Assessing the Acceptability and Feasibility of Adapted Cognitive Stimulation Therapy for Stroke (sCST) using the ADePT Framework

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I acknowledge that material from my ClinPsyD Thesis Proposal and my NHS Ethics Protocol has been used throughout this portfolio due to the inherent necessity to re-use materials in this instance. Information on acceptability of the intervention described in Chapter 2 from a stroke survivor perspective was used with permission from another ClinPsyD doctoral researcher due to inherent necessity in this instance also – this was with permission and approval from joint thesis supervisor.

Portfolio Abstract

Background: Informal stroke caregivers are often important in rehabilitation and management of disability following stroke. Dyadic interventions have demonstrated wellbeing gains for caregivers and functional gains for stroke survivors, but dyadic cognitive interventions are rare.

Aim: Develop an understanding of the acceptability, feasibility and benefits of dyadic cognitive interventions after stroke, particularly for stroke caregivers.

Method: A systematic review of dyadic interventions that assessed post-stroke cognition and caregiver wellbeing outcomes, was conducted to identify the measures used, if and how cognition was targeted and caregivers involved, and evidence of psychosocial gains for informal caregivers. An empirical paper explored pre-frail stroke caregiver acceptability of a pilot sCST (stroke Cognitive Stimulation Therapy) intervention that encouraged caregiver participation using Framework Analysis. A second empirical paper used 'A process for Decision-making after Pilot and feasibility Trials' (ADePT) to facilitate decision making and appraise solutions for feasibility and acceptability limitations identified through the pilot.

Results: The systematic review highlighted the most prevalent cognitive and wellbeing measures for stroke survivors and their caregivers. One cognitive trial actively inviting the participation of both in the dyad found significant gains in caregiver wellbeing. In the first empirical paper, four participants completed sCST, all caregivers reported anticipated or current psychosocial gains, 75% of caregivers reporting increased insight within dyads, and while 75% of caregivers would attend further sessions if at a different location, practical and emotional burdens affected acceptability. The ADePT paper suggested sCST strengths in feasibility and acceptability for dyads but the a priori recruitment target was not reached, logistic and psychosocial factors limited the acceptability of sCST for some dyads.

Conclusions: The findings of the portfolio suggest potential considerations for the inclusion of caregivers when piloting cognitive interventions for stroke survivor dyads and pre-frail stroke survivor dyads.

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I would like to dedicate this thesis to my late grandmother, a stroke caregiver whose memory was a source of strength in my journey on the Clinical Doctorate.

Chapter 1 - Introduction

Word count: 2976

Introduction

This thesis focuses on the acceptability, feasibility and benefits of dyadic interventions for post-stroke cognition. This first chapter introduces stroke and frailty as the conditions of interest, Cognitive Stimulation Therapy as an established treatment for people with dementia which may prove helpful as part of multicomponent interventions for frailty reduction after stroke, the role of caregivers in rehabilitation and management of disability and theories relating to this and the development of complex interventions, such as dyadic interventions for post-stroke cognition. Finally, this chapter ends with the aims of this thesis research and an introduction to the structure of the thesis portfolio.

Stroke

Globally, stroke is the second largest cause of death, and third primary cause of death and disability combined (Feigin et al., 2019). 12.2 million new strokes occur per year and 101 million people worldwide were living with stroke in 2019 (Feigin et al., 2019), nearly double the number 30 years prior (Owolabi et al., 2022). Strokes can be categorised as ischemic or haemorrhagic. Ischemic strokes occur due to a blockage of an artery or vein, limiting oxygen to an area of the brain and causing neurological damage (Janssen et al., 2024). A sub-type of ischemic stroke is a transient ischemic attack (TIA), this is due to a temporary blockage of the brain, resulting in temporary neurological dysfunction (Janssen et al., 2024). Haemorrhagic strokes occur due to bleeding from blood vessels in, or around, the brain (Janssen et al., 2024). Cognitive impairment following stroke is common (Jaillard et al., 2009; Jokinen et al., 2015; Renjen et al., 2015) and predictive of participation restrictions and chronic activity limitations (Mole & Demeyere, 2020; Stolwyk et al., 2021; Watson et al., 2020). Evaluation of post-stroke cognitive impairment and psychological effects are included as a top research priority (Hill et al., 2022).

Frailty

Frailty is a progressive state of vulnerability characterised by multisystem decline in physiological reserves needed to maintain homeostasis following stressors (Morley et al., 2013; Fried et al., 2001; Campbell & Buchner, 1997). Frailty after stroke is associated with worse functional outcomes and increased mortality (Li, Wan & Wang, 2024). Pre-frailty, a "state that may precede the onset of frailty, is associated with adverse health outcomes and reduced quality of life (Gill et al., 2006) but which might be reversed or attenuated by targeted interventions" (Sezgin et al. 2022). Multicomponent interventions (MCIs) have been researched as targeted interventions for frailty. These often include and combine physical, dietary and cognitive interventions, and are now the recommended treatment for frailty (Dent et al., 2019). Cognitive interventions have an important role in the reduction of frailty, having demonstrated beneficial effects, whether as part of MCIs or stand-alone interventions (Ng et al., 2015).

Cognitive Stimulation Therapy

Cognitive interventions for individuals with frailty involve the stimulation of memory and orientation abilities through tasks (Ng et al., 2015). Cognitive Stimulation Therapy (CST) is a NICE-recommended group-based cognitive intervention for people with mild to moderate dementia (NICE, 2018; Alvares-Pereira, Silva-Nunes, Spector, 2021). CST combines stimulation of cognitive abilities, including memory and orientation, with a social group environment. The group interaction in CST is lacking in more typical cognitive interventions for individuals with frailty (Ng et al., 2015). The social interaction of a group setting may support those with frailty in reducing feelings of isolation, a factor associated with frailty (Kojima et al., 2022).

The Role of Caregivers

Informal (unpaid) caregivers, usually spouses or close family members, are often key in rehabilitation and management of disability (Torregosa et al., 2018), with an economic value

estimated as far greater than NHS and care costs (Patel et al., 2020). The needs of informal caregivers in the stroke context are often different to the needs of caregivers in other contexts, such as Alzheimer's Disease, where the onset is less sudden and the condition is more progressive (Lutz et al., 2011; Moon, 2016). High levels of depression, anxiety, and burden are reported in informal caregivers following stroke, particularly in the first year (Pucciarelli et al., 2017). Dyadic interventions involving the stroke survivor and caregiver have demonstrated significant gains for both members of the caregiving dyad, including improved stroke survivor functioning, and reduced informal caregiver burden (Bakas et al., 2014; Bakas et al., 2022).

Different theoretical models provide insights into informal caregiver wellbeing. Two prominent models emphasise the role of primary and secondary stressors, mediated by appraisals (Gérain & Zech, 2019; Sörensen et al., 2006). Primary stressors are elements of the caregiving relationship including the caregiving tasks to be performed, the time these take, and the diagnosis of the person being cared for (Gérain & Zech, 2019). Secondary stressors are what is experienced as the consequences of these stressors, for example a lack of free time or financial strain. The Model of Carer Stress and Burden (MCSB; Sörensen et al., 2006) describes a linear process whereby primary stressors affect secondary stressors which in turn influence caregiver appraisals, and subsequent psychosocial, behavioural and physiological outcomes for the caregiver. Within the model, secondary stressors, caregiver appraisals and outcomes are also thought to be exacerbated or mitigated by caregiver personality, coping strategies and caregiver background and contextual factors, including sociodemographic and cultural phenomena.

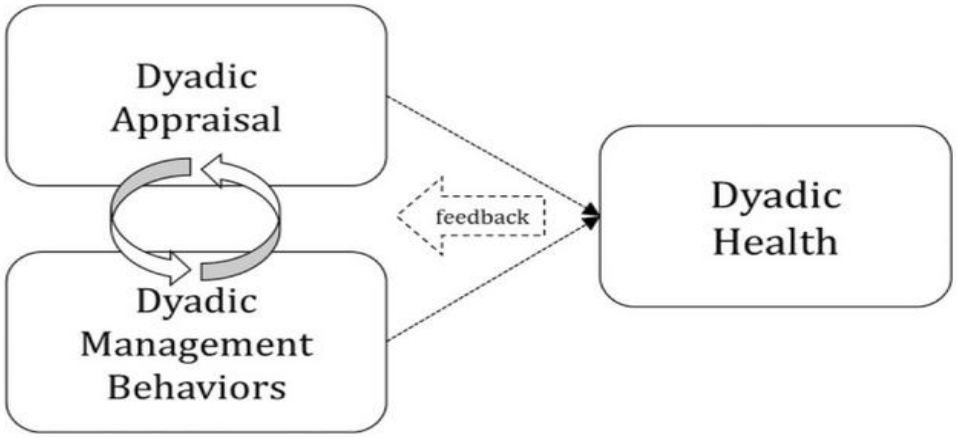
The Informal Caregiving Integrative Model (ICIM; Gérain & Zech, 2019) follows a similar linear model but includes feedback loops. Determinants (e.g., primary stressors) are followed by mediators (e.g., appraisal), followed by specific outcomes (e.g., burnout) and general outcomes (e.g., quality of life), with outcomes feeding back to determinants. The ICIM (Gérain &

Zech, 2019) builds on the notion that primary and secondary stressors impact caregivers and the model incorporates sociodemographic, physical and psychological factors, including emotional regulation, that are specific to the caregiver as other determinants of outcomes. The final determinant is the current social environment. This includes the extent of informal support, professional support and sociocultural norms relative to the environment. How the determinants are appraised is considered a mediator between determinants and outcomes, as is the coping and relationship quality in the dyad. Specific outcomes are grouped under burnout, subdivided into emotional exhaustion, depersonalization, and personal accomplishment. General outcomes are specific to the caregiver and the care-recipient and include quality of life.

Whilst both of these theoretical models acknowledge the effect of the person being cared for on the caregiver, Lyons and Lee (2018) postulate that the management of chronic illness is a dyadic phenomenon, and thus the way that dyads appraise an illness together can influence the behaviours they enact to manage it. An illustrative example is presented whereby both members of a dyad appraise yawning and exacerbation of cognitive difficulties as caused by post-stroke fatigue. This consensus appraisal leads to collaborative dyadic management behaviours, for example encouraging regular breaks and reducing cognitive and physical load. This in turn leads to better dyadic health outcomes including reduced fatigue and fewer fatigue-related complications for both dyad members. The dyadic health benefits from working collaboratively thus feedback and reinforce the importance of collaborative appraisal and behaviour management, as shown in figure 1.

Figure 1

Theory of Dyadic Illness Management (Lyons & Lee, 2018)



The Development of Complex Interventions

Dyadic interventions for stroke survivors and caregivers fit the UK Medical Research Council (MRC) definition of complex interventions as those with several interacting components, that depend on behaviours of those delivering and receiving treatment, target several groups, with a range of outcomes and need to tailor intervention to context and setting (Skivington et. al. 2021).

Updated MRC guidance (Skivington et al., 2021) suggests that the development and evaluation of complex interventions, such as dyadic post stroke interventions, follows four stages: (1) intervention development or adaptation; (2) assessment of feasibility and acceptability of intervention; (3) evaluation; and (4) implementation. Pilot feasibility trials help to avoid unsuccessful randomized controlled trials (RCTs) of complex interventions, which are not only common but also costly (Sully et al., 2013). They enable design parameters to be established to then inform future research (NICE, 2021), justifying trial methods and execution, and reducing issues limiting effective trial delivery (Blatch-Jones et al., 2018). One subtype of these trials, known as pragmatic feasibility trials, focuses on the design and implementation of intervention trials in routine clinical settings, rather than intervention efficacy (Bond et al. 2023) and will be the focus of two chapters of this thesis.

Aims and Structure of the Thesis Portfolio

This thesis portfolio aimed to increase understanding of the acceptability, feasibility and benefits of dyadic interventions for post-stroke cognition, particularly from the perspective of stroke caregivers. To achieve these aims, the portfolio includes a systematic review (Chapter 2) providing a narrative synthesis of randomised controlled trials with post-stroke cognition and caregiver psychosocial wellbeing outcomes to identify the outcome measures and cognitive interventions used, how caregivers were involved, and any evidence of psychosocial wellbeing benefits for caregivers. Following this, two empirical papers are presented on the acceptability and feasibility of a new form of Cognitive Stimulation Therapy adapted for pre-frail stroke survivors (sCST) with caregivers, whose involvement in the intervention was encouraged. A non-randomised, pragmatic single arm pilot study was used to evaluate the acceptability and feasibility of this new adaptation, following MRC guidance on the development of complex interventions such as dyadic post-stroke cognitive interventions, as a candidate cognitive intervention for use in future MCI trials for frailty reduction after stroke. The first empirical paper (Chapter 3) examines the acceptability of sCST with a Framework Analysis of semi-structured interviews with the stroke caregivers, guided by the Theoretical Framework of Acceptability (TFA; Sekhon et al., 2022) following their involvement in the pilot sCST intervention. The second empirical paper (Chapter 4) presents an analysis of feasibility findings of the pilot of sCST using Shanyinde's (2011) 14 methodological issues for feasibility research and an appraisal of solutions to address feasibility and acceptability limitations using 'A process for Decision-making after Pilot and feasibility Trials' (ADePT; Bugge et al., 2013) structure. The final chapter (Chapter 5) summarises the thesis findings in the context of relevant theoretical frameworks and evidence and suggests clinical practice implications and potential future research.

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Chapter 2 - Systematic Review

Interventions Measuring Post-Stroke Cognition and Informal Stroke Caregiver Outcomes: A Systematic Review

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(see Appendix A for author guidelines for manuscript preparation)

Interventions Measuring Post-Stroke Cognition and Informal Stroke Caregiver Outcomes: A Systematic Review

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All authors have seen and approved the manuscript

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Abstract

Purpose: Dyadic cognitive interventions may have potential to improve both cognition after stroke and caregiver wellbeing. This systematic review of dyadic interventions that assessed post-stroke cognition and caregiver psychosocial outcomes, was conducted to identify the measures used, if and how cognition was targeted and caregivers involved, and evidence of psychosocial gains for informal caregivers.

Materials and Methods: Four databases (CINAHL, MEDLINE, PsychINFO and Scopus) were searched for randomized controlled trials (RCTs) with post-stroke cognition and psychosocial caregiver outcomes. Quality and risk of bias was assessed using the JBI Critical Appraisal Tool. Narrative synthesis was used to synthesize study outcome measures, nature of cognitive intervention, caregiver involvement and evidence of caregiver gains. (PROSPERO ID: CRD42024539798).

Results: 13 trials were included. The Stroke Impact Scale (memory domain) and Caregiver Strain Index were the most used outcomes. Three trials targeted cognition directly, including a multicomponent intervention for aphasia reporting significant improvement in caregiver burden. Ten trials did not report blinding participants.

Conclusions: Current evidence for dyadic cognitive interventions improving caregiver outcomes is limited due to the small number of studies, methodological limitations and heterogeneity. Further trials assessing SIS-M and CSI outcomes are required and behavioural and cognitive stimulation interventions should not be excluded.

Introduction

Stroke is the third leading global cause of death and disability combined (Feigin et al., 2021). When stroke results in disability, family members are often enlisted as caregivers or supporters (Torregosa et al., 2018). In the UK, the value of this informal care is estimated at £15.8 billion, almost double the estimated £8.6 billion for formal health and social care costs (Patel et al., 2020). Caring for a family member after stroke has been described as improving or strengthening relationships and giving a sense of meaning and purpose (Mackenzie & Greenwood, 2012). However, caregivers also describe lives turned upside-down by stroke (Bulley et al. 2010) with a loss of autonomy and certainty (Lou et al. 2016) and risk of psychological strain and burden (Panzeri, Rossi Ferrario, & Vidotto 2019).

Post-stroke cognitive impairment is common, with prevalence estimated between 60-75%, depending on the assessments used and time since stroke (Jaillard et al., 2009; Jokinen et al., 2015; Renjen et al., 2015). Cognitive impairment is also, however, one of the most commonly reported unmet needs after stroke (e.g., Kim et al. 2021; Lin et al. 2021) itself associated with having other needs not fully met (Andrew et al. 2014). Moreover, a recent meta-analysis indicates that post-stroke cognitive impairment is associated with higher caregiver burden, and lower quality of life for caregivers and stroke survivors regardless of time post-stroke (Stolwyk et al., 2024).

