at MPFT

Full Study Title: Informal carers' experience of delivering individual cognitive stimulation therapy to a person living with dementia: A Reflexive Thematic Analysis

On behalf of Ruth Lambley-Burke (Head of R&I), this email confirms that **Midlands Partnership University NHS Foundation Trust** has the capacity and capability to deliver the above referenced study; please find the agreed Organisation Information Document attached as confirmation.

If you wish to discuss further, please do not hesitate to contact me; good luck with your study.

Many thanks,
Chris

Chris Flanagan
Research Support Administrator
Branch Chair – UNISON South Staffs & Shropshire Healthcare Branch (12278)
Pronouns: he/him #pushforpronouns

Midlands Partnership University NHS Foundation Trust
Telephone: 01785 783170 (internal ext: 7128770) / 07580 971489
Working days – Monday, Wednesday, Thursday, Friday

mpft.nhs.uk
@mpftnhs
@mpftnhs
@mpftnhs
mpftnhs

Together we are making life better for our communities

Appendix F. *Research Risk Assessment.*

RISK ASSESSMENT

Identified Risks	Likelihood	Potential Impact/Outcome	Risk Management/Mitigating Factors
Identify the risks/hazards present	High/Medium/Low	Who might be harmed and how?	Evaluate the risks and decide on the precautions, e.g., Health & Safety
Discussion of a sensitive topic in an interview has potential to cause distress to participant	Medium	Participant: • Psychological stress Researcher: • Anxiety about dealing with a complex situation	• Offer to cease interview in incidents of heightened distress. • Signpost participant to support services following interview (in debrief form) including clinician with knowledge of dementia care within MPFT and third sector dementia specialist organisations.
Travel risks to location of research project: • Road accident	Low	Researcher: • Physical injury • Psychological harm	• Researcher to be aware of physical environment. • Research to be aware of health and safety policies of research location: • Fire alarms • Location of fire alarms & exits
Disclosure of information about poor practice	Low	Response may be required from service providers.	• Ensure all verbal and written information about research indicates possible researcher response to disclosure
Disclosure of unmet health or social care needs	Medium	Response may be required from service providers.	• Ensure all verbal and written information about research indicates possible researcher response to disclosure.

Research participant in danger of harm to self or others	Low	Response may be required from service providers.	• Ensure all verbal and written information about research indicates possible researcher response to disclosure.
Researcher in danger of harm to self (in participant's home environment).	Low	Researcher: • Injury	• Researcher will act in accordance with Midland's Partnership NHS Foundation Trust lone working policy which can be found at: Lone Working SOP.pdf (sharepoint.com) • Key points include: • Researcher to ensure diary is up to date ahead of meeting with addresses and locations of interviews so that colleagues/supervisor can access where researcher is. • Researcher to make arrangements with a colleague/supervisor ahead of meeting, and agree that they will make contact with each other at pre-arranged intervals to check in. • Following interview, the researcher will check in again with buddy to ensure that they are OK following the meeting. • Researcher will have Mobile Phone charged and with them at the interview in case of any escalation in risk.

Appendix G. *Study advert.*

Appendix H. *Participant Information Sheet.*

INFORMATION SHEET FOR PARTICIPANTS

***IRAS Project ID**:* 325146

Title of study: Informal carer's experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis.

My name is Gemma Ryan and I am a trainee clinical psychologist currently studying at Staffordshire University. I would like to invite you to participate in this research project which forms part of my doctoral research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to contact me through the details provided below if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The primary purpose of the study is to explore your experience of delivering individual cognitive stimulation therapy to a person living with dementia, following your engagement in the 'train the carers' group delivered by Midlands Partnership NHS Foundation Trust (MPFT). Currently, there is limited research that considers what it is like to try and deliver individual cognitive stimulation therapy on a one-to-one basis in a person's home environment. There is even less research on how carers experience delivering this therapy, which is why I would like to explore your experiences in my research.

Why have I been invited to take part?

I am inviting you to take part in the study because you have recently attended the 'train the carers' group delivered online by Midlands Partnership NHS Foundation Trust. You are invited to take part in the study if:

- You attended all three sessions of the 'train the carers' group.

What will happen if I take part?

If you choose to take part, you will be invited to take part in an interview. The interview will last approximately 30 minutes to one hour. The interview itself will be an open-ended conversation focusing on your experience of delivering individual cognitive stimulation therapy including questions such as: "Can you please tell me about your experience of being part of the train the carer group?"

The location of the interview is dependent on your preference. The interview can be held online or alternatively, we can meet face-to-face, either at a Midlands Partnership NHS Foundation trust location most convenient for you or at your home address. It is important that if we meet online or at your home, you are able to ensure access to a quiet and confidential space in which you would feel able to talk freely about your experiences.

As part of the interview process, our meeting will be audio recorded. The interview will be recorded on a secure NHS mobile phone, both for face-to-face and online interviews. This will only occur if you are happy to consent to the recording, and I will indicate the start of the recording. The reason for audio recording is so I can then write up our conversation and ensure nothing is missed when I come to analyse your responses.

I will be analysing your responses alongside others who have also attended the group to collect a broad range of experiences and collate them into fitting themes and patterns. As the

interview questions will be open-ended, this offers you the opportunity to be as open as you are comfortable with in your response.
Once I have completed analysis of the interviews, I would like to meet with participants once more to gather feedback from those who have participated in my interviews on their perspective of my overall study findings and my summary of results. This however would be entirely voluntary, and you would be under no obligation to meet with me and provide feedback, even if you have participated in a previous interview.

Do I have to take part?
No. Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, I will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?
Whilst I am not intending to cause any harm or distress through my research, it is worth noting the topic of dementia can at times be an understandably emotive discussion. As a result, it is possible that the topics discussed in the interview may leave you feeling upset. Should taking part in the interview leave you feeling in need of support, a clinician with knowledge in dementia care within Midlands Partnership NHS Foundation Trust has made themselves available to provide emotional support after the interview. Her details can be found below, as well as more general sources of support.

Midlands Partnership NHS Foundation Trust Clinician:
Dr Angela Smith
Midlands Partnership NHS Foundation Trust
Telephone: 0300 303 3428 (West) 0300 303 3427 (East)
Email: angela.smith2@mpft.nhs.uk

Other resources:

A number of charities and voluntary organisations provide support and advice for dementia carers on their websites and via their helplines:

- Alzheimer's Society's Dementia Connect support line on 0333 150 3456
- Alzheimer's Society's online community: 'Talking Point' (free and available 24 hours a day)
- Age UK Advice Line on 0800 678 1602 (free)
- Carers UK helpline on 0800 808 7777 (free)
- Carers Direct helpline on 0300 123 1053 (free)
- Dementia Carers Count has a virtual carers centre that provides a range of online support and resources.
- Mind Infoline on 0300 123 3393 – Provides information and signposting service on mental health difficulties.