Evaluation of cognitive dysfunction and interventions to reduce this are among the top research priorities for rehabilitation and long-term care after stroke (Hill et al. 2022). Cognitive interventions have a high degree of heterogeneity and include: cognitive stimulation often in group settings (Clare & Woods, 2003), cognitive training through repeated practice (Lampit, Valenzuela, & Gates, 2015; Mowszowski et al., 2016; Reijnders et al., 2013; Shah et al., 2017), cognitive training involving compensatory behaviours (Alashram, 2024), psychoeducation to increase awareness and understanding of cognitive changes (Ekhtiari et al., 2017), feedback

from cognitive assessment to increase awareness and behavioural or physical interventions associated with cognitive benefits (Cumming et al., 2012). Despite this wide range of intervention types, Cochrane reviews have noted poor-quality evidence for post-stroke cognitive rehabilitation targeting neglect (Longley et al., 2021), attention (Loetscher et al, 2019), memory (das Nair, 2016) and executive function (Chung et al., 2013). Poor reporting of cognitive rehabilitation research has also hampered implementation, with a lack of clarity in descriptions of interventions, staff involved and outcome measurement (Small et al 2022), despite a call for increased standardisation of stroke rehabilitation outcomes (Oremus et al., 2012).

Dyadic interventions show potential to improve the wellbeing not only of stroke survivors, but also informal caregivers (Pucciarelli et al., 2021; Zhang et al., 2023). These interventions involve informal caregivers either as active participants with stroke survivors (Bakas et al., 2014), or without stroke survivors (e.g. (Zhang, Zhang, & Sun. 2019), in the development of study design or treatment (Pucciarelli et al., 2021), or in outcome measurement only (Zhang et al., 2023). Pucciarelli et al (2021) reported improvement in stroke survivor memory following dyadic interventions. A review by Bakas et al (2022) identified one caregiver intervention study that reported improvements in survivor cognition (Zhang, Zhang, & Sun. 2019). To our knowledge, however, to date the impact of dyadic interventions that assess post-stroke cognitive outcomes on the psychosocial wellbeing of stroke caregivers has not been reviewed.

This systematic review aimed to synthesize research on dyadic interventions that assessed post-stroke cognition and informal caregiver psychosocial wellbeing to identify: 1) the measures commonly used; 2) whether interventions targeted cognition and if so, with what types of intervention and level of caregiver involvement; and 3) whether dyadic trials targeting cognition after stroke report psychosocial gains for informal caregivers.

Method

Protocol and Registration

The systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO ID: CRD42024539798; Appendix B), developed according to the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA; Moher et al., 2009; Appendix C).

Inclusion and Exclusion Criteria

Studies were included if they were: 1) randomized controlled trials; 2) published in English; 3) measured at least one post-stroke cognitive outcome and one psychosocial caregiver outcome; 4) in dyads where both people were 18 years or older; and 5) one was a family member or friend who provided support, but was not in a paid professional relationship with the stroke survivor, though may have received caregiver's allowance. Studies were excluded if they were: 1) unpublished; 2) conference abstracts; 3) systematic reviews or meta-analyses; 4) commentaries without original data; 5) study protocols; 6) single time point designs; or 7) qualitative research; or focused on: 8) participants under 18 years of age; 9) paid caregivers; 10) caregivers described as having a neurological diagnosis such as dementia or stroke; or 11) stroke survivors described as having an additional neurological diagnosis to stroke, such as dementia.

Search Strategy

Four electronic databases (CINAHL, MEDLINE, PsychINFO and Scopus) were searched from inception to May 2024 on 21 May 2024 using the following search terms (detailed search strategies can be found in Appendix D):

- ((Medical Subject Heading (MH) "Stroke+") OR (MH "Intracranial Hemorrhages+") OR (MH "Cerebrovascular Trauma") OR "stroke*" OR "intracranial hemorrhage*" OR "cerebrovascular trauma*" OR "transient ischemic attack*" OR "infarct*")

AND

- ((MH “Caregivers”) OR “carer*” OR “caregiver*” OR “informal care*” OR “family care*” OR “wife” OR “husband”)

AND

- ((“Randomized Controlled Trials as Topic+”) OR “randomized control* trial*” OR “randomised control* trial*” OR “RCT”).

Study Selection

Search results were exported to Rayyan Intelligent Systematic Review Software. Duplicates were removed by a single reviewer. Titles and abstracts were screened by the primary author to identify studies that might meet inclusion criteria. Full-text articles were then screened against inclusion and exclusion criteria. A second reviewer (SA) screened a random sample of 20% of articles at full text screen to check inclusion and exclusion.

Data Extraction and Narrative Synthesis

The following data were extracted from included studies: date of publication; country; setting of intervention; sample size; attrition; mean age and standard deviation of stroke survivor intervention group and control group; mean age and standard deviation of informal caregiver intervention and control group; ethnicity, type of intervention (cognitive rehabilitation strategies, cognitive training, psychoeducation, cognitive assessment feedback, or another intervention type proposed to improve cognition); details of control conditions; significant results for survivors and caregivers, level of significance; intervention duration; lengths of individual sessions for intervention and control; delivery modes intervention and control; delivery formats intervention and control. Trials were grouped by intervention type. When it was unclear whether a trial had a cognitive focus, the author was emailed to clarify this (appendix E).

A narrative synthesis was completed following guidance by Popay et al. (2006). Heterogeneity in study methodological characteristics (intervention type, intervention length, and quality of studies) made a meta-analysis unsuitable.

Quality Assessment

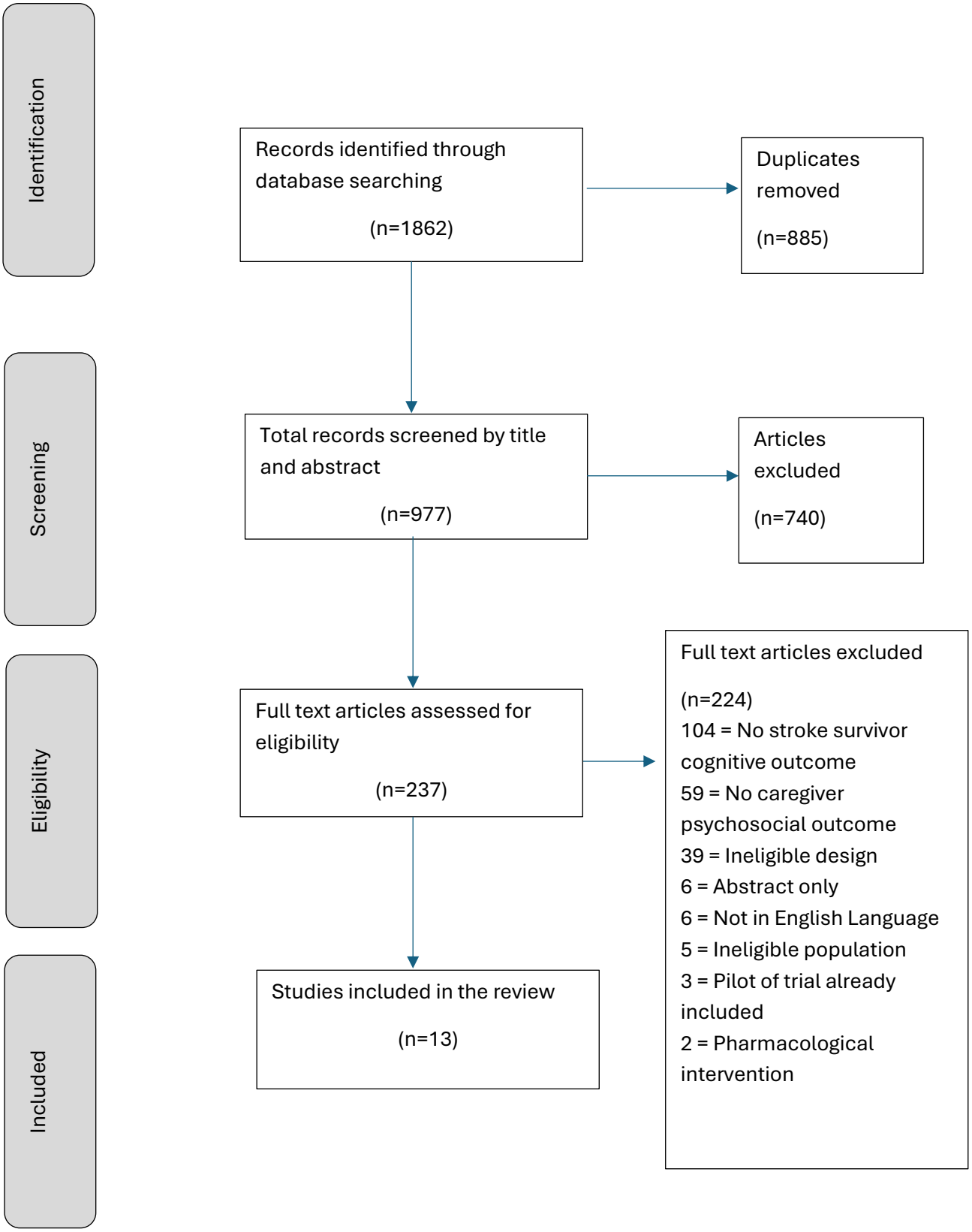
Quality and risk of bias were assessed using the Joanna Briggs Institute (JBI) Revised Critical Appraisal Checklist for Randomized Controlled Trials tool (Barker, 2023). A second reviewer (SL) screened 20% of included articles using the JBI checklist, and any disagreements were addressed by a third reviewer (CF). The JBI checklist identifies methodological bias with questions grouped according to internal validity and statistical conclusion validity. The checklist covers bias related to: selection and allocation, administration of intervention/exposure, assessment, detection, and outcome measurement and participant retention. The revised JBI is deemed appropriate for crossover RCT designs (Barker, 2023). Following guidance for the tool (Barker, 2023), a total methodological quality score was not recorded in isolation. Rather, a narrative description of the methodological quality of the study overall, and at domain level, was recorded. However, a total score for each study was taken by calculating the percentage of questions answered in the affirmative and excluding the questions assessing statistical conclusion validity in line with guidance by Barker (2023). This supplemented the above information, rather than replacing it.

Results

The systematic search produced 1862 references. Duplicates were removed (n=885), and the remaining 977 titles and abstracts were screened. 740 abstracts did not meet inclusion criteria. 237 papers were subject to full-text screen, and 13 met inclusion criteria as outlined in the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) diagram (figure 2).

Figure 2

PRISMA Flow Diagram of Studies



Study Characteristics

Table 1 presents the characteristics of the 13 studies included in this review; appendix F includes characteristics of the interventions. Publication dates ranged from 2000 to 2023. Studies were conducted across a number of geographical locations, including England (3), Sweden (2), Australia (2), Norway (1), India (1), Hong-Kong (1), America (1), Finland (1), and Holland (1). Trial designs included two randomised crossover control designs, two cluster-randomised control designs, three pilot RCTs and one proof of concept design.

The overall sample was 2527 stroke survivors and 2145 informal caregivers. The mean age of stroke survivors ranged from 54.0 (Kashyap et al, 2023) to 73.9 (Fjaertoft et al, 2004). Informal caregiver ages ranged from 49.7 (Mou et al, 2023) to 73.9 (Marsden et al, 2010). The total split of stroke survivor participants was 48.7% male and 51.3% female, however baseline demographics for informal caregivers were not available for all studies. Ethnicity of participants was only reported in two studies, both involving majority “white” participants (Forster et al., 2013; Ostwald et al., 2014).

Intervention duration varied from five weeks (Mou et al., 2023), to six months (Ostwald et al., 2014). Intervention duration was recorded for all studies with the exception of a study assessing the impact of neuropsychological assessment and feedback (McKinney et al., 2002). The duration of intervention sessions also varied across studies, from 30 (Vloothuis et al., 2019; van den Berg et al., 2016) to 240 minutes (H-RT; Bunketorp-Käll et al., 2017). The duration of intervention sessions in four trials varied across participants or was not reported (Bertilsson et al., 2014; Fjaertoft et al., 2004; Forster et al., 2013; McKinney et al., 2002).

Table 1.

Systematic Review Study Characteristics

Study ID	Country	Setting	Stroke Survivors				Informal Caregivers			Total Attrition
			N	Mean Age (SD)	% Male	Includes Stroke, TIA, or Mix	N	Mean Age (SD)	% Male	
Bertilsson 2014	Sweden	Other inpatient to community	280	74 (10) T 71 (10.8) C	57 T 63 C	Stroke including 26 with premorbid TIA	180[a]	60 (14.6) EG 64 (13.1) CG	35.6 T 24.7 C	28
Bunketorp-Käll 2017	Sweden	Community	123	62.7 (6.7) R-MT 62.6 (6.5) H-RT 63.7 (6.7) C	56.1 R-MT 58.5 H-RT 53.7 C	Stroke	106	NR	NR	22
Fjaertoft 2004	Norway	Hospital to community	320	74 (NR) T 73.8 (NR) C	54 T 44 C	Stroke	257[a]	NR	NR	62
Forster 2013	England	Other inpatient to community	928[b]	71 (12.76) T 71.3 (12.18) C	57.1 T 44.8 C	Stroke	928[b]	61.1 (14.64) T 60.8 (13.91) C	31.1 T 32 C	609
Kashyap 2023	India	Community	80	52.85 (13.7) T 55.18 (13.24) C	73	Stroke including 13 with premorbid TIA/Stroke	80	NR	NR	18

Marsden 2010	Australia	Community	25	70 (9) T 73.1 (9.3) C	76	Stroke	17	66.3 (10.1) T 69.6 (11.5) C	12	2
McKinney 2002	England	Hospital to community	228	Total 72[mdn]	57	Stroke	65[a]	NR	NR	121
Mou 2023	Hong-Kong	Hospital to Community	162	54.63 (11.8) T 57.52 (10.37) C	65.4 T 74.1 C	Stroke	162	48.38 (11.77) T 51.07 (11.76) C	51.9 T 38.3 C	70
Ostwald 2014	America	Community	159	66.98 (9.04) T 65.75 (9.26) C	68.75 T 81.01 C	Stroke	159	63.61 (11.02) T 61.34 (9.77) C	31.25 T 18.99 C	25
Siponkoski 2022	Finland	Community	50	63.5 (10.3) T 64.5 (14) C	52 T 37 C	Stroke and One TBI Survivor	43[b]	NR	NR	12[c]
van den Berg 2016	Australia	Hospital or Other Inpatient to Community	63	64.5 (18.5) T 70.1 (12.4) C	61.3 T 65.6 C	Stroke	63	NR	NR	3
Vloothuis 2019	Holland	Hospital or Other Inpatient to Community	66	60.53 (14.82) T 59.26 (15.01) C	66 T 59 C	Stroke	66	53.91 (14.9) T 54 (12.26) C	28 T 38 C	5
Wolfe 2000	England	Community	43	72 (12) T 76 (7.04) C	43 T 40 C	Stroke	19[a]	NR	NR	11

Note: a =Only available number is from follow-up outcomes not baseline; b=Only available number taken from total sample/registered sample not baseline; c= includes 1 participant who participated in follow-up measurement; mdn=median figures only; T = test group; C = control group; NR = not reported; RM-T = Rhythm Music Therapy; HR-T = Horse Riding Therapy; Other Inpatient = either geriatric, medical, non-hospital in-patient stroke rehabilitation units, nursing homes and rehabilitation centers; TIA = Transient Ischemic Attack.

Interventions were delivered either in person, remotely by phone or teleconferencing, guided by an app, or delivered by mail, with six studies reporting a mixed delivery method (typically an in-person group and home practice guided by an app or teleconferencing). One study did not report how the intervention was delivered (McKinney et al, 2002).

Six trials reported on cohabitation (Bertilsson et al., 2014; Forster et al., 2013; Marsden et al., 2010; Mou et al., 2023; Ostwald et al., 2014; Vloothuis et al., 2019). Cohabitation percentages were calculated between control and intervention groups, with Bertilsson (2014) having the lowest rate of cohabitation (52.7% intervention group; 60.3% control group). Ostwald (2014) had the highest rates of cohabitation with all dyads cohabiting across both experimental groups.

Quality Assessment

Included studies were examined using the JBI checklist (Barker, 2023), with summary results presented in Table 2. Each trial was scored a percentage relative to questions answered in the affirmative related to internal validity bias with a higher mark indicating higher validity (Table 2). Unclear answers were not recorded as affirmative to account for potential risk of bias. The mean score for selection and allocation was 53.3%; 43.2% for intervention administration; 84.2% for assessment, detection, and measurement of the outcome; and 100% for participant retention. While the authors of the revised JBI checklist (Barker, 2023) do not advocate to overall rating of bias for trials, they stipulate any summary score should not include items 11-13. 12 of 13 trials did not exceed a score of 70% affirmative answers in questions pertaining to internal validity. The lowest average affirmative answers related to bias in selection and allocation. Four trials showed no significant differences between baseline demographic characteristics of participants (Forster et al., 2013; Siponkoski et al., 2022; Vloothuis et al., 2019; Ostwald et al., 2014). Three reported blinding of participants to allocation of groups (Forster et al., 2013; Marsden et al, 2010; Siponkoski et al., 2022). Only one trial blinded

intervention facilitators (Forster et al., 2013). The validity of statistical conclusions is challenged as effect size and power was reported inconsistently with a number of trials underpowered, hampering the reviewer's ability to draw meaningful statistical conclusions about their data.

Table 2.

Systematic Review JBI Risk of Bias Summary Table

	Domain	Internal Validity Bias Related to: Selection and Allocation				Administration of Intervention or Exposure				Assessment, Detection, and Measurement of the Outcome				Participant Retention			Statistical Conclusion Validity		
First Author and (Year)	**Question No. Outcome**	**1**	**2**	**3**	**Domain %**	**4**	**5**	**6**	**Domain %**	**7**	**8**	**9**	**Domain %**	**10**	**Domain %**	**Total %**	**11**	**12**	**13**
Fjærtoft (2004)	MMSE	Y	Y	?	66	?	N	Y	33	Y	Y	Y	100	Y	100	70	N	?	Y
	CSI									Y	Y	Y	100	Y	100		N	?	
Bertilsson (2014)	SIS – Memory	Y	Y	N	66	?	N	Y	33	Y	Y	N	66	Y	100	60	Y	Y	N
	CBS									Y	Y	N	66	Y	100		NA	Y	
	Lisat-11									Y	Y	N	66	Y	100		NA	Y	
Forster (2013)	SIS Memory	Y	N	Y	66	Y	Y	Y	100	?	Y	N	33	Y	100	70	Y	Y	Y
	HADS-A									?	Y	N	33	Y	100		Y	Y	
	HADS-D									?	Y	N	33	Y	100		Y	Y	
Marsden (2010)	SIS – Memory	N	?	N	0	Y	N	Y	66	Y	Y	Y	100	Y	100	56.7	Y	N	Y
	CSI									Y	Y	Y	100	Y	100		Y	N	
	HIS – Emotion									N	Y	Y	66	Y	100		Y	N	
McKinney (2002)	CFQ	Y	Y	N	66	N	?	Y	33	Y	Y	Y	100	Y	100	70	?	?	Y
	CSI									Y	Y	Y	100	Y	100		?	?	
	GHQ-28									Y	Y	Y	100	Y	100		?	?	
Kashyap (2023)	MoCA	Y	?	N	33	?	?	Y	33	?	Y	?	33	Y	100	40	Y	?	Y
	FAB									?	Y	?	33	Y	100		Y	?	
	CBS									?	Y	?	33	Y	100		Y	?	

Siponkoski (2022)	VMI	Y	?	Y	66	Y	N	Y	66	Y	Y	Y	100	Y	100	80	Y	Y	Y
	SIS – Memory									Y	Y	Y	100	Y	100		Y	Y	
	Carer Burden Index									Y	Y	Y	100	Y	100		Y	Y	
Bunketorp-Käll (2018)	BNIS	Y	Y	?	66	N	N	Y	33	Y	Y	?	66	Y	100	60	Y	N	Y
	LNS									Y	Y	?	66	Y	100		Y	N	
	LISS									Y	Y	?	66	Y	100		N	N	
van den Berg (2016)	SIS – Memory	Y	Y	N	66	N	N	Y	33	Y	Y	Y	100	Y	100	70	Y	Y	Y
	HADS									Y	Y	Y	100	Y	100		Y	Y	
	CSI									Y	Y	Y	100	Y	100		Y	Y	
	FSS									Y	Y	Y	100	Y	100		Y	Y	
	GSES									Y	Y	Y	100	Y	100		Y	Y	
	Carer-QoL									Y	Y	Y	100	Y	100		Y	Y	
Vloothuis (2019)	SIS – Memory	Y	N	Y	66	N	N	Y	33	Y	Y	Y	100	Y	100	70	N	N	Y
	HADS-A									Y	Y	Y	100	Y	100		N	N	
	HADS-D									Y	Y	Y	100	Y	100		N	N	
	CSI									Y	Y	Y	100	Y	100		N	N	
	FSS									Y	Y	Y	100	Y	100		N	N	
	GSES									Y	Y	Y	100	Y	100		N	N	
	Carer QoL									Y	Y	Y	100	Y	100		N	N	
Wolfe (2000)	MMSE	?	?	?	0	N	?	Y	33	N	Y	N	33	Y	100	30	Y	N	Y
	CSI									N	Y	N	33	Y	100		Y	N	
Mou (2003)	SIS – Memory	Y	Y	N	66	N	N	Y	33	Y	Y	Y	100	Y	100	70	Y	Y	Y
	Caregiver Burden									Y	Y	Y	100	Y	100		Y	Y	
	F-COPES									Y	Y	Y	100	Y	100		Y	Y	
	PHQ-9									Y	Y	Y	100	Y	100		Y	Y	
	GAD-7									Y	Y	Y	100	Y	100		Y	Y	
Ostwald (2014)	SIS - Memory	Y	N	Y	66	N	?	Y	33	Y	Y	Y	100	Y	100	70	Y	Y	Y
	FIM – Cog									Y	Y	Y	100	Y	100		Y	Y	
	GDS									Y	Y	Y	100	Y	100		Y	Y	
	PSS									Y	Y	Y	100	Y	100		Y	Y	

	ZBI										Y	Y	Y	100		Y		100				Y	Y		
	F-COPES										Y	Y	Y	100		Y		100				Y	Y		
Sample Total %				53.3				43.2						84.2			100			62.8					

Note: Question (1) Was true randomisation used for assignment of participants to treatment groups? Question (2) Was allocation to groups concealed? (3) Were treatment groups similar at baseline? (4) Were participants blind to treatment assignment? (5) Were those delivering treatment blind to treatment assignment? (6) Were treatment groups treated identically other than the intervention of interest? (7) Were outcome assessors blind to treatment assignment? (8) Were outcomes measured in the same way for treatment groups? (9) Were outcomes measured in a reliable way? (10) Was follow up complete and, if not, were differences between groups adequately described and analysed? (11) Were participants analysed in the groups to which they were randomised? (12) Was appropriate statistical analysis used? (13) Was the trial design appropriate and any deviations from standard RCT design (individual randomisation, parallel groups) accounted for in the conduct and analysis of the trial?

Informal Caregiver Psychosocial Measures

Informal caregiver psychosocial measures are presented in table 3 below.

Table 3

Measures of Caregiver Psychosocial Wellbeing

Measures of Caregiver Psychosocial Wellbeing.	k	Study ID
Caregiver Strain Index	6	Fjærtoft 2004 Marsden 2010 McKinney 2002 van den Berg 2016 Vloothuis 2019 Wolfe 2000
Hospital Anxiety and Depression Scale	3	Forster 2013 van den Berg 2016 Vloothuis 2019
Caregiver Burden Scale	3	Bertilsson 2014 Forster 2013 Kashyap 2023
Zarit Burden Interview	2	Siponkoski 2022 Ostwald 2014
Fatigue Severity Scale	2	Mou 2023
General Self-Efficacy Scale	1	van den Berg 2016 Vloothuis 2019
Carer Quality of Life		van den Berg 2016 Vloothuis 2019
Family Crisis Oriented Personal Evaluation Scales	2	Ostwald 2014 Mou 2023
Caregiver Burden Inventory	1	Mou 2023
General Health Questionnaire-12	1	Siponkoski 2022
General Health Questionnaire-28	1	McKinney 2002
Life Satisfaction among Spouses after the Stroke Event scale	1	Bunketorp-Käll 2018
Perceived Stress Scale	1	Ostwald 2014
Geriatric Depression Scale-7	1	Mou 2023
Patient Health Questionnaire-9	1	Mou 2023
Health Impact Scale	1	Marsden 2010

Stroke Survivor Cognitive Measures

Stroke Survivor cognitive measures are presented in Table 4 below.

Table 4

Measures of Stroke Survivor Cognition

Measures of Post-Stroke Cognition Used	k	Study ID
Stroke Impact Scale – Memory	7	Bertilsson 2014 Forster 2013 Marsden 2010 Siponkoski 2022 van den Berg 2016 Vloothuis 2019 Mou 2023 Ostwald 2014
Mini-Mental State Examination	2	Fjærtoft 2004 Wolfe 2000
Montreal Cognitive Assessment	1	Kashyap 2023
Frontal Assessment Battery	1	Kashyap 2023
Weschler Memory Scale III Logical Memory and Word Lists Subtests	1	Siponkoski 2022
Finnish KAT Verbal Working Memory Task	1	Siponkoski 2022
Functional Independence Measure – Cognitive Subtotal	1	Ostwald 2014
Cognitive Failures Questionnaire	1	McKinney 2002
Letter-Number Sequencing from Wechsler Adult Intelligence Scale III	1	Bunketorp-Käll 2018
Barrow Neurological Institute Screen for Higher Cerebral Functions in Stroke patients	1	Bunketorp-Käll 2018

Intervention Types and Caregiver Involvement

Intervention types and caregiver involvement are described in Table 5. Two interventions were classed as psychoeducation on cognition (Marsden et al., 2010; Forster et al., 2013). One trial was classed as cognitive rehabilitation and involved the use of a meta-cognitive "goal-plan-do" strategy (Bertilsson et al., 2014). One trial was classed as a neuropsychological assessment and feedback session (McKinney et al., 2002). Three trials were classed as behavioural interventions that targeted cognition as either a primary (Kashyap et al., 2023; Siponkoski et al., 2022) or secondary outcome (Bunketorp-Käll et al., 2018). Five trials were classed as trials that included

cognitive outcome measures but either did not have a cognitive focus or this was unclear (van den Berg et al., 2016; Vloothuis et al., 2019; Fjærtoft et al. 2004; Mou et al., 2023; Ostwald et al., 2014; Wolfe et al., 2000).

Caregiver involvement included attending the intervention together (van den Berg et al., 2016; Vloothuis et al., 2019; Fjærtoft et al. 2004; Mou et al., 2023; Ostwald et al., 2014); caregivers being invited to the intervention (Marsden et al., 2010; McKinney et al., 2002; Siponkoski et al., 2022); caregivers only being offered an intervention (Forster et al., 2013), caregivers acting as informants only (Kashyap et al., 2023; Bunketorp-Käll et al., 2018; Wolfe et al., 2000) or caregivers being informed of the intervention by attending rehabilitation review meetings (Fjærtoft et al. 2004; Bertilsson et al., 2014).

Table 5

Narrative Synthesis Table

Type of Intervention Included	Design	Cognitive Measure	Psychosocial Caregiver Measure	Level of Caregiver Involvement	Cognitive Outcomes	Psychosocial Outcomes
Cognitive Rehabilitation Strategies						
Bertilsson (2014)	Multicenter RCT	SIS-M	CBS Lisat-11	Caregiver invited to Survivor Intervention	SIS-M – NS (*)	CBS - NS.
Psychoeducation						
Forster (2013)	Multicenter Cluster Randomised RCT	SIS-M	CBS HADS-A HADS-D	Caregiver Intervention Only	SIS-M NS 6 months (*).	HADS-A NS 6 months (*).
Marsden (2010)	Randomised Crossover Controlled Trial	SIS-M	CSI HIS-E	Caregiver invited to Survivor Intervention	SIS-M NS on either week 1, 9 or 21.	CSI NS on either week 1, 9, or 21 HIS-E NS on either week 9 or 21 but trend favouring intervention group over control (*).
Cognitive Assessment Feedback						
McKinney (2002)	Multicenter RCT	CFQ	CSI GHQ-28	Caregiver invited to Survivor Intervention	CFQ NS at either 3 or 6 months.	CSI NS at either 3 or 6 months but Area Under the Curve trend favouring intervention group over control (*)

Behavioural Interventions for Cognition Kashyap (2023)	RCT	MoCA FAB	CBS	Informant only	Intervention vs Baseline MoCA total Sig 6 months** MoCA visuospatial; abstraction 6 months * MoCA attention; recall; orientation 6 months** MoCA naming; language NS 6 months FAB total Sig 6 months** FAB mental flexibility 6 months * FAB all other domains but environmental autonomy Sig 6 months** FAB environmental autonomy NS 6 months Intervention vs Control MoCA total Sig 6 months* MoCA	Intervention vs Baseline CBS Sig 6 months** Control vs Baseline CBS Sig 6 months** Intervention vs Control CBS NS 6 months

					visuospatial, naming, recall Sig 6 months* FAB total Sig 6 months* FAB programming, interference, inhibitory control Sig 6 months*.	
Siponkoski (2022)	Randomised Crossover Controlled Trial	VMI SIS-M	Carer Burden from GHQ-12 and ZBI-22	Caregiver invited to Survivor intervention	VMI% NS 5 months. SIS-M NS 5 months.	Intervention vs. Control CBI Sig 5 months* *ηp2*=0.177
Bunketorp-Käll (2018)	Three-Armed RCT	BNIS LNS	LISS	Informant only	R-MT vs Control LNS in R-MT Group Sig 6 months* however after outliers addressed, adjusted figure NS (*).	R-MT and H-RT vs Control LISS in R-MT and H-RT Sig immediately after the intervention*. LISS in R-MT and H-RT Sig 3 months*. LISS in R-MT and H-RT NS 6 months. LISS worries in R-MT and H-RT Sig 3 months*.
Other Interventions						
van den Berg (2016)	Randomised Pilot Study	SIS-M	HADS CSI FSS GSES CQoL	Attend Intervention Together	Intervention vs Control SIS-M Sig 12 months**.	Intervention vs Control GSES Sig 12 months**. FSS Sig 12 months *.

Vloothuis (2019)	Multicenter RCT	SIS-M	HADS-A HADS-D CSI FSS GSES CQoL	Attend Intervention Together	Intervention vs. Control SIS-M NS any time point.	Intervention vs. Control HADS-D Sig 8 weeks**.
Wolfe (2000)	RCT	MMSE	CSI	Informant only	Intervention vs. Control MMSE NS any time point.	Intervention vs. Control CSI NS any time point.
Mou (2023)	RCT	SIS-M	CBI FCOPES PHQ-9 GAD-7	Attend intervention together	SIS-M Sig time effect** SIS-M NS group effect SIS-M NS group x time effect.	CBI Sig group effect* CBI Sig time effect** CBI Sig group x time effect*. CBI social relationships Sig group effect** All CBI domains Sig time effect** CBI development, physical health, social relationships Sig group x time effect*.
Ostwald (2014)	RCT	SIS-M FIM-C	GDS PSS ZBI-22 FCOPES	Attended intervention together	Intervention vs. Control SIS-M NS any time point Intervention vs. Control FIM-C Intervention Sig 6 months*	Intervention vs. Control GDS, PSS, ZBI NS at any time point. FCOPES total NS at any time point. FCOPES acquiring social support and mobilising family support Sig 12 months*.