What are the possible benefits of taking part?
There are no set rewards for taking part in the study. Although taking part in a research study may not be of immediate benefit to you, it is hoped the findings of this research will help further understanding of how best to support individuals diagnosed with dementia and their

caregivers. This has the potential to have implications for the future of dementia care, which may one day benefit others in a similar situation to yourself.

Data handling and confidentiality

Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2016 (GDPR).

After your interview is completed, the interview recording be written up by the researcher for the purpose of data analysis. At the point of transcription, your responses and information will become anonymised. This means that any identifiable information such as your name will not be included throughout analysis and the final write up of the research. Instead, a pseudonym (a fictitious name), will be used throughout, to ensure confidentiality. The pseudonym chosen can either be assigned by the researcher or you are welcome to choose this yourself.

The interview recording itself will be stored on Staffordshire University One Drive (a Microsoft service which stores and protects files) on a password protected laptop, ensuring it will not be accessible to anyone who is not authorised to do so, meaning only those involved in the research will have access to the recording. As such, any data from your interview will only be shared within the research team (myself and Dr Helen Scott) and this will be anonymised before it is shared. Research completed at Staffordshire University is auditable and, therefore, the University may require access to the anonymised data for audit purposes. The interview recording will be deleted after the interview has been written up by the researcher. The consent forms will be stored separately to any of your interview data in a locked cabinet at the university and destroyed three months after study completion. The transcribed data will be stored securely by the university for 10 years after the study and destroyed thereafter.

Data Protection Statement

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection and data portability. Questions, comments and requests about your personal data can also be sent to the Staffordshire University Data Protection Officer. If you wish to lodge a complaint with the Information Commissioners Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

You have the right to withdraw from the study, either before the interview, during it, or after you have taken part up until the point of data analysis, after interviews with all participants are completed. After this point, it is not possible for your responses to be withdrawn from the study as the responses from all participants in the study will have been anonymised and combined for the purpose of analysis. You do not have to give a reason for withdrawing, and withdrawing will not affect you in anyway. To withdraw, you will need to contact me with your unique ID (provided at interview) which we allow me to identify and withdraw your data.

What will happen to the results of the study?

It is a requirement of my Doctorate in Clinical Psychology that I carry out a piece of research, and as such the results of my research will be written up to be used within my doctoral thesis. Following completion of the study, I intend to try and publish my findings in a peer reviewed journal, which could mean the anonymised results would be more readily and publicly available. I will also share my anonymised findings with relevant stakeholders at Midlands Partnership NHS Foundation Trust, including the older adult team who developed and delivered the 'train the carers' group.

If you would like to receive a summary of the research findings, there will be an opportunity for you to provide your email address and receive a copy of the results summary following completion of the study.

Who should I contact for further information?

If you would like to take part in the study, or if you have any questions or require more information about this study, please contact me using the following contact details: Gemma Ryan: gemma.ryan@mpft.nhs.uk

Alternatively, you are welcome to contact my research supervisor at Staffordshire University. Her contact details are Dr Helen Scott: h.scott@staffs.ac.uk

The research is being sponsored by Staffordshire University.

What if I have further questions, or if something goes wrong?

If this study harms you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor (Dr Helen Scott) or the Chair of the Staffordshire University Ethics Committee for further advice and information: Professor Nachiappan Chockalingham at n.chockalingam@staffs.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix I. *Interview Schedule*

iCST Draft Interview Schedule

Establishing Rapport, Reading Information Sheet and Gaining Consent
My name is Gemma and I am a trainee Clinical Psychologist studying at Staffordshire University. I am interested in experiences of the 'train the carer' group which focused on individual cognitive stimulation therapy, as well as your experience of implementing individual cognitive stimulation therapy since the group concluded. I hope to use this information to feed back to services and improve these services.
To start with, can I ask some general questions about yourself?

- What is your age?
- What is your gender?
- What is your ethnicity?
- What type of dementia does (insert name of person living with dementia) have?
- What is your relationship to (insert name of person living with dementia)?
- How long have you been caring for (insert name of person living with dementia)?
- How many hours on average, per week, do you think you spend providing care for (insert name of person living with dementia)?

Thank you.
I want to check before we get started, do you give consent for me to audio record this interview?
Begin audio recording on device.
(TRANSITION: Let me begin by finding out more about the train the carer group).

Train the Carer Group

Can you please tell me about your experience of being part of the train the carer group?
What, if anything, do you think was helpful about the group?
What, if anything, did you think was not helpful about being in the group?
Potential PROMPTS:

- *Could you say some more about that?*
- *'What do you mean by that . . .?'*

(TRANSITION: I'm going to ask you a little bit more about your experiences of individual cognitive stimulation therapy since the group ended).

Experience since the group:

Since your participation in the group, how have you found using individual cognitive stimulation therapy with the person you care for?
Have there been any challenges associated with using iCST?
Have there been any benefits associated with using iCST?
Potential PROMPTS:

- *Could you say some more about that?*
- *'What do you mean by that . . .?'*

Thank you. I will now stop the recording.
Stop recording on device.

Closing Statement

Thank you for participating.
Provide debrief sheet.

How are you feeling?
If the participant is not feeling 'okay' and they require additional support, the researcher will obtain consent from the participant and pass on their details/inform their support team accordingly.
If you do not wish for me to pass your details on and require any additional support, please refer to the sources of support listed on the debrief sheet.
You can withdraw your data for up to four weeks following the interview.

Appendix J. *Consent Form*

NHS
Midlands Partnership University
NHS Foundation Trust

RESEARCH PROJECT CONSENT FORM

Title of Project: Informal carer's experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis.

Researcher: Gemma Ryan

			INITIAL
I have read and understood the information sheet. I have been given the opportunity to ask questions, and I have had any questions answered satisfactorily.	Yes ☐	No ☐	☐
I understand that my participation in this study is entirely voluntary and that I can withdraw at any time, up until up until the point of data analysis (suspected to be September 2023) without having to give an explanation, without my medical care or legal rights being affected.	Yes ☐	No ☐	☐
I understand that the interview will be audio-recorded, and that the researcher will make me aware once the recording has started. I consent to the interview being audio-recorded.	Yes ☐	No ☐	☐
I consent that data collected could be used for publication in a scientific journal, could be presented in scientific forums (conferences, seminars, workshops) or can be used for future research purposes, and understand that all data will be presented anonymously.	Yes ☐	No ☐	☐
I understand that Staffordshire University may require access to the anonymised data for audit and quality control purposes.	Yes ☐	No ☐	☐
I understand that all data will be sorted safely on Staffordshire University One Drive (electronic data) or locked away securely (hard copies of data) for 10 years before being destroyed.	Yes ☐	No ☐	☐
I hereby give consent to take part in this study.	Yes ☐	No ☐	☐

The next section of the consent form is voluntary and you are under no obligation to complete this part, unless you would like to consent to being involved. If you choose not to consent, this will in no way affect your experience of the interview, nor will it affect your medical care or legal rights.