Fjærtoft (2004)	RCT	MMSE	CSI	Caregiver invited to Survivor Intervention	Intervention vs. Control MMSE NS 52 weeks.	Intervention vs. Control CSI NS 52 weeks (*)

*note: WMS III Logical Memory and Word Lists subtests of Wechsler Memory Scale III & Finnish KAT verbal working memory task combined to create verbal memory index = VMI; Barrow Neurological Institute Screen = BNIS; Letter Number Sequencing = LNS; Functional Independence Measure – Cognitive Domain FIM-C; Montreal Cognitive Assessment = MoCA; Frontal Assessment Battery = FAB; Cognitive Failures Questionnaire = CFQ; Health Impact Scale – Emotion Domain = HIS-E; General Health Questionnaire–28 = GHQ-28; General Health Questionnaire-12 =GHQ-12 and Zarit Burden Interview = ZBI-22 combined to generate average percentage score for Carer Burden; Life Situation among Spouses after the Stroke Event = LISS; Life Satisfaction Questionnaire 11 = LiSAT-11; Fatigue Severity Scale = FSS; General Self-Efficacy Scale = GSES; Carer Quality of Life = CQoL; Family Crisis Oriented Personal Evaluation Scales = F-Copes; Geriatric Depression Scale = GDS; Perceived Stress Scale = PSS; Caregiver Burden Scale = CBS; Caregiver Strain Index = CSI; Caregiver Burden Inventory = CBI; Timepoint = T; Intention-to-Treat = ITT; (*) = p <0.1; * = p ≤0.05; ** = p ≤0.01. NS = Not significant.*

CBS, CBI, CSI, CFQ, GHQ-12, GHQ-28, ZBI-22, FSS, GDS, PSS, HADS a higher score denotes more negative outcome on these measures

Psychosocial Caregiver Benefits

Only one trial demonstrated a significant effect in caregiver psychosocial outcomes when caregivers were invited to be actively involved in the intervention and cognition was a focus of the intervention (Siponkoski et al., 2022). The other trials meeting this description did not but demonstrated non-significant trends in the HIS-E and CSI respectively (Marsden et al., 2010; McKinney et al., 2002). Siponkoski's (2022) study was a crossover trial for those with aphasia[1] that demonstrated a significant reduction in an index comprising the GHQ-12 and ZBI-22 for both caregiver groups between baseline and 5 months follow up and a significantly greater reduction for the intervention group. Siponkoski's (2022) study was a 16-week multicomponent intervention that included weekly group-based singing where caregivers were invited to join for one hour, and melodic intonation therapy for 30 minutes in person, in combination with app-facilitated training sessions three times per week for 30 minutes per session. Marsden's (2010) study was a cross-over pilot trial involving a seven-week group programme involving caregivers which included psychoeducation about memory hosted in person. Marsden (2010) describe that the trial required more participants to maximise group dynamics and be sufficiently powered. McKinney's (2002) study was a multi-centre single-blind trial involving detailed neuropsychological assessment and a feedback session with the provision of information and strategies, to which the caregiver was invited. McKinney (2002) reported a non-significant trend towards the intervention group using an area under the curve summary measures analysis.

Two cognitively focused trials reported significant benefits for caregiver wellbeing, but involved caregivers as informants only (Kashyap et al., 2023; Bunketorp-Käll et al., 2018). Four

[1] One caregiver supported an aphasic traumatic brain injury survivor.

trials not deemed as cognitively focused reported significant effects for caregiver wellbeing where caregivers were invited to be involved above the level of informant only (van den Berg et al., 2016; Vloothuis et al., 2019; Mou et al., 2023; Ostwald et al., 2014). Two trials demonstrated no significant effect for caregiver wellbeing (Bertilsson et al., 2014; Wolfe et al., 2000); four trials demonstrated a trend toward improved caregiver wellbeing but no significant effect (Forster et al., 2013; Marsden et al., 2010; McKinney et al., 2002; Fjærtoft et al., 2004).

Discussion

Post-stroke cognitive interventions are a priority for stroke survivors (Hill et al., 2022) and dyadic cognitive interventions have potential to improve both cognition after stroke and caregiver wellbeing (Bakas et al., 2022). To our knowledge, this is the first systematic review of dyadic interventions assessing post-stroke cognition and caregiver wellbeing outcomes.

We found that the most common outcomes assessed were the memory domain of the Stroke Impact Scale (Duncan et al., 2003), and the Caregiver Strain Index (Robinson, 1983). Interventions targeted post-stroke cognition through psychoeducation, cognitive rehabilitation, neuropsychological assessment feedback sessions, and cognitive outcomes of behavioural interventions. Six other trials reported cognitive outcomes, but their interventions had no clear cognitive components, for example Vloothuis (2019) who used a physical therapy app. Ten trials invited the active involvement of the caregiver, including four trials where consenting dyads were required to attend the intervention together, five trials where caregivers were invited to attend at least one element of the intervention with the stroke survivor, and one intervention involving only the caregiver. Three trials targeted post-stroke cognition and invited active involvement of informal caregivers and stroke survivors (Marsden et al., 2010; McKinney et al., 2002; and Siponkoski et al., 2022). Of these, one reported a significant reduction in caregiver burden (Siponkoski et al., 2022).

The lack of trials available limits the conclusions we can draw about dyadic cognitive trials to improve caregiver psychosocial outcomes.

The significant reduction of caregiver burden in Siponkoski's (2022) study lends support to Zhang (2023), showing potential for dyadic interventions to reduce caregiver burden. While confounded by a lack of available trials, the results of this systematic review appear to echo other reviews and meta-analyses of dyadic caregiver interventions showing that interventions with in-person components are linked to improved caregiver outcomes (Pucciarelli et al., 2021; Bakas et al., 2022; Zhang et al., 2023; Siponkoski et al., 2022; Mou., 2023; Bunketorp-Käll et al., 2018; Kashyap et al., 2023). However, Bakas (2022) recommends person-centered interventions over group interventions and Siponkoski (2022) and Marsden (2010) were not person-centered trials despite having in-person components. McKinney's (2002) trial was person-centred. Despite Pucciarelli's (2021) meta-analysis finding a significant reduction of caregiver depressive symptoms in dyadic stroke interventions that included a psychoeducational component, this review found no cognitively focused intervention that actively invited both members of the dyad and measured caregiver depressive symptoms.

A key strength of the review was that we included data on reporting of dyad members' demographic characteristics. This demonstrated inconsistent reporting of caregiver demographics, yet these data are important. They are included in the informal caregiving model (ICIM) as demands and resources, influencing caregiver specific outcomes and as dyadic general outcomes (ICIM; Gérain & Zech, 2019). A further strength of the review is the inclusion of smaller pilot trials. Despite the limited power of such trials to detect significant outcomes, they do provide important data on which outcome measures were used, how caregivers were involved and what type of cognitive interventions were used.

Our review findings are necessarily limited by the methodological quality of the trials included. There was a lack of clarity about how outcomes were gathered and how participants were blinded. It was also difficult to draw conclusions about the extent of caregiver involvement due to lack of reporting clarity. Our findings were also constrained by exclusion criteria and the restriction to English publications limiting generalisability to the English-speaking world, clearly problematic as two thirds of strokes occur in developing countries, where English is rarely the first language (Krishnamurthi et al., 2013).

This review contrasts with other reviews (Pucciarelli et al., 2021; Bakas et al., 2022) by including trials where caregivers provided outcome measures only, and including trials where active behavioural interventions such as singing were deployed. This approach increased the heterogeneity of the review sample and made the data somewhat more difficult to synthesize. Nonetheless, it provided additional information regarding differing levels of caregiver involvement that would have otherwise been screened out. We also included participants from in-patient environments who had cognitive impairments, demonstrating a broader focus than a recent review (Pucciarelli et al., 2021). Our broader focus provides insight into the experiences of caregivers supporting stroke survivors with whom they are not cohabiting or supporting the transition home from in-patient services (Luker et al., 2017).

Compared to other reviews (Pucciarelli et al., 2021; Bakas et al., 2022; Zhang et al., 2023), far fewer trials met our inclusion criteria, which involved both cognitive outcome measures and caregiver psychosocial outcome measures. Fewer still could be described as dyadic cognitive interventions where caregivers were actively invited to participate. This suggests this field of research is underdeveloped relative to more general educative or psychosocial dyadic interventions for stroke caregiver and survivor dyads. We also searched fewer databases than Zhang (2023) and we included only trials published in the English language. Whereas Zhang (2023)

included English and Chinese language papers, addressing potential western bias more than the current review.

In the recent meta-analysis by Pucciarelli (2021), results were linked to the theory of dyadic illness management (Lyons & Lee., 2018). Lyons and Lee (2018) suggest that caregiver and survivor dyadic health is influenced by each member of the dyad. Dyadic health is influenced positively by more similar appraisals of the illness and behaviours the dyad performs to manage the illness (Lyons & Lee, 2018). As evidence of intervention effectiveness was inconclusive, it is not possible to gauge whether improvements in caregiver psychosocial outcomes support the theory of dyadic illness management (Lyons & Lee., 2018). We suggest further research in this area will be important to further explore the theory of dyadic illness management for stroke survivor and caregiver dyads.

Implications and suggestions for clinical practice arising from this review are again limited by the lack of available trials, but build upon the work of previous reviews (Pucciarelli et al., 2021; Bakas et al., 2022). They include the advocacy for dyadic skill-building and psychoeducational interventions that involve an active cognitive focus, encompassing more behavioural interventions such as singing or modified intonation therapy rather than purely psychoeducational interventions. The importance of singing-based interventions is supported by research for non-clinical older age adults (Coulton et al., 2015; Pentikäinen et al., 2021) and for caregivers of people with dementia (Lee et al., 2022), particularly important as 25-30% of ischaemic stroke survivors develop vascular dementia or vascular cognitive impairment (Kalaria, Akinyemi, & Ihara, 2016).

Future research in this area is important, due to the established link between caregiver wellbeing and survivor cognition (Stolwyk et al., 2024), the lack of high methodological quality trials in our review and recent calls for high quality research trials to address post-stroke cognitive

difficulties (Hill et al., 2022). Future trials exploring cognitive interventions for stroke survivors should include an active skills-based or psychoeducational component for caregivers (Pucciarelli et al., 2021; Bakas et al., 2022). No cognitive stimulation trials were identified in this review. The dearth of dyadic cognitive stimulation interventions is perhaps surprising as many of these trials were conducted in the homes of dyads where there is often a contextual link to everyday activities (Clare & Woods, 2003). The area of dyadic cognitive stimulation trials is one that bears exploration.

There was a broad range of caregiver psychosocial outcomes but the most prevalent was the caregiver strain index (Robinson 1983). Continued use of the Caregiver Strain Index (Robinson 1983) as a standardised tool to measure this outcome would be advantageous as consistent outcome measurement helps to address concerns about the heterogeneity of the evidence. Owing to the lack of papers assessing caregiver wellbeing in the context of cognitive interventions for stroke survivors, it will be important to analyse qualitative papers and feasibility studies in future reviews to establish a deeper understanding of caregiver's perceptions about these interventions (Seers, 2015). A qualitative understanding can be particularly important as stroke caregivers' priorities are often an important variable in choice of rehabilitation (National Clinical Guidelines for Stroke; NCGS, 2023).

Conclusions

This review aimed to explore intervention RCTs reporting on both stroke survivor cognition and caregiver wellbeing. 13 trials were identified. It found the memory domain of the Stroke Impact Scale (Duncan et al., 2003) and the Caregiver Strain Index (Robinson, 1983) to be the most prevalent measures to record outcomes, with seven trials involving cognitive interventions, and ten trials inviting caregivers to be actively involved over and above the role of informant. Three trials satisfied both criteria. One found a significant improvement in caregiver wellbeing (Siponkoski et

al., 2022). One was underpowered but reported a trend in improvement (Marsden et al., 2010). The third also reported a trend in increased caregiver wellbeing, using a summary measures analysis (McKinney et al., 2002). Clearly while there is promise that dyadic cognitive interventions can improve stroke caregiver outcomes, the evidence for this is limited. This area of research is underdeveloped and limited by methodological biases, and further trials will be required to explore this potentially valuable area of research.

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Chapter 3 - Empirical Paper

Assessing the Acceptability of Adapted Cognitive Stimulation Therapy for Stroke (sCST): Caregiver Perspectives

Prepared for the journal of Disability and Rehabilitation

(see appendix A. for author guidelines for manuscript preparation)

Assessing the Acceptability of Adapted Cognitive Stimulation Therapy for Stroke (sCST): Caregiver Perspectives

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Abstract

Purpose: Caregiver involvement in cognitive interventions aimed at frailty reduction may enhance patient engagement and benefit carers. We explored the acceptability of a novel adaptation of Cognitive Stimulation Therapy (CST) for pre-frail stroke survivors (sCST) where caregiver involvement in the intervention was encouraged.

Materials and Methods: A non-randomised, single arm pilot intervention acceptability study was conducted. Five pre-frail or emerging frail stroke survivors with cognitive impairment, recruited from an acute stroke service, attended a novel eight-session sCST intervention over four weeks, supported by caregivers delivering cognitive psychoeducation and suggested home-based activities. Semi-structured interviews with caregivers post-intervention were analysed using Framework Analysis guided by the Theoretical Framework of Acceptability (TFA).

Results: Four participants completed the group. Themes consistent with six of the seven domains of TFA acceptability (affective attitude, burden, ethicality, intervention coherence, perceived effectiveness, and self-efficacy) emerged, with two additional themes (general acceptability and suggestions), and several subthemes identified.

Conclusions: Caregivers described increased survivor confidence and independence and dyadic insight as a result of the intervention with only one caregiver reporting they would not attend further sessions. Barriers to acceptability included the practical burdens of sCST and intervention difficulty level.

Introduction

Globally, stroke is the second largest cause of death, and third primary cause of death and disability combined (Feigin et al., 2019). In 2019 there were 12.2 million new strokes per year and 101 million people living with stroke (Feigin et al., 2019), nearly double the number 30 years prior (Owolabi et al., 2022). Stroke is an important cause of frailty, a progressive state of vulnerability characterised by multisystem decline in physiological reserves needed to maintain homeostasis following stressors (Morley et al., 2013; Fried et al., 2001; Campbell & Buchner, 1997). Frailty in particular after stroke is associated with worse functional outcomes and increased mortality (Li, Wan & Wang, 2024). Pre-frailty, a "state that may precede the onset of frailty, is associated with adverse health outcomes and reduced quality of life (Gill et al., 2006) but which might be reversed or attenuated by targeted interventions" (Sezgin et al. 2022) is also common after stroke. A systematic review and meta-analysis found a pooled prevalence of frailty of 21% in stroke survivors and 48% for pre-frailty, and that stroke survivors were more than twice as likely to be frail as those who have not had a stroke (Palmer et al., 2019).

Stroke survivors are often supported by family caregivers, who play an important role in rehabilitation and supporting activities of daily living (Torregosa et al., 2018). In the UK alone, the value of care by informal caregivers is estimated at £15.8 billion, almost double the £8.6 billion in NHS and care home and professional carer costs (Patel et al., 2020). Caregivers often experience emotional and physical health-related difficulties related to their caregiving role, which novel interventions could look to target (Bakas et al., 2014; Farahani et al., 2020; Young et al., 2020). Moreover, with 75% of strokes occurring in people aged 65 and over (Simmons, Poupore, & Nathaniel., 2023), and frailty associated with aging (Zampino, Ferrucci, & Semba., 2022), it is likely some family caregivers supporting stroke survivors themselves may also be frail or pre-frail. Recent systematic reviews have thus examined the benefits of including caregivers in dyadic stroke

interventions, with Pucciarelli (2021) finding evidence that dyadic stroke interventions may improve physical functioning, memory and quality of life in stroke survivors and reduce depression levels in caregivers.

Multicomponent interventions (MCIs) combining physical, dietary and cognitive interventions are recommended treatments for frailty (Dent et al., 2019). Cognitive interventions have been found to reduce frailty whether as part of MCIs or stand-alone interventions (Ng et al., 2015). These utilise a range of cognitive activities, including "spot the difference", sorting or colouring tasks, visual reasoning or maze neuropsychological tasks and virtual reality orientation tasks (Doumas et al., 2009; Verghese et al., 2010; Li et al., 2010; Smith-Ray et al., 2015; Willis et al., 2006). As yet, however, no consensus has been reached on the most effective cognitive interventions for MCIs seeking to target frailty, in terms of either mode of delivery, content, session number and session duration (e.g. Apóstolo et al., 2018; Chen et al., 2020; Murukesu et al., 2020; Ng et al., 2015).

Cognitive Stimulation Therapy (CST) is a NICE-recommended group-based cognitive intervention for people with mild to moderate dementia (NICE, 2018; Alvares-Pereira, Silva-Nunes, Spector, 2021). Used globally, CST has been found to improve cognition, quality of life, well-being, activities of daily living, and mood in the dementia population (Aguirre et al., 2013; Lobbia et al., 2019). Important aspects of CST involve enjoyment, learning, strengthening abilities and social relationships, and the stimulation of cognitive abilities, such as memory and orientation, through group activities (Spector et al., 2006; Hall et al., 2013). While other cognitive interventions used in MCIs for frailty stimulate memory and orientation through tasks (Ng, 2015), they may lack the social environment of a group setting (Doumas et al., 2009; Verghese et al., 2010; Li et al., 2010; Smith-Ray et al., 2015). Inclusion of CST as part of MCIs for frailty may be advantageous, as it may provide not only cognitive stimulation, but also a social environment to reduce the isolation often

associated with frailty (Kojima et al., 2022). Moreover, family caregivers may themselves benefit, due to the improvement in cognitive skills seen in those they support (Aguirre et al., 2014). Qualitative research has identified benefits of CST for family caregivers (Lauritzen et al., 2022, Rai et al., 2021), particularly when they are involved in the delivery of CST (Bailey et al., 2017., Leung et al., 2017; Orrell et al., 2017; Rai et al., 2021). For example, participants with dementia attending CST interventions with family caregivers become more able to communicate socially and interact with others, leading to more positive relationships with the caregiver (Bailey et al., 2017; Orrell et al., 2017).