		INITIAL
I consent to being contacted by the researcher at a later date, following analysis of all participant interviews, to discuss meeting for a further discussion focused on providing feedback of the research findings.	Yes ☐ No ☐	☐
I would like to receive a summary of the research results and understand that my email address is kept for this reason, but will be deleted as soon as the summary is sent out.	Yes ☐ No ☐	☐

Email address:

.....

Please turn over.

_____	_____	_____
Name Participant (print)	Date	Signature
_____	_____	_____
Name Researcher (print)	Date	Signature

1 Copy to participant, 1 copy to study file.

Appendix K. *Virtual Consent Form*

NHS
Midlands Partnership University
NHS Foundation Trust

STAFFORDSHIRE UNIVERSITY

RESEARCH PROJECT CONSENT FORM

IRAS Project ID: 325146

Title of Project: Informal carer's experience of delivering individual Cognitive Stimulation Therapy to a person living with dementia: A Reflexive Thematic Analysis.

Researcher: Gemma Ryan

I have read and understood the information sheet. I have been given the opportunity to ask questions, and I have had any questions answered satisfactorily.	Yes ☐	No ☐
I understand that my participation in this study is entirely voluntary and that I can withdraw at any time, up until up until the point of data analysis (suspected to be September 2023) without having to give an explanation, without my medical care or legal rights being affected.	Yes ☐	No ☐
I understand that the interview will be audio-recorded, and that the researcher will make me aware once the recording has started. I consent to the interview being audio-recorded.	Yes ☐	No ☐
I consent that data collected could be used for publication in a scientific journal, could be presented in scientific forums (conferences, seminars, workshops) or can be used for future research purposes, and understand that all data will be presented anonymously.	Yes ☐	No ☐
I understand that Staffordshire University may require access to the anonymised data for audit and quality control purposes.	Yes ☐	No ☐
I understand that all data will be sorted safely on Staffordshire University One Drive (electronic data) or locked away securely (hard copies of data) for 10 years before being destroyed.	Yes ☐	No ☐
I hereby give consent to take part in this study.	Yes ☐	No ☐

Appendix L. *Debrief form.*

DEBRIEF SHEET FOR PARTICIPANTS:

The current research aims to explore carer's experience of delivering individual cognitive stimulation therapy (iCST) to a person living with dementia. There is currently limited research that considers carer delivered iCST, particularly from the perspective of the carer. The current research therefore aims to better understand your experiences and ultimately add to the research considering how best to support people living with dementia and their carers.

Can I still withdraw?

Yes. Even though you have participated in the interview, you still have the right to withdraw from the current research. You can request that your interview responses are withdrawn from the study by getting in contact with Gemma Ryan (details below) and providing your unique ID. Please note, however, that withdrawing from the study will not be possible after data analysis has begun, which will be shortly after the final participant interview is completed (suspected to be December 2023).

Sources of support:

Though the current research was not intending to cause any harm or distress through my research, the topic of dementia can be understandably emotive. If you find yourself feeling upset after taking part in the interview, a clinician with knowledge in dementia care has made themselves available to provide support after the interview. Her details can be found below, as well as more general sources of support.

Midlands Partnership NHS Foundation Trust Clinician:

Dr Angela Smith
Telephone: 0300 303 3428 (West) 0300 303 3427 (East)
Email: angela.smith2@mpft.nhs.uk

A number of charities and voluntary organisations also provide support and advice for dementia carers on their websites and via their helplines:

- Alzheimer's Society's Dementia Connect support line on 0333 150 3456
- Alzheimer's Society's online community: 'Talking Point' (free and available 24 hours a day)
- Age UK Advice Line on 0800 678 1602 (free)
- Independent Age Helpline on 0800 319 6789 (free)
- Carers UK helpline on 0800 808 7777 (free)
- Carers Direct helpline on 0300 123 1053 (free)
- Dementia Carers Count has a virtual carers centre that provides a range of online support and resources.

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor Dr Helen Scott (h.scott@staffs.ac.uk) or the Chair of the Staffordshire University Ethics Committee for further advice and information: Professor Nachiappan Chockalingham at n.chockalingam@staffs.ac.uk

What next?

If you have consented to providing feedback on my research findings and executive summary, I will be in contact once I have completed analysis to arrange a suitable time to meet with you again. Please note this is voluntary, and even if you have consented today to meeting with me again, you are under no obligation to do so if you change your mind.
If you have provided your email address for a summary of the results, I will email this out to you once the study is complete.
If you have any further questions, please contact Gemma Ryan: gemma.ryan@mpft.nhs.uk.
Alternatively, you are also welcome to contact the research supervisor at Staffordshire University. Her contact details are Dr Helen Scott: h.scott@staffs.ac.uk
Thank you again for your participation.

Appendix M. *Braun and Clarke's Six-Step Reflexive Thematic Analysis Framework*

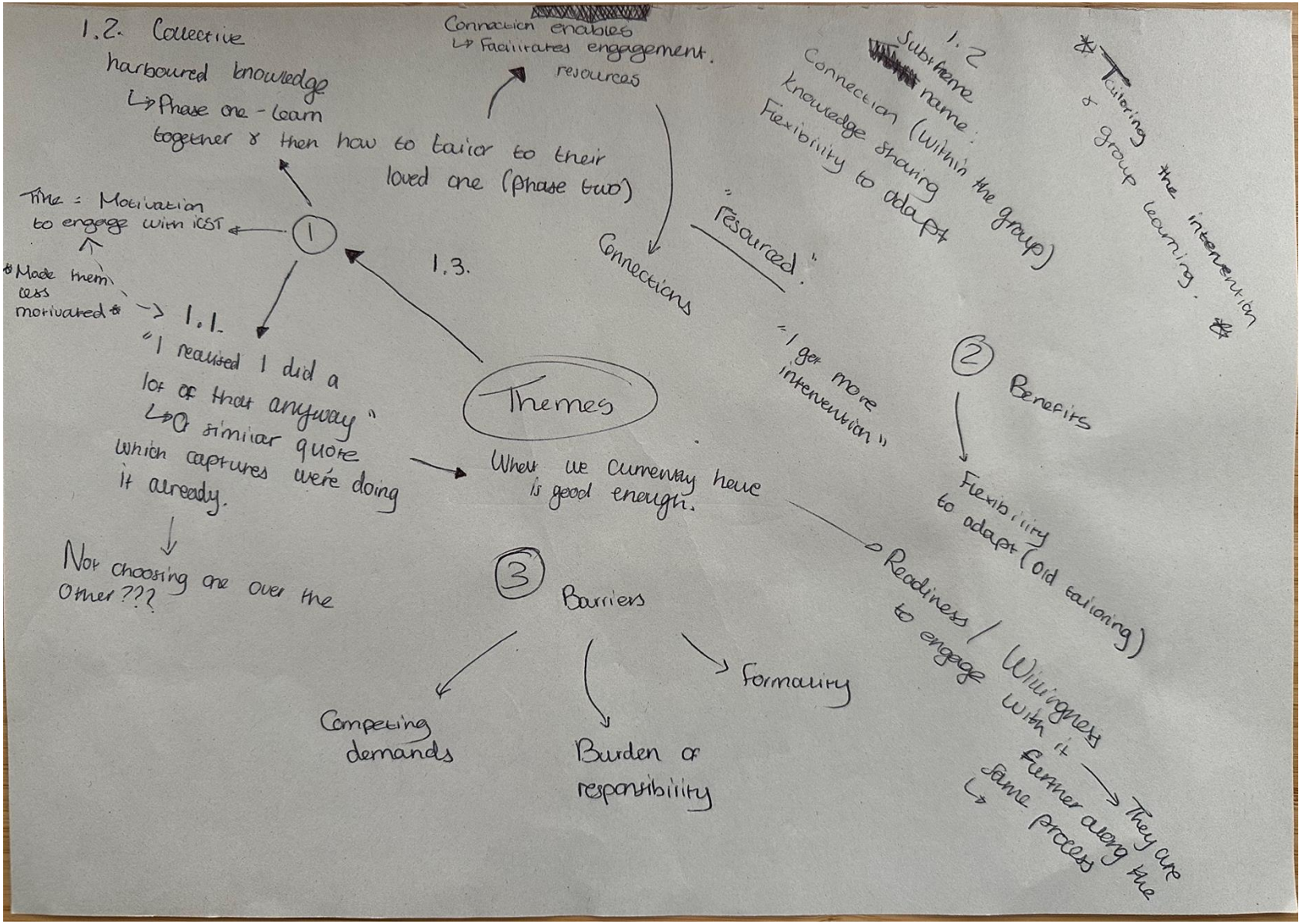
Phase	Examples of procedure for each step
1. Familiarising oneself with the data	Transcribing data, reading and re-reading, noting down initial codes. Notes of reflexivity added to record the researcher's initial reaction to the data.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the data-set, collating data relevant to each code.
3. Searching for the themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Involved reviewing the themes	Checking that the themes work in relation to the coded extracts and the entire data-set, generate a thematic 'map'. Quality check to be completed on themes by researcher and academic supervisor.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme and subthemes within these, generation of clear names for each theme.
6. Producing the report	Final opportunity for analysis selecting appropriate extracts, discussion of the analysis and relating back to the research question or literature. Produce report.

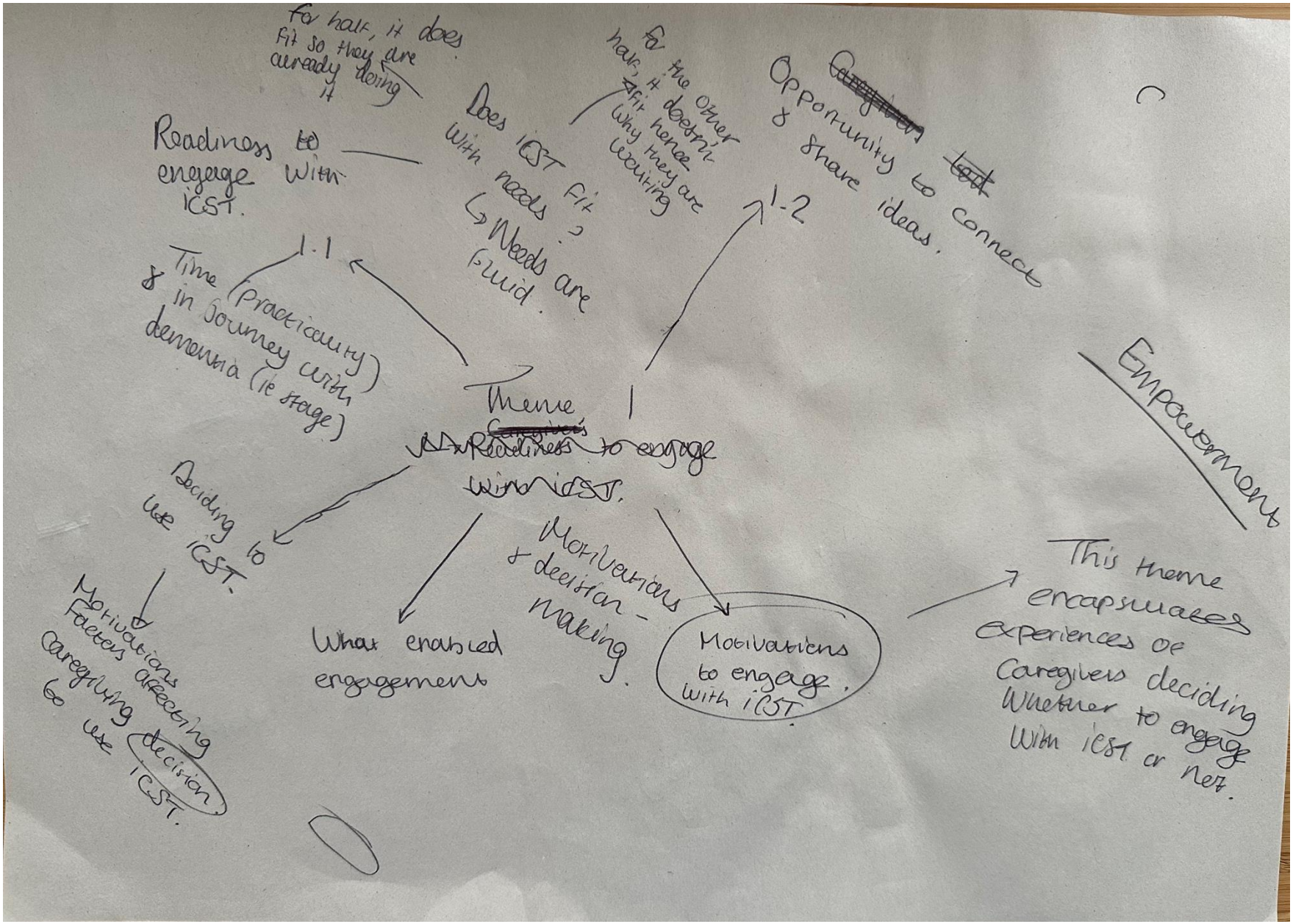
Appendix N. *Initial coding of transcript.*