No manualized intervention of CST for stroke survivors has yet been published. We have developed a manualised adaptation known as Stroke Cognitive Stimulation Therapy (sCST). Given that caregiver involvement in cognitive interventions aimed at frailty reduction may enhance patient engagement and benefit carers, we recruited dyads of pre-frail stroke survivors and family caregivers to pilot sessions of this new adaptation. Family caregivers were asked to support stroke survivors to attend the intervention and were provided information about the intervention and related activities to extend the intervention at home. Guided by the Theoretical Framework of Acceptability (TFA, Sekhon et al., 2022, Appendix G) in production of the topic guide (Appendix H), we used framework analysis, where the TFA was also used as a narrative framework. Framework analysis is a qualitative methodology, utilised to evaluate the acceptability of sCST for stroke survivors (reported elsewhere in a doctoral thesis by Livsey 2025) and family caregivers (reported here) as a potential candidate cognitive intervention for post-stroke frailty MCI trials.

Frailty and Its Effects on Stroke Treatments and Outcomes Project (FIESTO)

A linked study follows this paper, analysing the feasibility of the sCST intervention conducted in this trial but for both pre-frail stroke survivors and their caregivers, also assessing

potential solutions to possible feasibility issues. This is in context of the FIESTO project, where a future multicomponent feasibility RCT will be conducted to understand the feasibility of a multicomponent intervention for pre-frail stroke survivors, including sCST as the cognitive stimulation component. If this multicomponent intervention was assessed as feasible, a future RCT would be conducted to understand the efficacy of this in potentially reversing the trajectory of the pre-frail stroke survivor's progression into frailty and associated outcomes. The inclusion of caregivers in this intervention is investigated in these papers.

Aims

The aims of this paper are to test the acceptability of a newly developed dyadic pre-frail stroke survivor adaptation of CST (sCST) for the caregivers of the stroke survivors, with the acceptability to stroke survivors reported elsewhere (Livsey et al., 2025) and the feasibility reported elsewhere (Bramley et al., 2025).

If this intervention is acceptable and feasible, then it is intended to become a component of a MCI for post-stroke frailty. As such it would form part of a feasibility RCT, testing the feasibility of the full MCI ahead of a full RCT, testing the efficacy of the full MCI.

Method

A qualitative approach was adopted to explore caregiver views on the acceptability of the intervention. Online semi-structured interviews with stroke caregivers were conducted following the pilot intervention. These were informed by the Theoretical Framework of Acceptability (TFA) (Sekhon et al., 2022). The interviews were not part of the intervention and were therefore not evaluated as part of the intervention.

The underpinning philosophical stance adopted was pragmatism, where reality is understood to be dynamic, influenced by actions, unlikely to ever be wholly understood, though it is accepted that knowledge can be generated by understanding what works best within the specific context (Kaushik & Walsh, 2019). This has been written in accordance with consolidated standards of reporting trials guidelines for pilot and feasibility studies (CONSORT; appendix I).

Research Team and Patient and Public Involvement

The sCST group sessions were adapted from CST (Spector et al., 2006) and facilitated by two Trainee Clinical Psychologists experienced in running CST groups with older adults and working with stroke survivors and caregivers. Group sessions were also attended by a Consultant in Stroke Medicine. The research was supervised by a Professor in Clinical Psychology and a Consultant Clinical Neuropsychologist.

Patient and Public Involvement (PPIE) with a stroke survivor and caregiver dyad facilitated decision-making regarding the processes, content and materials used in the sCST group sessions. The PPIE consultation process facilitated a number of adaptations to CST, reported in more detail elsewhere (Livsey et al., 2025), including explaining frailty and pre-frailty in non-medical terms and ensuring music playing in the group song was of adequate volume to minimise stroke survivor self-consciousness.

Adapted Cognitive Stimulation Therapy for Stroke (sCST)

Adapted Cognitive Stimulation Therapy group sessions were conducted in a hospital setting for four weeks with two of eight 45-minute sCST sessions delivered weekly between August and September 2024 separated by a 15-minute comfort break. Participant flow is reported in Figure 3. Caregivers supported stroke survivors to attend the sCST sessions as needed. Stroke survivors were given an information handout per session to share with their caregiver. These handouts

provided summary information about the sessions, the activities used, their purpose and suggested benefits, and details of a relevant cognitive strategy and optional activities to complete as a dyad (Appendix J). Caregivers were asked to support stroke survivors to attend the group, read the session handouts and invited to complete the optional activities with the stroke survivor at home. Session and handout topics included Current Affairs, Sounds, Using Money, Faces, Categorising Objects, Orientation, Word Association, Food and associated cognitive strategies. Homework activities described in the handouts included summarising a news story, creating a playlist, budgeting a meal, using mnemonics to remember a character, fluency tasks, planning an errand using visual or written instructions, an inhibition task, and chunking items on a shopping list.

Semi-Structured Interviews

Following the final sCST session, caregivers recruited to the pilot took part in semi-structured video-recorded interviews with one of the group facilitators, online using MS Teams, within three weeks of the final sCST session in September-October 2024. The interview topic guide was developed in discussion with members of the research team (MB, SL & CF) and designed to explore the seven domains of acceptability from the TFA.As interviews were conducted by a sCST group facilitator, the topic guide began with encouragement to be candid about the intervention. Support was offered to problem solve any technical difficulties with the online meeting platform and a break was offered mid-way through interviews. Caregivers attended the remote interviews from their homes.

Ethical Approval

Ethical, governance and legal approvals were granted by the National Health Service (NHS) Yorkshire and The Humber – Bradford Leeds Research Ethics Committee (REF:24/YH/0075;

appendix K). Capacity and capability was confirmed by the recruiting NHS trust, Cambridge University Hospitals NHS Foundation Trust (REF: A096977; appendix L) and sponsorship was confirmed by University of East Anglia Research and Innovation Department (appendix M). The study was conducted in accordance with the Helsinki Declaration of 1975, as revised in 2000, and registered on ClinicalTrials.gov (Identifier: NCT06733103). A non-substantial ethical amendment to respond to recruitment challenges was approved (appendix N). One serious adverse event (SAE) was reported to the research ethics committee, when a caregiver sprained a hip pushing a wheelchair to the group; no further action was indicated.

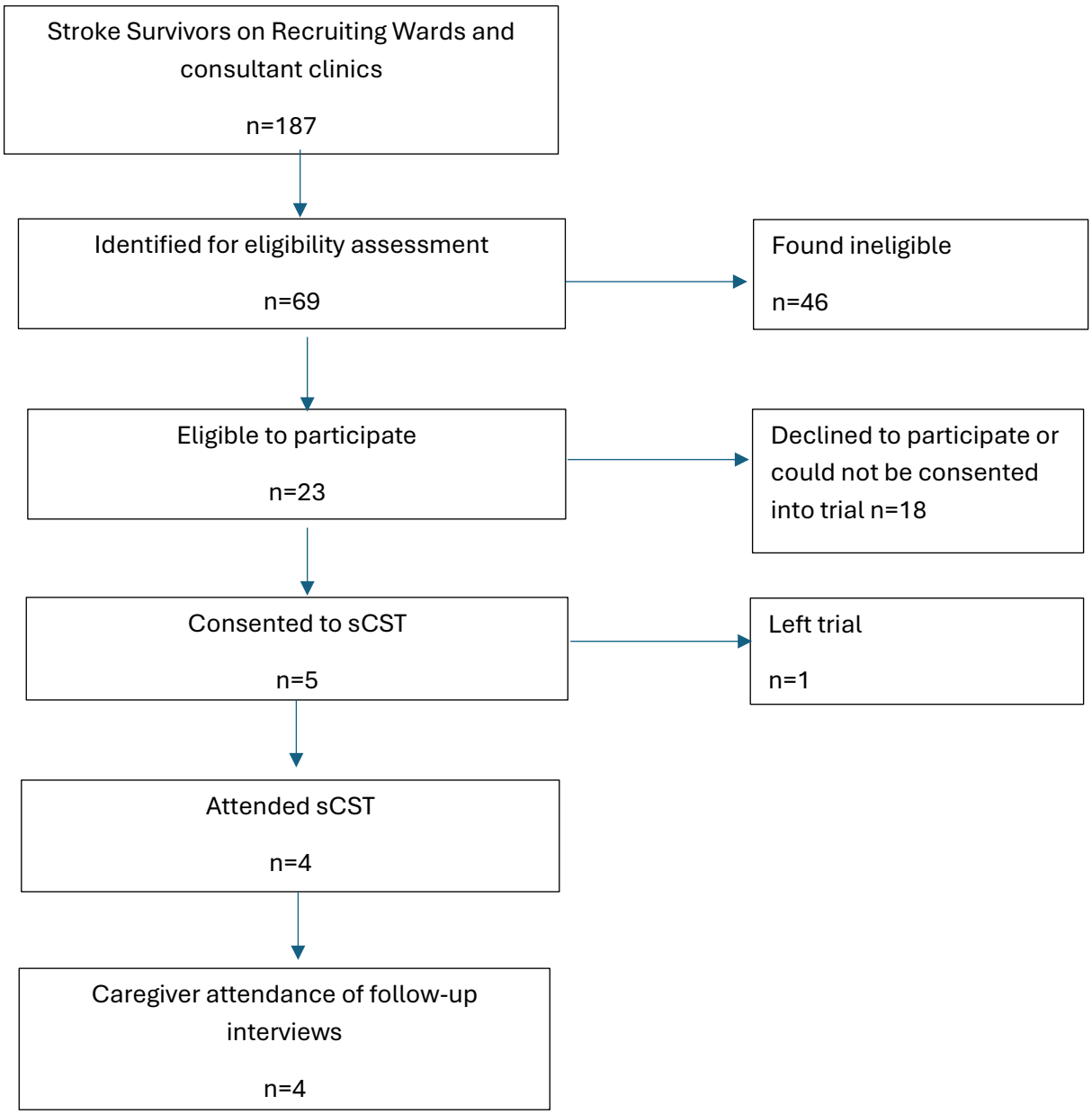
Participants

Caregiver and stroke survivor dyads were identified as potentially eligible to participate by members of the research team at Addenbrookes Hospital (Bramley et al., 2025). Stroke caregiver participants were (a) aged 18 years or above; (b) regularly supported a stroke survivor who had consented to participate in sCST group sessions; (c) had sufficient English to read summaries of sCST sessions and take-home activities and participate in an online interview; and (d) the person they supported was: 18 years old or above, community-dwelling when the group began, had sustained stroke within the previous 12 months; scored 3-5 on the Clinical Frailty Scale (CFS, Appendix O; Rockwood et al., 2005) indicating pre-frailty or emerging frailty (Flaatten et al., 2017; Muessig et al., 2018), showed cognitive changes on a standardised cognitive screening or assessment measure, and had sufficient communication in English to participate fully in the group intervention and an online interview. Potential stroke caregiver participants were excluded if they: (a) did not have access to a computer, laptop or tablet to access an online interview; (b) were a paid carer for the person they supported; (c) were under investigation by a safeguarding team; or (d) the person they supported: had difficulties with language, memory or thinking that would impede full group participation, lacked mental capacity to consent to participation, had a diagnosis of

dementia, or did not have access to a computer, laptop or tablet from which they could access an online interview.

Figure 3

Participant Flow



Data Analysis

Interviews were recorded and transcribed using the Microsoft Teams functions. The lead researcher listened again to each transcript from start to finish. This was to correct any mistranscriptions and anonymise data, including redaction of names of the caregiver or stroke survivor and any other identifiable data, this extended to the pronouns of the caregiver and survivor as this could identify them to other participants.

Interview data were analysed using Framework Analysis (Gale et al., 2013), guided by the Theoretical Framework of Acceptability (TFA) (Sekhon et al., 2022) to explore features that facilitated and hindered intervention acceptability from caregivers' perspectives. The framework analysis (FA) (Ritchie & Spencer, 1994; Gale et al., 2013) involved: (1) familiarisation and immersion with the data noticing within and between participant differences; (2) using the TFA as a theoretical framework to organise themes and manage data meaningfully; (3) indexing transcripts into framework categories and applying a code; (4) charting/rearranging data and thematic framework to create order and identify subthemes; and (5) mapping and interpretation by summarising across participants and themes.

To support the quality, rigour and trustworthiness of this study, Yardley's (2000) guidelines for methodological rigour were considered. Sensitivity to context was promoted through writing a reflexive statement (appendix P). Sensitivity to context and commitment to rigour were promoted through discussions with stroke survivors, caregivers and professionals and correspondence with a research team that previously employed framework analysis to explore the acceptability of a frailty intervention (Western et al., 2023). Transparency and coherence were considered in the reporting of the framework analysis. The transparency, coherence, impact and importance of the research are also considered in discussion of the results.

Results

Four stroke caregivers (three male, one female), aged 60-78 years (mean = 72, SD = 10.2) were interviewed online, with interview duration between 95 – 136 minutes, with an average of 117 minutes with a 10-minute break, though this was declined for the shortest interview. The four caregivers were all White British/Irish. Two had higher education qualifications, one had O Level / GCSE qualifications and one preferred not to say. Two of the stroke survivors they supported had attended all group sessions and two had attended six of the eight sessions (N = 2). One caregiver had read handout sheets for all group sessions, two had read the sheets for some but not all sessions, and one caregiver had not read the sheets. Three caregivers had carried out some, but not all, the suggested at home activities with the person they supported, and one had not carried out home-based activities.

Eight themes, including six of the seven themes of the TFA and two additional themes, were identified from interviews with the four stroke caregivers, as shown in Table 6. No subthemes relating the Opportunity Costs domain of the TFA were identified.

Table 6

Themes and Subthemes

Theoretical Framework of Acceptability Domains (Themes) and descriptions	Sub-Themes
1. Affective Attitude *How an individual feels about the group*	a. Interest in sCST b. Dyadic Benefit c. Stroke Survivor Anxiety and Frustration Difficult
2. Burden *The amount of effort required to participate in the group*	a. Practical Burdens b. "Caring without pushing too much" c. Not Burdensome
3. Ethicality *The fit to the individual's value system*	a. Demands of the Group were Fair b. Group Demands were Not Distressing
4. Perceived Efficacy *The extent which the group has achieved it's intended purpose*	a. Psychosocial Efficacy b. Cognitive and Functional Efficacy c. Impact of Mood, Stress or Functioning on Efficacy
5. Intervention Coherence *The extent to which the individual understands how the group works*	a. Clear Purpose of sCST and Research b. Misunderstandings or Ambiguity
6. Self-Efficacy *Confidence the individual can perform as required for the group*	a. Clarity of Materials and Stroke Survivor Reactions
7. Opportunity Costs *The benefits, profits or values given up for group*	No subthemes identified; participants instead listed the activities that would mean they didn't attend a session, for example holidays.
8. General Acceptability *Other acceptability considerations not outlined elsewhere*	a. Positive Group Features and Content b. Issues with Group Practical Features and Content c. Views on More Sessions
9. Future Suggestions *Suggestions for other iterations of the group*	a. Changes to Session Structure or Content b. Changes to Materials or Sheets c. Important Elements to Retain

Table 7.