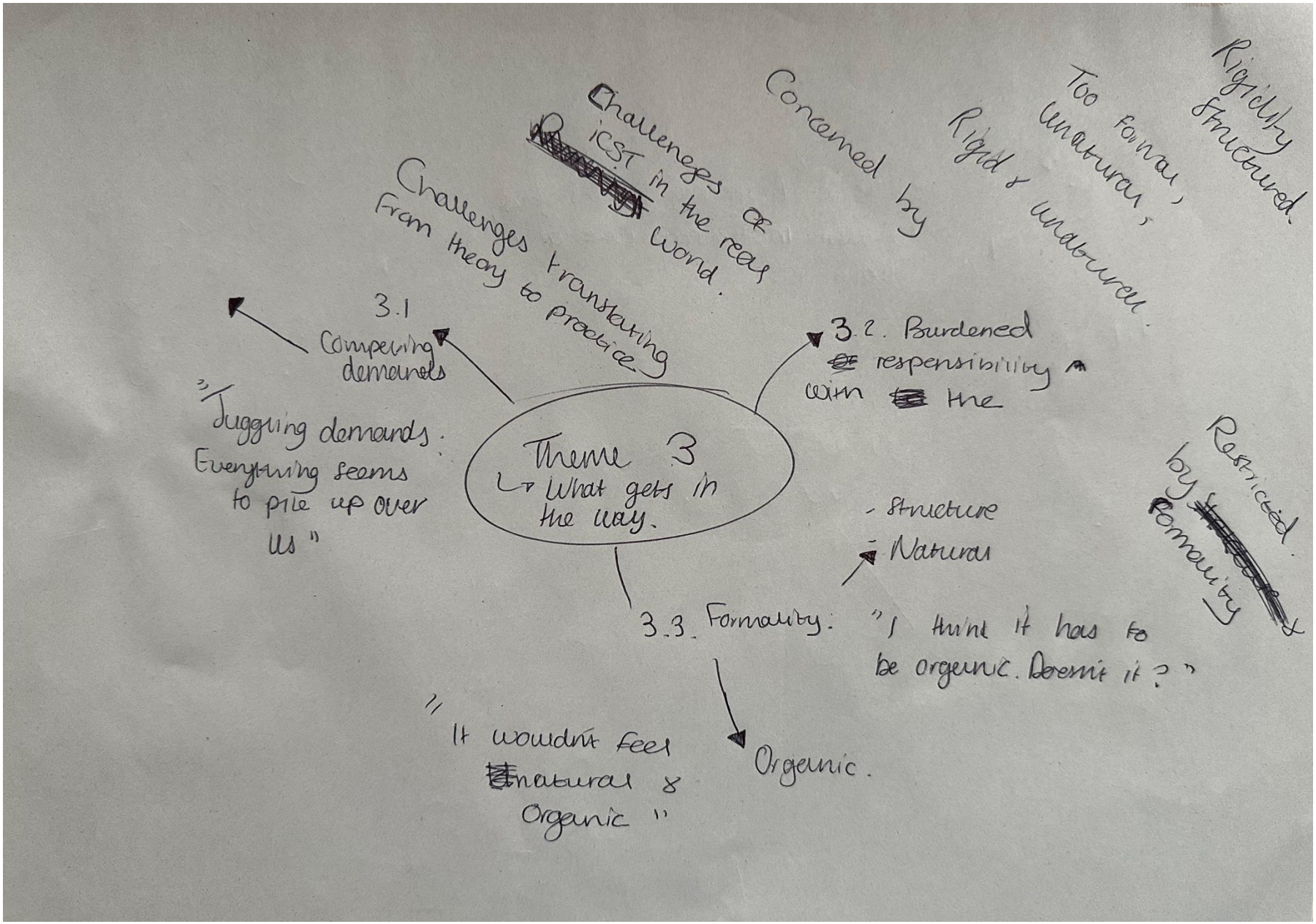
Transcript	**Initial Coding/noting**
Kate: Erm difficult situation really for us because we are in the middle of a building project.	Competing demands
Researcher: Gosh, okay.	
Kate: All right. So I have had all this other stuff going on over the past four weeks since that finished.	Multiple competing demands Reason for non-adherence
Researcher: Yeah.	
Kate: Which is I have had to attend to because Ron isn't able to. He'll input of course, but you know, he's not able to make decisions. So I've had all this thinking to do about this building project and talking to all these different people thinking Oh I know I've got to do that and Oh I know I've got to do that. So we haven't had time if I'm perfectly honest, and uh, I will be honest here, to sit down and look at this and put any of it into place.	Carer burden – Increased load because of dementia. Request load on caregiver time and energy Time as a barrier.
Researcher: Yeah.	
Kate: Formally, yeah, and I think if I'm honest, that's the problem. The formal bit. Because reading through it again, which I did last night to remind myself	Formality as a barrier.
Researcher: Yeah, thank you.	
Kate: It's very much. It seems to be perhaps it's too much orientated towards, you got to do a formal thing. You've got to sit down and you've got to put this together and you've got to have this and you've got to have that.	Rules and constraints to be obeyed. Demands on caregivers.
Researcher: Yeah, yeah.	

Kate: And I think that would put people off.	Dislike of formality.
Researcher: Mmmmm.	
Kate: I'm fairly used to working in that way. So I would have done it. But it put me off in respect of I didn't think I'd got time to do any of it because I knew we were already short of time. Yeah. So perhaps the formality is too much for people to take on board. I don't know what the other girls have said. Or X even. I don't know how they felt about that. But I felt the fact that you've got to do something formal. And it also makes you approach it differently. And I don't think you get such a good result from people when you speak into them.	Formality increases time Time as a barrier Increases caregiver burden Changes approach to the model Formality negatively impacts outcomes
Researcher: Interesting, as in the person living with dementia, like for you, Ron?	
Kate: Yeah.	
Researcher: Could you elaborate on that?	
Kate: Yeah. If I sat down with a piece of paper and said tomorrow, we're going to do this. And I know I wouldn't do that but yeah, he'd be like that (gestured)	Dislike of formality (for both PLWD and caregivers)
Researcher: Yeah, absolutely.	
Kate: And funnily enough, I was thinking about this last night. Right I'm seeing Gemma tomorrow, I must put the thinking cap on (laughing). And actually, we go out a huge amount, we do a lot of stuff. A) because we've always been like that and b) because I know it's good for Ron to be out mixing with people. So again, we don't have a lot of time to sit down do something structured.	Naturally occurring stimulation = good Motivated caregiver Time as a barrier

Appendix O. *Thematic Maps.*




For half, it does fit so they are already doing it
For the other half, it doesn't fit hence why they are waiting
Does iCST fit with needs?
↳ Needs are fluid.
Readiness to engage with iCST.
1.1
Time (practically) & in journey with dementia (ie stage)
1.2
Opportunity to connect & share ideas.
Empowerments
Theme
Readiness to engage with iCST.
Deciding to use iCST.
Motivations & decision-making.
What enabled engagement
Motivations to engage with iCST.
Motivations Factors affecting caregiving decision to use iCST.
This theme encapsulates experiences of caregivers deciding whether to engage with iCST or not.