Framework Matrix

	Participant 1	Participant 2	Participant 3	Participant 4
Affective Attitude	Liked the non-"medicalized" ethos and materials and thought activities were "valid and interesting" but was aware the stroke survivor felt "irritable", finding the tasks too "simple" and the hospital setting may have made the survivor feel a "victim".	The group was "something positive to focus on" and the handouts were "interesting". The survivor sense of "focus" was "satisfying" for them. Feeling "involved" with others and the survivor enjoying the group was "the main point".	Found it "interesting" and enjoyed respite. Aware the survivor was initially "anxious", due to uncertainty, but "determined" to go. Caregiver liked survivor's chance to "interact with everybody". Thought that knowledge of group benefit could enable caregiver in their role.	Caregiver took "comfort" in group's purpose but was aware the survivor was "timid" and that supporting the survivor to attend the group was a "military operation". Handouts were not attempted, while they were "a good idea", the caregiver doubted they would be enjoyable.
Burden	Found the hospital location "quite negative" and session timing "difficult" due to difficulties with "tiredness" and health of dyad. Found it hard balancing "gentle positive" encouragement despite survivor misgivings.	"Didn't find anything difficult because of [survivor's] enthusiasm to go". Both were "tired" when reading handouts but saw them as a "a matter of life".	While a full course of sessions is "a long time", the group as planned was not burdensome. Fatigue expected, so not difficult. Role balanced as "neither carer nor oblivious", "caring without pushing too much".	"Biggest burden was getting here". Family support enlisted for logistics. Balancing helping and "not maki[ng] an issue of something". There was also a "high stress factor" relative to the survivor. Duties are already a struggle, "further attendance" would "add to stress".
Ethicality	Session demands were fair	Sessions were fair for the survivor, covering the past is important, nothing made the supporter uncomfortable or distressed.	Supporter comfortable with what was asked of them and the survivor.	Sessions were "very reasonable", fair, with supporter confident in ability to withdraw if felt unfair. The survivor needed encouraging before

				sessions and this was stressful.
Perceived Efficacy	Greater knowledge of stroke. and activities mean post-stroke changes are “now up for discussion”. More sessions may keep hope of “improvement” “alive”. Survivor “rejected out of hand” certain activities but caregiver uses them. Activities in group setting may “switch off” some participants.	Gave “answers” and insight to survivor’s difficulties. It “helped [them] to not feel so alone”. Mood and functioning improved, helping independence, aiding caregiver. Gave “focus” and “achievement”. More sessions may aid cognition.	“We found out about stroke” which was “confidence-boosting” for the survivor. They were “cheerful” aiding the caregiver to have a “nice…life”. The group helped the survivor “push forward.” More sessions may aid cognition, but caregiver is “comfortable with my life”.	More sessions may aid survivor “morale”, memory and mobility but they are at a “low ebb”, lost “confidence”, limiting efficacy. “In the short term… [survivor] gained a lot of benefit”. “Benefits [of more sessions] could be enormous but the practical side…would be too much”.
Intervention Coherence	“I thought the purpose was clear…always laid out on the take-home sheets.” The purpose was to “explore how to… improving [stroke survivor’s] experience” in interaction with others and in relation to difficulties.	Caregiver described the activities aimed to “get the brain stimulated” to operate differently. Believed their aim also involved “getting a bit healthier”, though this was not the intended purpose.	Purpose felt clear, stimulating activities to “bypass” or “replace damaged pathways”. Purpose maybe unclear for some survivors, but “depends on the damage done”. One activity felt “obscure”.	Purpose of input “to improve their condition” further felt clear. Purpose on take-home sheets “covered most angles” but benefit of doing more at home unclear.
Self-Efficacy	Confident survivor would participate in group as “convivial” but due to frustration in first week caregiver did not feel confident in certain take-home activities, modifying or taking “a judgement call” on	Some aspects of the sheets and activities “tricky” due to detail, format and “academic” topics. “Trepidation” that the survivor may struggle with group as “unknown	Confident and “willing” to participate. “Trepidation” about survivor anxiety “kick[ing] in” preventing them from going but confident once there would be able to fulfill	Not confident in discussing contents of take-home sheets as “best you can [do is] don’t make an issue about something” and cause stroke survivor to feel “uptight”. Supporter feels the survivor is

	components to improve survivor acceptability.	territory", but confident survivor could commute.	what was asked confidently.	"intelligent" and would be "useful" in the group.
Opportunity Costs	The large time commitment meant the caregiver spent their respite time occupied.	No opportunity costs stated.	No opportunity costs stated but the full course was described as a long time.	No opportunity costs stated.
General Acceptability	Feel positive about further group sessions if these were at a different site. Sheets were "helpful", "useful" and relevant. No need to change session frequency, duration and member numbers. Acoustics, gender-split, time of day and audio volume difficult for survivor, who also "didn't look forward to" the song.	Feel positive about further group. Appreciate "practical learning" based in "the real world". Travel was "easy" for survivor, they also appreciated the consultant's presence and length of sessions. Sheets had too much text, and music strategy felt redundant.	Would attend a further group, "[survivor] could benefit from more sessions". Pleased by seeing the consultant. Activities were applicable and grounded but "one or two of them were obscure". Independent travel was "nice" for survivor. However, room was small and "airless".	Would not attend a further group "the benefits could be enormous but the practical side of it would be too much" for the dyad. Length and frequency of sessions "helpful" for survivor. Sheets could not be improved, but "not really… interested", "I couldn't offer anymore" than the sessions.
Future Suggestions	Further sessions add "cumulative" benefit. Proposed changing to "less structured" sessions and members "split" based on "interact[ion]". Keep focus on "specific topics", emphasising "tolerance" but "better cups of tea" and a classical song may be less alienating.	Changes to sheets to improve ability to "recite" and revisit. Suggestion of finances, "pets", "internet safety" and "puzzle" sessions, with space to revisit accounting for processing difficulties. Real-world relevance should be retained.	Suggestion of "puzzle[s]" and "as regards to writing crosswords are probably best" while retaining ethos of "fun" and discovery. An initial session suggested "to observe how they gel together". Sheets can have "simpler word" summary and "even bullet points".	No future suggestions provided

1) Affective Attitude

Three subthemes related to how caregivers felt about the sCST intervention.

Interest in sCST

An interest in sCST was expressed by all caregivers in relation to the group's aims or approach.

"*Yes, it seemed a really good idea to to try to extend away from just the the medicalised measurement of what's happened to stroke victims into their subjective experience.*" (P1)

Dyadic Benefit

All caregivers described positive emotions in relation to perceived gains the person they support had made from the group. In one caregiver this was prospective, as they felt further sessions would promote optimism that further improvement would be possible, but all other caregivers reported that they were either comforted, satisfied or pleased by the gains made by the person they support.

Interviewer: "Do you feel you gained anything from [PERSON I SUPPORT] coming to the sessions?"

"*Yeah, I get confident [partner]. I get a [partner], I get a [partner] who is cheerful.*" (P3)

"*I think I got a certain…I got a feeling of comfort, I suppose, as much as anything else, that something is being done about it.*" (P4)

Stroke Survivor Anxiety and Frustration Difficult

Finding stroke survivor anxiety and frustration related to the group difficult was expressed by all participants. They mentioned challenges associated with stroke survivor anxiety about attending the group, including one caregiver who spoke about their feelings when the person they support expressed frustration about the level of group activities. All caregivers remarked upon

anxiety or frustration decreasing as sessions progressed. Two caregivers reporting trepidation ahead of sessions, easing as they attended; these caregivers were less involved with logistics compared to the other caregivers.

> "*Barriers would be, they are quite intolerant of being infantilised. They are quite intolerant of the assumption that: these very simple tasks are appropriate when they feel that they can do much more difficult things.*" (P1)

> "*The only reason I say that there was a certain, anxiety, respect regarding that is that it's meeting new people…*" (P3)

2) Burden

Three subthemes related to the effort required to participate in the group. For one dyad this included enlisting the support of another family member.

Practical Issues

Practical issues were expressed by all participants relating to the logistics of attending the group. Two caregivers reported on the burden of travel, including one who enlisted the support of another relative. For the other caregivers, the logistical issues pertained to the time taken to do handout sheets for one caregiver, and a misunderstanding with whether they were to attend the sessions themselves on the first session. The latter two caregivers were least involved in practical logistic support for caregivers attending sessions, and the stroke survivors they supported could mobilise on foot and did not need to use a wheelchair.

> "*Look, the biggest burden was getting here, there, that was all*." (P4)

"Caring without pushing too much"

Three participants spoke about the effort required to motivate stroke survivors to attend the group or to allay their anxieties about the group. They spoke about the need to position themselves carefully. The other caregiver reported no burdens as the stroke survivor was motivated to attend

the sessions on their own, however spoke about the logistical implications of the research as pertained to arranging a time for an interview. Caregivers reporting this theme included caregivers who read all take-home sheets and a caregiver who did not read them during the trial period.

> "*they might not say it, but they do not want to be cared for. Therefore, you have to find a a path where you are neither carer nor oblivious of everything that's going on. It is a very, very difficult path to be caring without pushing too much. I don't it it is difficult.*" (P3)

Not Burdensome

Three caregivers did not regard the group as burdensome or felt that the potential for it to be so had been well managed, despite the burdens identified above. The other caregiver identified factors relative to the above two subthemes.

> Interviewer: "*What did you find difficult about the sessions or the process of supporting [PERSON I SUPPORT] to to attend the sessions?*"
>
> "*I didn't find anything difficult because of their enthusiasm to go*" (P2)

3) Ethicality

Three subthemes related to the fit of the intervention with participant values.

Demands of the Group were Fair

When asked about what was asked of caregivers, all expressed that they felt what was asked of them was fair, with one suggesting this was implicit. However, this participant also said that a survivor expressed resistance to the group.

> "*Oh yeah? Well, I think everything's fair, actually. I mean, if it's not fair I'll tell you.*" (P4)
>
> "*I wouldn't say they were done willingly, I think they were done under a bit of persuasion, to be honest, but but that's not to do nothing to do with you or the research or anything like that. That purely a personal problem of the of the physical factors involved in both their physical and mental factors involved.*" (P4)

Group Demands were Not Distressing

Four participants described the intervention as not distressing for the stroke survivors they support. However, one participant characterised this as being no more uncomfortable than they have been after the stroke, that this wasn't due to the sessions, but they were irritable after the first week.

Participant: "*You know, it was it was difficult for [PERSON I SUPPORT] to to come to terms with it. And then, yeah.*"

Interviewer: "*Did that make you feel uncomfortable or distressed in itself?*"

Participant: "*No, not at all.*" (P4)

4) Perceived Efficacy

Three subthemes related to the extent to which sCST was perceived as achieving its purpose.

Psychosocial Efficacy

All participants remarked on the impact of the group on the mood or confidence of the stroke survivors they supported, with some describing how they benefitted from this too. However, one dyad reported while the stroke survivor's mood had improved following the first session, the survivor meeting their goals would be influenced by morale and they did not think the sheets would be enjoyable, though they did not complete them.

Interviewer: "*Do you feel [PERSON SUPPORTED] gained anything from coming to the sessions or was helped by coming to the sessions?*"

Participant: **"***Yes, I do. And like I said earlier, confidence. But confidence is the biggest thing it really is.*" (P3)

Cognitive and Functional Efficacy

Four caregivers reported cognitive or functional gains, however in the case of one caregiver this related to the potential for these gains given further sessions. This included three caregivers reporting increased insight, two caregivers reporting the group could improve stroke survivor cognition, and one supporter thought survivor mobility would improve. Increased insight was important for participant 1 as they learnt about the person they support's stroke and because they had both participated in the group, the caregiver was able to discuss potential changes when this would not have been possible before.

> "*I can isolate the different elements of the things that you covered in the group sessions that we were at, that they were at. And that's helped me to recognise that the elements of the effects of the stroke which they won't perhaps be able to say verbally because of because of their self-perceived identity that you wouldn't necessarily speak about their feelings…these are things that are now up for discussion because they've been to the group…*" (P1)
>
> "*The mnemonic idea was good*" (P1)

Impact of Mood and Stress or Functioning on Efficacy

All caregivers reported that the mood, stress, cognition and general functioning of the stroke survivors they supported affected their participation in the group or its effectiveness or had potential to do so. One caregiver described a disconnect between what they could do prior to stroke and what was being asked in the group.

> "*I mean, it's not everything sticks and that's that's I know you. If you throw mud piles little bits stick and I think at the moment they're getting little splatters rather in the main focus of things.*" (P2)
>
> Interviewer: "*So you've mentioned morale, I believe.*"
>
> Participant: "*Well morale? Yes, it's well. I mean. Any treatment, any treatment, will be*

beneficial now, but you've gotta be in the right frame of mind to benefit from that treatment. And I don't think that the frames of mind around the round here at the moment would be. Will be receptive if you'd like to something as concentrated as that." (P4)

5) Intervention Coherence

Three subthemes related to the caregivers' understanding of the purpose of the intervention.

Clear Purpose of sCST and Research

Four participants expressed they felt the purpose of the group and the research study was clear to them or that they appeared to understand the general purpose of the group. One caregiver expressed the purpose of the group as clear but had not read the handout sheets until they were discussed in interview.

"*Yes, I thought the purpose was clear. The purpose was always laid out in the take home sheets, you know, categorization and orientation and summarising. And they were all to explore how to go about improving the the person's experience who's had the stroke, how? How, how to go about improving their interactions with other people. And how to deal with themselves with difficulties that they are experiencing*" (P1)

Misunderstandings or Ambiguity

Interviews with three of the four caregivers suggested they had misunderstood elements of the group or research or found it ambiguous. This included a caregiver who felt one optional activity that was designed to stimulate executive functioning abilities involving unusual food pairings, may not have been clear to stroke survivors, and one caregiver who said it didn't occur to them to do the activities and didn't know how they could suggest improvements. One caregiver thought the group might address wider issues, for example, exercise and healthy physical choices.

"*getting some kind of answers to the way they feel. Why they get so tired? And we have we have, we have talked about getting a bit healthier. You know do a bit more exercise.*" (P2)

6) Self-Efficacy

One subtheme related to confidence group members can perform what is required for the group.

Clarity of Materials and Survivor Reactions

All participants reported on the impact of stroke survivor lack of confidence or reaction to either the group or handout sheet activities. Some expressed concern about how the person they supported would react to either the group sessions or the handout sheets, this appeared to reflect their perceptions of stroke survivor anxiety or frustration. One caregiver cited difficulties engaging with the handout sheets due to their format and topics covered. Another caregiver said that they were willing and confident to try the take-home sheets with the stroke survivor despite trepidation ahead of group sessions.

"*Yes. Now that was interesting. After session one, the take home session was summarising and I think on the sheet it suggested hang on I've got it here it suggested that you took it as a game and you would take turns in summarising something from current affairs…We I took a judgement call on that because they [stroke survivor] were so irritable.*" (P1)

8) General Acceptability

Three subthemes related to other acceptability considerations not discussed above.

a. Positive Group Features and Content

All caregivers expressed positives about group features and content. All caregivers thought the session length was appropriate, two remarked on appreciating the presence of the consultant stroke physician, two felt the sessions were in an appropriate location, two felt there was an

appropriate amount of participants, and two caregivers appreciated the applicability of the sheets to daily life.

> "*So there are all sorts of bits and pieces of daily life experience that were paid attention to and are useful.*" (P1)

b. Issues with Group Features and Content

All participants raised some issues with group features and content. One caregiver thought the sheets were hard to read and another that they would not be enjoyable. One caregiver thought the gender and ability mix was difficult for the stroke survivor, as there was only one male in the group. This caregiver also felt the group song was not to the stroke survivor's taste, group tasks may not hold the stroke survivor's attention due to hearing impairment, and that the group was at a tricky time when the stroke survivor was often fatigued and needed to sleep.

> "*But by the same token, it's a tiny room, possibly airless as well, and that is not good for anybody with a problem…same reason I said about the sessions themselves, if you want to improve those pathways, you need oxygen…to move, to help if its not there, all you're going to do is have half a dozen sleepy people*". (P3)

c. Views on More Sessions

Three caregivers said they would feel positive about participating in a full course of sessions over 14 weeks, though one said they would only participate if the location changed. One participant would not participate in a full course of sessions as they felt the practical implications and stress would be too much for them.

> "*I think they could benefit from more sessions*" (P3)

> "*I would say that with the benefit benefits could be enormous, but the practical side of it would be too much.*" (P4)

9) Future Suggestions

Three subthemes related to future suggestions for sCST.

a. Changes to Session Structure and Content

Three participants suggested changes to the group structure and content such as the addition of an initial session to understand group dynamics.

> "*So so being flexible about the structure of the group initially might allow people to suss out which group or which groups would work. If if perhaps it were to start with a number of double the number that you did have, and I think, OK, these people might be able to... See life in that way or might get on... I would hope to split a group in half or whatever size you start with and however many groups you have the funding to run.*" (P1)

b. Changes to Materials or Sheets

Three participants suggested changes to the materials or sheets, for example using bullet-points and better catering.