Challenges of ICST in the real world.
Challenges translating from theory to practice
Concerned by
Too formal, unnatural.
Rigid & unnatural.
Rigidity structured.
3.1 Competing demands
"Juggling demands. Everything seems to pile up over us"
Theme 3
What gets in the way.
3.2. Burdened responsibility with the
Restricted by formality
- Structure
- Natural
3.3. Formality.
"I think it has to be organic. Doesn't it?"
"It wouldn't feel natural & Organic"
Organic.

Appendix P. *Thematic Analysis Sample.*

Theme	**Subtheme**	**Supported by**	**Example quotes**	**Participant**
1. Motivations to engage with iCST	1.1. Choosing the right time.	Sylvie, Kate, Mary	"I realised I did a lot of that anyway. Because sometimes you don't realise, do you? You sometimes need a prompt and that makes you sort of more self-aware of, you know what, what you actually do… we do talk a lot anyway about the past". "We go out a lot, drive out a lot, talk a lot in the car, go for walks. He's doing everything he was taught to do… he did that anyway".	Sylvie
			"But we frequently get the photograph albums out, and I'm very careful when we're looking at those to say… if I look at a photograph and I see something that pings in my brain then I will talk about that and then he'll add something to it and you know, we bounce off one another". "So I think in a lot of ways we are doing it without realising we're doing it…" "But at the moment, because he's so and he's very active physically as well. I mean, he will walk five, seven miles, no problem two or three times a week and we walk with a walking group. Yeah, he's getting that. We go on a lot of coach trips to go to historic places. So I mean, we did the imperial war museum in London not long ago. Because we got back from that, we'd got a lot to talk about and discuss. Yeah. So there again, I'm pulling stuff out that he might skim over and say, well, what about so and so, and such and such".	Kate

			"And actually, we go out a huge amount, we do a lot of stuff. A) because we've always been like that and b) because I know it's good for Ron to be out mixing with people. So again, we don't have a lot of time to sit down do something structured".	
			"I mean, there's probably evenings, where there's nothing on the telly, and where we could be doing this. But during the day, we're either going places or he's busy you know in the garage or erm gardening and doing, you know?"	Mary
	1.2. Opportunity to meet and share ideas.	Howard, Jayne, Mary, Kate,	"A particular example was one lady wanted something for her husband. He was a retired school teacher… They wanted to know what things to do to stimulate. So I said I used to work with prisoners. The prisoners used to make match stick models, which is simple enough to do. So that was useful. So two or three have said we're going to go and try it now". "I don't know anybody else that's got vascular dementia…. I wanted to learn off someone else what they do." "One of her gifts is she bakes. She bakes lovely cakes. She works in pounds and ounces because of old fashioned recipes and she kept saying the scales of set to metric and she wants to go back to imperial. So I'm teaching her to do that."	Howard
			"I got more information. I'd been asking for things that I could try and share. He loves hiss crosswords, and anything like that and he's continued doing them and can do them. But Dr felt he should do something different… So, I wanted something a bit different. So, we've got sort of the idea of models, which is something that he's never done".	Jayne

			"Um and yeah, quite often we were like, people were like, yeah, oh, yeah, well, yeah, we've done that and we do that, so you know, yeah um, it made you feel like you weren't alone".	Mary
			"So it was nice to be among a group of people sort of like minded who were interested in what I was doing for Ron. And they got things that they were doing and I'm thinking, Oh, that's a good idea".	Kate
2. "It's just that it helps you to make the most of the day you've got"	2.1. Feeling empowered, resourced and directed.	Sarah, Jayne, Kate, Derek	"I think it sounds selfish, but when when the day of reckoning does come, I know I've done everything I can for my mom. I've been there for her I've tried to help her and I think it will give me closure, you know, closure". "When I'm around there when I go to see my mom, you know, it's it gets her from sitting staring at the television. You know what I mean? It fills the time. If you understand, you know, I know we can't we can't sit there and do it every day all day. But you know, we can do it."	Sarah
			Yeah, I've got the book, because if there's anything that can help. Yeah. When I mean, everything won't help everybody. But anything that can help. It's worth trying. So as far as I'm concerned, anything that's going to assist in the road we're on is worth it". "It's just that it helps you to make the most of the day you've got".	Jayne
			"Let's see if we can be as normal as we can, the better it is for both of us really".	Kate

			"Mostly I feel better about the talking I didn't do before. It makes me feel better".	Derek
	2.2 Opportunity for connection within dyads.	Mary, Sylvie, Sarah, Kate	"I just think it's er, it's just great. You forget about things don't you, you know, and then when you start you're like oh god yeh when we did that when we went there. And it's things that even yourself remembers, from when we were happy and we were doing stuff or going places".	Mary
			Sylvie: "He loves to have a little stimulation, he loves attention from me".	Sylvie
			"You know, when they're there don't you? It's like my mom again". "And I could see the cogs moving. I could actually see her taking it in".	Sarah
			"I mean, he's enjoying it. And you can see he's benefiting from it when we doing stuff.	Kate
	2.3 Increased autonomy reduces carer load: 'Obviously if it's benefit to him, it's benefit to me' (sic)	Jayne, Kate, Mary	"Because I would just say oh, well it's Wednesday, we're going to get the children and he's say: Yeah. But now because… he'll say yeah, oh, yeah, me too. Yes. We've got to go out haven't we, so I'll have to get such and such done. And that's you know instead of me saying, it's about five to eight, you've got to get your shoes on, we're going now. Yeah, and he'll say now "Oh, yeah, better get sorted. Got to get my shoes on, see what I mean?"	Jayne

			"Whereas as it is now, it's usually I'll take the car keys and he's in the car waiting. He doesn't drive but he's in the car ready. Like Sunday we went to church and he was out and had defrosted all the windows and everything while I was still upstairs sorting things. So yes, more that".	
			"Obviously if it's benefit to him, it's benefit to me. If it's improving his behaviour, then that's beneficial to me. If it improves his attitude to things I suggest we do, then that's beneficial to me."	Kate
3. Challenges of implementing iCST into real life.	3.1. Juggling demands: "Everything seems to pile up over us"	Sylvie, Sarah, Kate, Derek, Mary	"I still work part time still. He goes out a couple of times a week, to do various sports".	Sylvie
			"The only problem with me is time with like, with everything, because that's sort of the juggling in between work." "Only problem is work, because I'm self-employed, you know. It's just juggling that but we managed".	Sarah
			"The time is difficult, because everything seems to pile up over us nowadays. Because everything that you've got to do takes a lot longer to do". "Well the time factor, to be honest, I mean, clearly, as I said to you early because we we do a lot of stuff and we're out a lot, which is good for him anyway. But also the fact that because everything that has to be done in the house takes so much longer because I have to follow him around, reminding him to do it or not do that or do this, that sort of thing. So obviously, we're much shorter, much shorter time, probably".	Kate

			"So I was doing that (talking) before this other thing came which is where we've got to talk to her about food. You must walk. You must go out and do some walking. Because if you don't, you have a problem. It's a different problem to the memory".	Derek
			"As I say, as the bad weather comes, and we're sort of sat there thinking what we're going to do this afternoon. Oh, we'll get the photograph albums out. We'll look at we went through things erm music, martial arts, all the old photos that he's got and and erm then start talking about things. That's that was my plan. Too busy at the moment".	Mary
	3.2 Burden with the responsibility	Sylvie, Jayne, Kate, Derek	"I mean, it's more for me to think about".	Sylvie
			"For me. It's harder work, because I've got to, instead of just saying, Oh, it's so and so, I've got to then sort of try and work out paths to go down to get him where he needs to be".	Jayne
			"So there again, I'm pulling out stuff that he might skim over and saying well what about so, and so."	Kate
			"It came from the group that I should do that".	Derek
	3.3. Restricted by formality: "It wouldn't feel natural and organic"	Sylvie, Kate, Mary	"It wouldn't suits us. We're not that, not those types of people. It wouldn't feel natural and organic. I think it has to be organic. Doesn't it?"	Sylvie
			"Formally, yeah, and I think if I'm honest, that's the problem. The formal bit. Because reading through it again, which I did last night to remind myself. It seems to be perhaps it's too much orientated towards, you got to do a formal thing. You've got to sit down and you've got to put this together and you've got to	Kate

			have this and you've got to have that, and I think that would put people off. It put me off in respect of I didn't think I'd got time to do any of it because I knew we were already short of time. Yeah. So perhaps the formality is too much for people to take on board".	
			"We haven't, I must admit, done any of that or anything that's as structured".	Mary

Paper 3: Executive Summary

"Anything that's going to assist in the road we're on is worth it" - Exploring the experiences of delivering individual cognitive stimulation therapy (iCST) for informal dementia caregivers: A thematic analysis.

This executive summary hopes to provide a concise and accessible summary of the key findings and recommendations arising from this study. The dementia caregivers who participated in this research are the intended target audience, though other dementia caregivers and professionals working alongside people living with dementia may also find this a helpful insight into their experience.

Thank you to participants who provided feedback on the language and layout of this summary.

Word count: 1748

Background:

Why was it important to complete the research?

- There are currently around 900,000 people living with dementia in the United Kingdom (Wittenberg et al., 2019).
- Dementia is an umbrella term used to describe a group of symptoms that are caused by different diseases which damage the brain (NICE, 2018).
    - The symptoms most seen include memory loss, confusion, problems with language and understanding and changes to behaviour and mood.
- Unsurprisingly due to the range of symptoms they experience, people living with dementia often require support to manage day-to-day.
    - Often that support comes from loved ones, usually a partner or a child.
    - There are approximately 700,000 informal carers (someone who provides unpaid help) supporting those living with dementia in the UK.

Available support for people living with dementia:

- There is currently no cure for dementia, but research has led to the development of treatments which aim to stabilise the symptoms of dementia and promote an individual's independence and wellbeing.
- Treatments can include medication, which can help in some instances but also psychosocial interventions, such as Cognitive Stimulation Therapy (CST).
- CST has repeatedly been shown to be effective in maintaining cognition and improving quality of life for people living with dementia (Cafferata et al., 2021; Chen, 2022; Saragih et al., 2022).

- Most often, CST is delivered in a group setting by health care professionals, directly to a person living with dementia.
- However, not everyone living with dementia can access a CST group.
    - This might be because there are no local groups available, a lack of transport available, mobility difficulties or individuals not wanting to engage in a group.
- To try to improve access to interventions, an individual version of CST (iCST) has been developed (Yates et al., 2014).

What is Individual Cognitive Stimulation Therapy (iCST)?

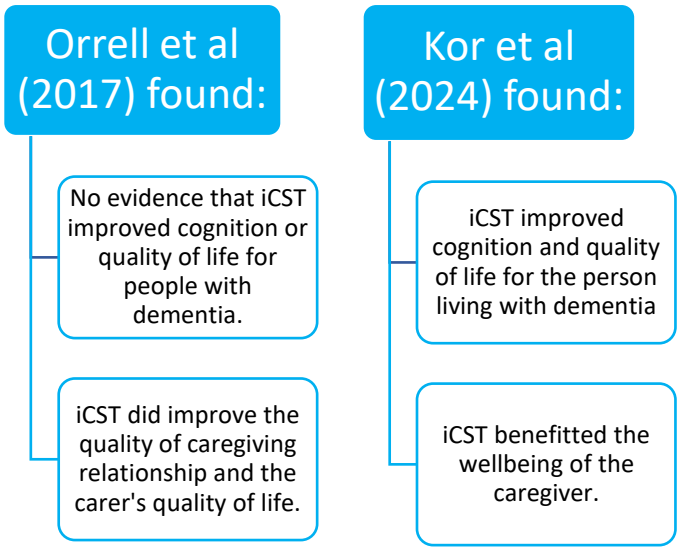
iCST is based on Cognitive Stimulation Therapy, which aims to enhance cognitive and social functioning through stimulating activities such as discussion of past and present events, word games, puzzles or music (Spector et al., 2003)

In iCST, carers are trained to deliver CST to a person living with dementia in their home environment.

iCST is one-to-one rather than group sessions, and it is recommended to carers that a 30-minute session is delivered three times a week.

In the current study, carers engaged in a 3-week group called 'train the carers' where they learnt the principles of iCST, learnt how to plan iCST sessions and how to review iCST sessions prior to trying to use iCST at home.

Currently, iCST is not widely offered in the NHS, and because it is relatively new, there has been little research into it. Previous research paints a mixed picture:



- These benefits are still important as not only is carers' wellbeing essential, but also positive outcomes for a carer may prolong their ability to provide care to a loved one (Yang et al., 2014).
- Research exploring the views of caregivers who have used iCST indicated that whilst they enjoyed using iCST, they had difficulties using it (Leung et al., 2017). For example, fitting it into their already busy schedules.

Why did we do the research?