> "*I think yeah, it could have been more clear if something, a very short bit of script at the top saying we are now trying to, we would now like to do this to to try and increase this side of what's happened... I'm not saying that that is wrong, but sometimes it needs to be put into simpler words and language which some will find not necessarily offensive, but annoying.*" (P3)

c. Important Elements to Retain

Three participants felt it was important to retain pre-existing elements or themes in the groups. These included participants who felt the focus on enjoyability or fun within the group, a principle of CST (Spector et al., 2006) should be retained as participants explore the session content. The importance of reiterating sessions was also expressed as potentially useful in aiding understanding, providing a cumulative effect.

"*I'd think there would be quite a few bits of benefit to it, because then it's it's focusing on how you be doing it, but then refocusing on how how things would be in the in the real world.*" (P2)

"Come and have fun. Just, just just enjoy it. We would like to know how you get on with these things." (P3)

Discussion

This study evaluated stroke caregivers' perspectives of the acceptability of a new adaptation of Cognitive Stimulation Therapy for stroke survivors, that could be incorporated into future trials of multi-component interventions for post-stroke frailty. Caregivers indicated they found the group to be interesting and the perceived psychosocial and cognitive gains the stroke survivors either achieved in the short pilot, or could achieve in further sessions, were a source of positivity for them. However, practical considerations and the considerations of caregivers presenting themselves as neither a carer nor uninterested needed to be considered, with stroke survivor anxiety and frustration needing to be carefully supported.

Caregiver experiences were shaped by the dyad they formed with the pre-frail stroke survivor, in understanding the potential acceptability of a dyadic cognitive stimulation intervention. The perceived strengths in acceptability of this dyadic cognitive intervention suggest that the inclusion of caregivers in cognitive interventions may hold promise and lend support to the dyadic illness management model (Lyons & Lee, 2018), though this should be considered in context of the small number of participants in this pilot. The dyadic illness management model (Lyons & Lee, 2018) suggests that caregivers, and the people they support, manage chronic illness together, and how the dyad appraises the illness is connected to the behaviours they enact to manage the illness, and in turn the health of both members of the dyad.

Strengths and Limitations

This study benefited from Patient and Publication Involvement and Engagement (PPIE) from a pre-frail stroke survivor and caregiver dyad, who helped adapt recruitment materials and group content to meet the needs of stroke survivors and caregivers. Framework analysis guided by the TFA proved a useful systematic approach to explore acceptability. This study contributes to the development of dyadic interventions for post-stroke cognitive impairment, which have been under-represented in research to date (Pucciarelli et al., 2021).

A number of study limitations should be acknowledged, however. The sample size is very small as the acceptability pilot did not meet the recruitment target of ten stroke survivor and supporter dyads. There is also very limited diversity within the sample, which consisted of dyads from a white Irish or British background, recruited from one hospital, limiting transferability of results and perpetuating underrepresentation of people from minority backgrounds in neuropsychology services (Boakye et al., 2021; Dunning & Teager, 2020). Moreover, data were not collected from a younger family member who was supporting one dyad. This could have provided a valuable insight into the dyad, perhaps advancing the notion that stroke is managed in dyads, to triads in some cases. This family member assisted the dyad in navigating some of the practical challenges of attending the group at the hospital location relative to age and mobility. Recent literature suggests older parents receive substantial practical support from their adult children, and this is often unseen or implicit (Boerner et al., 2022). Neglecting to include more than one caregiver per pre-frail stroke survivor resulted in a loss of potentially valuable acceptability data from this population. Another limitation includes the fact that one dyad withdrew from the trial. It is unclear whether withdrawal from the trial reflected perceptions about the acceptability of the trial. When the caregiver was contacted the following week, they were unaware of the stroke survivor leaving the session but confirmed their welfare. Neither were contactable following this, however.

A strength of the present trial in context of other research in the area is the use of framework analysis (Gale et al., 2013), guided by the Theoretical Framework for Acceptability (Sekhon et al., 2022). This methodology has increasingly been adopted for caregiver (Doumit et al., 2024) and stroke (McMahon et al., 2024) acceptability trials. Similarly to the present acceptability trial, TFA domains were found to map well as a framework to assess acceptability (Doumit et al., 2024; McMahon et al., 2024), with McMahon and colleagues (2024) advocating for its continued use in assessing acceptability of post-stroke interventions. The TFA (Sekhon et al., 2022) was also used in a recent thematic analysis of a stroke dyadic feasibility trial (Morris et al., 2023) who also reported subthemes that suggested stroke caregiver dyads' appraisals, illness management behaviours, and health may be linked. The consistent use of the TFA across feasibility trails may be useful in aiding transferability.

A limitation in context of other trials is that caregivers were inconsistent in reading take-home sheets and performing associated activities. This has provided important information on the acceptability of these sheets and may reflect both less mutuality in some dyads but also limitations of the use of take-home sheets, rather than a face-to-face intervention for caregivers. A recent pilot feasibility trial by Mou (2022) involved a psychoeducational intervention for stroke survivor and caregiver dyads which included three one-hour face-to-face education sessions with dyads, followed by weekly telephone counselling for four weeks. This aimed to examine functional and psychosocial outcomes of stroke survivors and caregivers. From conducting a content analysis to explore intervention feasibility, participants expressed that the face-to-face intervention was more appropriate than written materials, as the needs of dyads could be better known to researchers (Mou 2022). This may explain the inconsistency in caregivers reading take-home sheets in the present trial, caregivers had no face-to-face contact with researchers in the intervention and this may have affected whether take-home activities were completed.

Similar acceptability findings in relation to intervention logistics were described in a feasibility trial of stroke caregiver intervention (Walker et al., 2020). In the present trial, the hospital site was listed as a reason a caregiver would not attend further sessions. Another caregiver cited logistic difficulties and the stroke survivor's low mood, and noted they needed to enlist the support of another family member to address the logistical challenges. In Walker's (2020) feasibility trial of a psychosocial caregiver intervention, priorities to improve the accessibility of the intervention were listed, including an accessible venue and delivery of the intervention outside of the hospital grounds in further trials. This finding can perhaps be contextualised within the broader field of posttraumatic stress disorder (PTSD) occurring in stroke survivors. PTSD can occur after either experiencing or witnessing a life-threatening or other traumatic event. A recent systematic review by Janssen (2024) found a weighted mean PTSD prevalence of 17.5% in stroke survivors. While this has not been investigated in stroke caregivers to this author's knowledge, the negative alterations in arousal or reactivity, cognition or mood may have been important to consider for both stroke survivors and their caregivers, further emphasising the importance of considering non-hospital locations.

The present trial provides support to the notion that interventions which include both members of a stroke caregiving dyad are important in exploring acceptability as the appraisal of illness is dyadically shaped (Lyons & Lee, 2018; figure 1.), however must be considered in context of the small sample size of the pilot. Caregivers expressed benefits from perceived stroke survivor psychosocial gains, and trepidation from stroke survivor anxiety. The benefits, as well as the trepidation support the dyadic theory of illness management in its suggestion that appraisals of chronic illness are shaped by the dyad (Lyons & Lee, 2018). Two caregivers expressed initial trepidation before the group sessions, when they were uncertain about how the stroke survivors would experience the group. This gave way to satisfaction when stroke survivors returned with a

newfound sense of confidence, reflecting a change of appraisal of pre-frail stroke within the dyad. Caregivers commented on increased independence and explained that management behaviours were changed, including facing anxiety and travelling independently, which led to reports of positive psychosocial outcomes for dyads. The notion that gains for dyads develop over time in dyadic trials is emphasised in the recent trial by Morris (2023) where dyads described the importance of being patient and allowing time for gains, reflected in their subthemes “give it time” and “building confidence”.

The present trial further supports the dyadic theory of illness management (Lyons & Lee, 2018) as caregivers reported appreciating the increased understanding of the experiences of the stroke survivor, relayed in the psychoeducation materials. One caregiver reported that the group was “worth it’s weight in gold” to help them to understand what their partner has to “go through every day”. This reflects the caregiver gaining more knowledge of the survivor’s experience to shape their appraisal and finding this valuable. Another caregiver reported that, due to the take-home sheets, they were more able to discuss cognitive changes that they had noticed in their partner but were not able to contextualise. This reflects a change to appraisal and an opportunity for more mutuality in how they appraise these changes, as they were now “up for discussion”. This emphasises the value that caregivers can gain from their inclusion in dyadic interventions which include a psychoeducational component, as supported by Pucciarelli’s (2021) systematic review and meta-analysis.

While the majority of participants felt positive about attending further sCST sessions, further trials should carefully consider the location of groups. Hospital locations where it is difficult to park should be avoided, as should locations where it is difficult to escort the stroke survivor from the car park. Future groups should take care to understand dyad mobility needs. Concerns were most pronounced in the supporters of caregivers who required walking aids and did not use public

transport. The relationship of participant dyads with music and their previous experiences with groups and cognitive stimulation or cognitive exercises more generally should also be considered. The mix of participants in the group should be considered as supporters often needed to help the survivor to ease anxiety about meeting new stroke survivors and to help them process feelings of alienation or being different.

Suggestions for additions to the group session contents should be considered, such as puzzles, writing, in-person as well as online vulnerability awareness. Any further change to group content should take into account supporter emphasis on tolerance, fun and discovery. When addressing these themes, further iterations of sCST should keep in mind the specific role many supporters balance in providing support to the survivor without the dyad wanting to feel as though they are the supporter's carer. Further iterations of sCST should also integrate the timing of the group and factors related to fatigue, for example whether morning is better than evening and ways of managing fatigue after travel and the group itself. Finally, further research into sCST should examine whether it is feasible and acceptable to allow a pre-session at the beginning of the group where double the number of participants (n10) can socialise, and participants can learn with whom they identify and are comfortable before the group is split. This would allow for integration of supporters into the group as a network and careful gauging of group dynamics. Suggestions for addressing the challenges to acceptability in addition to feasibility issues are made in a related paper (Bramley et al., 2025).

Conclusions

Caregiver interviews indicated that adapted Cognitive Stimulation Therapy for stroke (sCST) had practical and psychosocial benefits for stroke survivor and caregiver dyads and supported increased independence and confidence in stroke survivors for the small pilot sample involved. This was a source of comfort and satisfaction to caregivers. They reported increased insight for

both members of the dyads, from survivors connecting with other survivors and caregivers connecting with survivor experiences through take-home psychoeducation. These results suggest that sCST warrants further development and research in this population.

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Chapter 4 - Further Empirical Paper

Assessing the Feasibility of Adapted Cognitive Stimulation Therapy for Stroke (sCST)

Prepared for the journal of Disability and Rehabilitation

(see Appendix A for author guidelines for manuscript preparation)

Assessing the Feasibility of Adapted Cognitive Stimulation Therapy for Pre-Frail Stroke (sCST)

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Abstract

Purpose: Caregiver involvement in cognitive interventions for frailty reduction may enhance patient engagement and benefit caregivers. We aimed to explore the feasibility of a novel adaptation of Cognitive Stimulation Therapy (CST; Spector et al., 2003) for pre-frail stroke survivors (sCST) with caregivers, whose involvement in the intervention was encouraged.

Materials and Methods: A non-randomised, pragmatic single arm pilot study was conducted. Acceptability findings for stroke survivors and caregivers are reported elsewhere (Livsey et al., 2025; Bramley et al., 2025). Feasibility was analysed using Shanyinde's (2011) issues for feasibility research. Solutions to address feasibility and acceptability limitations were appraised through 'A process for Decision-making after Pilot and feasibility Trials' (ADePT; Bugge et al., 2013) structure.

Results: Key feasibility and acceptability limitations related to recruitment rate and acceptability of content and delivery for dyads. ADePT suggests amendments to the intervention, trial design and context are supported by literature as potentially feasible and effective.

Conclusions: sCST was a feasible and acceptable cognitive intervention for post-stroke frailty with caregiver involvement for the pilot sample, but recruitment issues prevented reaching the a priori recruitment target. Logistic and psychosocial factors limited acceptability for some dyads. Literature supported the efficacy and feasibility of potential solutions using ADePT.

Introduction

Frailty is a progressive state of vulnerability characterised by multisystem decline in physiological reserves needed to maintain homeostasis following stressors (Morley et al., 2013; Fried et al., 2001; Campbell & Buchner, 1997). Frailty after stroke is associated with worse functional outcomes and increased mortality (Li, Wan & Wang, 2024). Pre-frailty, a "state that may precede the onset of frailty, is associated with adverse health outcomes and reduced quality of life (Gill et al., 2006) but which might be reversed or attenuated by targeted interventions" (Sezgin et al. 2022) is also common after stroke. Stroke survivors are more than twice as likely to be frail than those who have not suffered a stroke (Palmer et al., 2019).

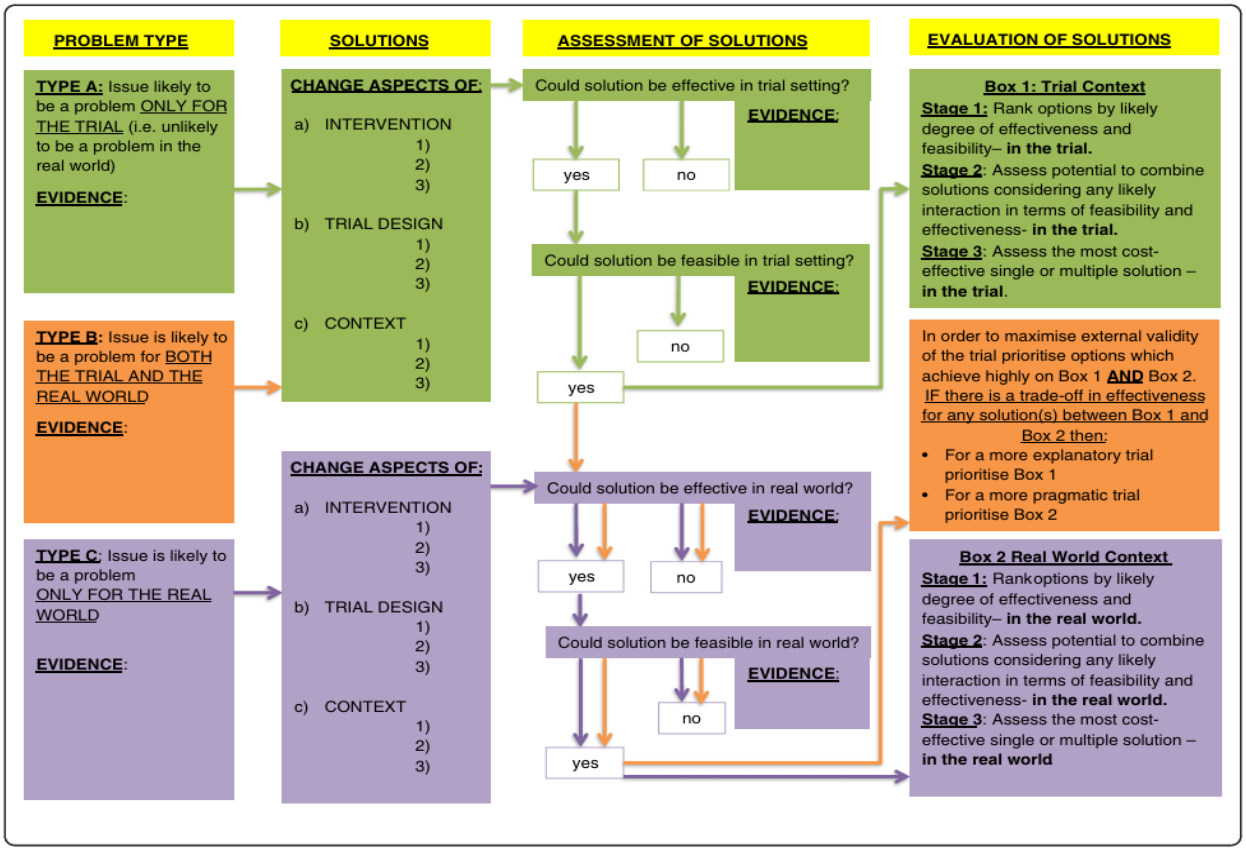
Cognitive interventions can reduce frailty as part of multicomponent and stand-alone interventions (Ng et al., 2015). Cognitive Stimulation Therapy (CST; Spector et al., 2003) is a NICE-recommended group-based cognitive intervention for people with mild to moderate dementia (NICE, 2018; Alvares-Pereira, Silva-Nunes, Spector, 2021), found to improve cognition, quality of life, well-being, activities of daily living, and mood (Aguirre et al., 2013; Lobbia et al., 2019). CST may have advantages as a component of multicomponent interventions for frailty as it not only provides cognitive stimulation, but also a social environment. Frailty is associated with isolation and may be reduced by social environments (Kojima et al., 2022). Family caregivers may also benefit from CST, due to improved cognitive skills in those for whom they support (Aguirre et al., 2014). Qualitative research has identified benefits of CST for family caregivers (Lauritzen et al., 2022, Rai et al., 2021), particularly when they are involved in the delivery of CST (Leung et al., 2017; Orrell et al., 2017; Rai et al., 2021). With 75% of strokes occurring in those aged 65 and over (Simmons, Poupore, & Nathaniel., 2023), and frailty associated with aging (Zampino, Ferrucci, & Semba., 2020), it is likely some family caregivers supporting stroke survivors may also be frail or pre-frail and may benefit from learning about CST.