- As there is not much research into iCST which captures the experience of carers trying to use iCST, further research is needed to understand the perspective of carers.
- This research is important so that NHS memory and dementia services can decide whether they want to train carers in iCST to help people living with dementia, but it is also important because it offers some choice to people living with dementia and their caregivers to decide if they would like to use iCST.

Aim of the research:

To explore the positive and negative aspects of carers' experiences using iCST with a person who they care for living with dementia after they have attended a 'train the carer' iCST intervention group.

Method:

How was this research completed?

Step 1

- Staffordshire University and NHS Research Ethics Committee both reviewed the research to ensure that it was safe and ethical.

Step 2

- Carers attended the 'train the carer' group. During the group, the carers were made aware of the research, and asked to let the group facilitator know if they were interested in participating.

Step 3

- Carers who wanted to participate were invited to an interview four weeks after the group ended. During the interview, they were asked about their experience of the 'train the carer' group as well as their experience of trying to use iCST after the group finished.

Step 4

- Before the interview started, carers were asked to read a consent form and confirm that they were happy to be involved in the research. Interviews were then audio-recorded and typed-up afterwards by the researcher. Interviews lasted between 15-45 minutes.

Step 5

- Interview transcripts were analysed using 'Reflexive Thematic Analysis' (RTA).

What is Reflexive Thematic Analysis (RTA)?

RTA is one method researchers use to analyse what people say. It is useful when researchers do not know much about an area of research and want to explore in depth the perspectives and experiences of a particular group. It was therefore helpful in the current study, as there is little research, and thus known, about the experience of caregivers using iCST.

Key findings:

What did this research find?

Three main themes were found, and each had sub-themes. A subtheme exists under the umbrella of a theme and tends to focus on one notable specific element of that theme. Below, key quotes are shown to give examples of the kinds of responses carers gave which made up the themes. The names given besides the quotes are not the real names of carers, and pseudonyms have been used to maintain the privacy of carers interviewed.

Theme One: Motivations to engage with iCST

"So I think in lots of ways we are doing it without realising we're doing it" (Kate)

In the first theme, carers reported different factors, which helped them to **decide whether to use iCST or not.** Some carers reported that they felt as though they **already engaged in iCST in** their day-to-day lives, through their hobbies and social engagements. For these carers, they appeared to **prefer to continue to engage in their usual stimulating engagements** rather than use iCST.

"I'd never of thought of anything like that alone" (Jayne)

Carers identified that **learning iCST in a group** made them **more likely to use iCST**, because it provided them with opportunities to connect with others in a similar situation and share ideas.

Theme Two: "It's just that it helps you to make the most of the day you've got"

"You know, it gets her from sitting staring at the television" (Sarah)

In the second theme, carers reported **different benefits** of the iCST intervention. Firstly, the intervention offered **something practical carers could use** to support a person living with dementia.

"Oh god yeh, when we did that when we went there [...] from when we were happy and we were doing stuff" (Mary)

The intervention also **provided opportunity for connection** between carers and the person living with dementia, which helped carers to feel more connected to the person living with dementia. For example, carers reported that they enjoyed the chance to reflect on shared happy memories with their loved one in iCST sessions.

"If it improves his attitude to things I suggest we do, then that's beneficial to me" (Kate)

Finally, carers reported that the sessions appeared to **increase the motivation** in their loved one living with dementia. This helped to reduce the stress levels of carers, because they noticed their loved one living with dementia was taking more initiative to do things for themselves.

Theme Three: Challenges of implementing iCST into real life

"The time is difficult because everything seems to pile up over us nowadays" (Kate)

The final theme **considers the barriers** reported by carers which **stopped them engaging with iCST**. The primary barrier reported by nearly all carers was their **competing demands**, including work, providing care and hobbies, which meant they were short on time.

"For me. It's harder work, because I've got to [...] sort of try and work paths to go down to get him where he needs to be" (Jayne)

Secondly, carers recognised that the **burden of responsibility** to organise iCST sessions fell to them, as did running the sessions, which added to their demands.

"I think it has to be organic. Doesn't it?" (Sylvie)

Finally, some carers reported that they saw iCST as **"formal",** which not only required a lot of effort from caregivers, but they also thought the formality would **put their loved ones with dementia off.**

Implications:

What do these findings mean?

- This study offered insight into the benefits and challenges encountered by carers when attempting iCST.
- Clearly there were some benefits for carers to using iCST which are important, as carers who experience positive aspects of caring report better well-being and morale (Quinn & Toms, 2019).

- There were, however, also challenges for carers when it came to using iCST at home, which tells us that perhaps the full iCST programme is not realistic for carers.
- This was the first study to teach iCST in a group. It appears this was very helpful for carers, as it provided opportunity to establish peer-support and learn from each other, which they reported helped them to use iCST at home.

Recommendations:

What does this mean for the future of dementia care?

- The benefits of iCST mean it could be offered as an option, in instances where group-based CST is not possible as it offers a way of reaching people with dementia who may not be willing or able to access a group-based CST.
- It could also be offered to families following engagement with group-based CST, to continue the intervention and maintain any benefits.
- There are however also clear challenges to using iCST in the home environment. Efforts need to be made to make iCST more realistic, to support caregivers to deliver the intervention. Involving caregivers in this process will be critical.
- To make iCST more feasible, carers could benefit from more frequent contact from health care providers following training in iCST; to access ongoing support from professional services, should they encounter challenges.
- If iCST is to be offered to dementia carers in the future, this research indicates that learning the intervention in a group could mean both that carers gain some emotional support, but also they are more likely to use the intervention.

Limitations:

What are the limits to this research?

The current research is limited by the fact the carers interviewed wanted to engage in the iCST group, indicating a high level of motivation. This means the findings might not be the same for carers who are less motivated.

The research only interviewed seven carers, all of whom were White-British, creating a small and non-diverse sample.

The research interviews took place only four weeks following completion of the 'train the carer' group. This is a relatively short timeframe, which makes it hard to learn about longer-term effects of iCST.

Future research:

What further research could be done on this topic?

- Research is needed to explore potential ways to improve usage of the intervention, for example: some researchers have started to develop an iCST mobile-phone application (Rai et al., 2021).
- More research is needed with larger and more diverse samples before drawing further conclusions.
- Longer-term research is needed to uncover whether any positive effects are maintained beyond the four-week period considered in this study.

Dissemination:

How will this research be used?

- This summary will be used to share the research findings with the dementia caregivers who participated in the research, as well as other dementia caregivers and professionals working alongside people living with dementia who may also be interested in the findings of the research.
- The completed report will be submitted to a peer-reviewed journal for publication so that it can be shared with a wider academic and professional audience.

Thank you for taking the time to read this summary, and a special thank you to the carers who made the time to participate in the research.

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