A pragmatic, non-randomised, single arm, feasibility pilot of a novel adaptation of CST for pre-frail stroke survivors supported by family caregivers (stroke CST, or sCST) was conducted. This is in line with the UK Medical Research Council (MRC) guidance (Skivington et al., 2021), following the development and adaptation, the intervention acceptability and feasibility is evaluated. As with many cognitive interventions for stroke survivors, this intervention relies on skilled facilitation, engagement of stroke survivors and caregivers, and an ability to tailor intervention to individual needs of group members. It is thus a complex intervention, defined as an intervention "dependent on the behaviours of those delivering and receiving the intervention," with "several interacting components," and "a need to tailor the intervention to different contexts and settings" (Rodriguez et al. 2020, p.35).

We assessed the feasibility and acceptability of sCST to guide decisions about further investigation of sCST as a standalone intervention or a component of a frailty reduction MCI using the ADePT framework (A process for Decision-making after Pilot and Feasibility Trials; Bugge et al., 2013, as illustrated in Figure 4). The framework incorporates Shanyinde's (2011) 14 methodological issues for feasibility research to systematically identify and appraise potential feasibility and acceptability considerations and solutions or adaptations relative to trial context or real-world context. The framework involves three steps: identifying problem types and evidence supporting this; identifying potential solutions and evidence supporting them; and assessment of the most feasible and efficacious options available relative to problem types. Below we set out our application of the ADePT framework to assess the feasibility and acceptability of sCST as a candidate cognitive intervention for frailty reduction. We also aim to illustrate how ADePT can be applied to the development of complex cognitive interventions post-stroke.

Figure 4

ADePT Framework (Bugge et al., 2013)



Aims

The feasibility of a dyadic, newly developed, pre-frail stroke survivor CST adaptation (sCST) is tested for the caregivers of the stroke survivors. Stroke survivor and caregiver acceptability to this intervention is reported elsewhere separately (Livsey et al., 2025; Bramley et al., 2025).

This intervention is intended to become a component of a MCI for post-stroke frailty if acceptable and feasible. Thus, it would become an element of a feasibility RCT. This RCT would test the feasibility of the MCI ahead of a full-scale RCT to examine efficacy of the MCI.

Method

Ethical Approval

The pilot study was registered prospectively on ClinicalTrials.gov (Identifier: NCT06733103). It received ethical approval from the National Health Service (NHS) Yorkshire and The Humber – Bradford Leeds Research Ethics Committee (REF:24/YH/0075; appendix K), and was conducted in accordance with the Helsinki Declaration of 1975, as revised in 2000. A non-substantial ethical amendment was submitted and subsequently approved to respond to recruitment challenges described below.

The sCST Intervention

The development of sCST has been reported in detail elsewhere (Livsey et al., 2025). It is an adaptation of Cognitive Stimulation Therapy, a group intervention originally developed for people with dementia (Spector et al., 2003). Eight 45-minute sCST group sessions were delivered in pairs separated by a comfort break, to a group of pre-frail stroke survivors, by two experienced CST facilitators (MB and SL), weekly over four weeks in a hospital stroke service setting. Participants were given take-home sheets to share with caregivers, providing information about session activities, their purpose and benefits, details of cognitive rehabilitation strategies and optional homework activities to complete as a dyad (Appendix J). We developed sCST to be delivered to 8-10 dyads, delivered by two facilitators promoting CST values of enjoyment, learning, strengthening abilities, social relationships and cognitive abilities such as memory, and orientation, in addition to executive functioning (Spector et al., 2006; Hall et al., 2013).

The Pragmatic Feasibility Pilot

Elements of intervention feasibility evaluated included: identification and successful recruitment of suitable group attendees; group attendance, attrition and adherence; intervention acceptability from pre-frail stroke survivor and caregiver perspectives. This feasibility study does

not seek to ascertain the feasibility of a future RCT, rather the feasibility of the sCST intervention itself. As such, this was a single-group design, not entailing blinding, randomization, nor the use of a control intervention. Feasibility of elements of the research design that would not be included in the intervention itself are not analysed, such as the acceptability interviews, questionnaires, nor ethical approvals and related amendments.

Data were collected in relation to pilot feasibility across the course of the recruitment and intervention process. Recruitment feasibility was monitored through the use of a recruitment screening log. Intervention cost was established through intervention budget requests. Stroke survivor attendance at group sessions was recorded and reasons for any non-attendance gathered. Participant acceptability was recorded through semi-structured interviews informed by the Theoretical Framework for Acceptability (TFA, Sekhon et al., 2022) as a topic guide and analysed using framework analysis (Gale et al., 2013), where the TFA (Sekhon et al., 2022) was used as an analytic framework. Acceptability findings are reported elsewhere for stroke survivors (Livsey et al., 2025) and caregivers (Bramley et al., 2025).

Participants

Stroke survivor and caregiver dyads were recruited from Addenbrookes' Hospital Stroke Unit between 24 May and 16 August 2024. A recruitment target of 8-10 dyads was set following guidance that CST groups should comprise five to eight members (Spector et al., 2006) taking into account the possibility of attrition.

As recruitment rate proved slow over the first two months, a non-substantial ethical amendment was submitted on 4 July 2024, and subsequently approved, to address this. The stroke survivor inclusion criteria were widened from stroke within 6 months to stroke within 12 months of the intervention. The criteria for caregivers were also widened to include people providing regular

unpaid support with physical or psychosocial needs at least three times a week, removing an initial criterion that caregivers must live with stroke survivors. The criterion for cognitive impairment was amended from impairment on the Oxford Cognitive Screen (Demeyere et al., 2015), to any standardised cognitive screen or assessment measure. Feedback arrangements were changed from focus group to individual interviews. The recruitment target of eight to ten dyads was reduced to five or more dyads in keeping with the minimum group size recommended for CST (Spector et al., 2006). The resulting participant inclusion and exclusion criteria are detailed in table 8.

Table 8

Participant Inclusion and Exclusion Criteria

Inclusion Criteria		Exclusion Criteria	
Stroke Survivors	Stroke Caregivers	Stroke Survivors	Stroke Caregivers
18 years old and above		No access to a computer, laptop or tablet to access an online interview	
Sufficient communication in English to participate fully in the group intervention and an online interview		Diagnosis of dementia or difficulties with language, memory or thinking that would impede full group participation	
Stroke within 12 months of the group intervention	Regularly supporting an eligible stroke survivor with physical or psychosocial needs on three or more occasions / week		Paid caregiver
Discharged to the community after stroke			Under investigation by a safeguarding team
Clinical Frailty Scale (CFS, Appendix O; Rockwood et al., 2005) score 3-5 indicating pre-frailty or emerging frailty (Flaatten et al., 2017; Muessig et al., 2018)			
Cognitive deficits in two or more domains			

on a cognitive screen
or assessment.

Procedure

Stroke survivor and caregiver dyads were identified by the research team, which included a Consultant in Stroke Medicine (NE), Principal Clinical Psychologist in Stroke (HG) and two Trainee Clinical Psychologists (MB and SL). Eligibility was screened weekly from stroke ward lists by the Principal Clinical Psychologist in Stroke and at stroke clinics by the Consultant in Stroke Medicine. Eligible dyads were asked to complete a consent to contact form (Appendix Q) and then contacted by researchers who explained the study and sent Participant Information Sheets (PIS; Appendices R & S) for each member of interested dyads with a cover letter. The latter was a recommendation from Patient Public Involvement and Engagement (PPIE) consultation, to explain frailty in more detail. Consent visits were scheduled to answer questions about the pilot, seek consent (Appendix T), and if appropriate, administer an optional demographic questionnaire (Appendix U). Closer to the date of the group, a hospital map was provided and the time and date of sessions confirmed. Once the recruitment target of five dyads was reached, recruitment ceased.

Following the final group session, dyads were invited to separate individual semi-structured online interviews with one of the group facilitators, lasting up to two hours, conducted using Microsoft Teams. The interview topic guide was developed according to the Theoretical Framework of Acceptability (TFA; Sekhon et al., 2022). Interviews were transcribed and then analysed using Framework Analysis (Gale et al., 2013), guided by the TFA (Sekhon et al., 2022) as an analytic framework. Stroke survivors were also asked to complete the TFA questionnaire (Sekhon et al., 2022) and emailed a link to the form to complete online.

Analysis

We report descriptive statistics on recruitment and attrition rates, demographic characteristics, serious adverse events (SAEs) and adverse events (AEs). Intervention costs are also reported, including reimbursement for parking for dyads group refreshments and staff time.

Results

Five dyads were recruited, of whom four completed the intervention. Three stroke survivors were female and one male, with ages ranging from 64 to 89 years (M=77.68, SD=10.75). Two survivors reported having higher education qualifications, one reported having no educational qualifications and one chose not to disclose educational level. Two of the five survivors had a stroke more than six months before the date of the group. All stroke survivors were married to the recruited caregivers. Four caregivers were male and one female, with ages ranging from 60 to 78 years (mean = 71.62, SD = 10.21). One caregiver did not provide their age. Two caregivers reported having higher education qualifications, one was educated to O-Level/GCSE, and another chose not to disclose level of education. All participants identified as White British or White Irish.

Feasibility findings according to the 14 methodological issues assessed in feasibility trials (Shanyinde et al., 2011) are summarized in table 9. Recruitment took place over approximately three months. The screening log used to monitor eligibility of potential participants showed that 69 dyads were identified for eligibility screening. The largest factors influencing eligibility were the absence of standardised measures of cognitive functioning or lack of cognitive impairment, mortality or discharge to residential or nursing care. Of eligible participants, one quarter consented to the trial. The recruitment target of eight to ten dyads was not met. Five dyads began the intervention. One dyad left the intervention after the first session and was uncontactable. Two survivors did not attend the final week as they either had pre-booked holidays or urgent medical appointments.

Participant views of sCST acceptability are reported elsewhere, with stroke survivors indicating the intervention was received positively (Livsey et al., 2025) and three of four caregivers indicating they would attend further sessions if at another non-hospital location (Bramley et al., 2025). One caregiver reported that they would not attend further sessions as they felt the stress of the intervention would be too much for themself from the caregiver's perspective. Survivors reported finding the group inclusive and stimulating, gaining confidence and knowledge of useful strategies. Some felt a larger, more homogeneous group could be useful, others found the group size was acceptable, as did caregivers. Caregivers reported being impressed with increased survivor confidence and independence which was a comfort to them and benefitted them as caregivers. Barriers to acceptability included the intervention location (distance of the intervention location from the hospital car park and heating and acoustic properties of the room used within the stroke ward) and cognitive level of sessions, perceived by some as too simple and others as over complex. Other limitations to acceptability relative to dyad psychosocial, fatigue and engagement factors are described in Appendix V.

One SAE was reported during the intervention. This occurred when a caregiver sprained their hip pushing the stroke survivor's wheelchair from the car park to the group location in the hospital. The research team were informed of this after the intervention during the acceptability interviews. Furthermore, the SAE was reported to the research ethics committees involved; no further action was indicated.

Table 9

Methodological Issues of Feasibility (Shanyinde et al., 2011)

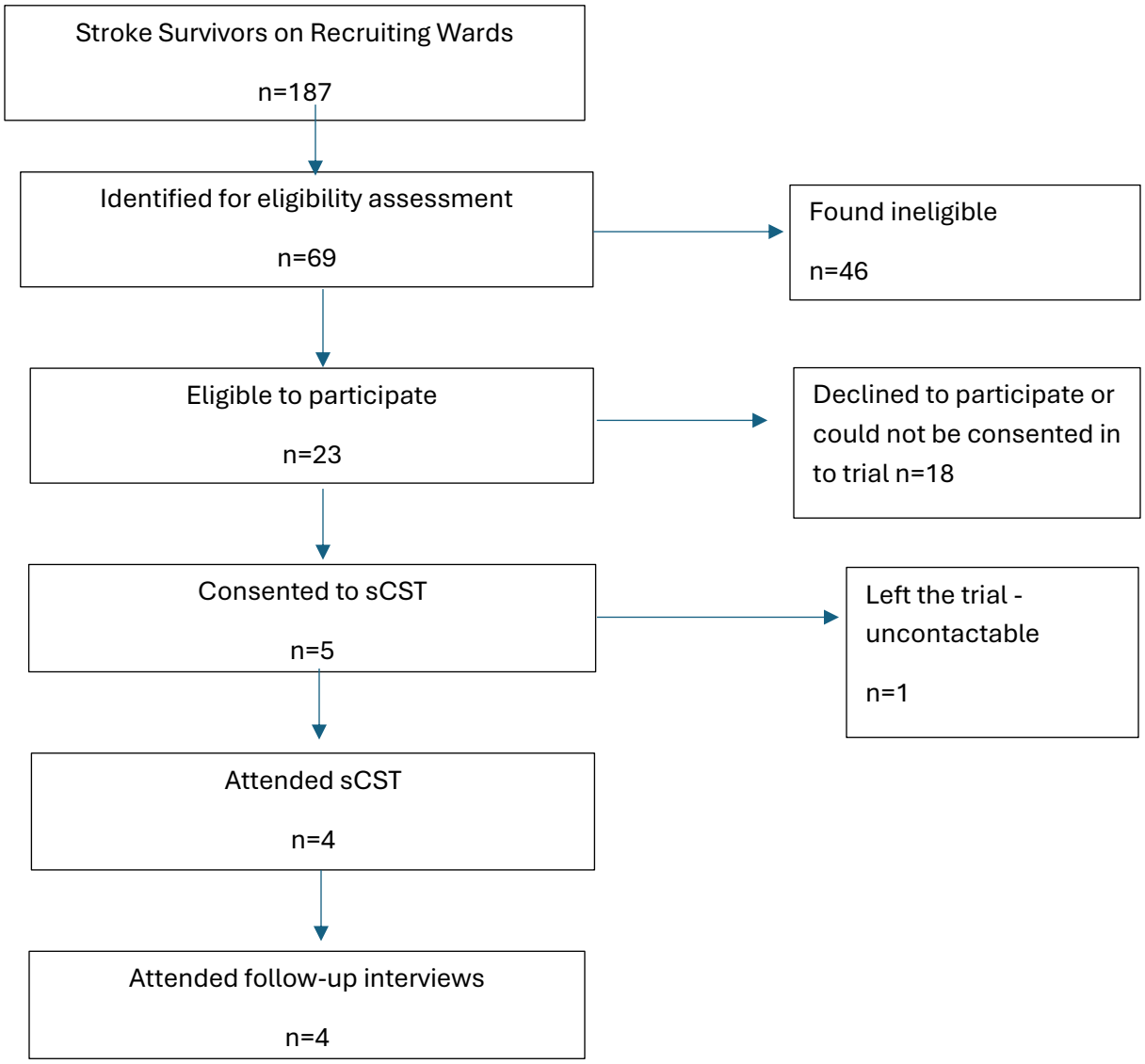
Methodological Issues	Findings	Evidence
1. Did the pilot study allow a sample size	No sample-size was calculated for the main trial.	We did not aim to calculate a sample size for a main trial. Our primary aim was to evaluate intervention feasibility and acceptability prior to a feasibility RCT.

calculation for the main trial?		
2, What factors influenced eligibility and what proportion of those approached were eligible?	The most common factor found to influence eligibility was whether the cognitive ability had been formally assessed.	Of 175 stroke survivors discharged from recruiting wards, and 12 additional survivors seen in clinic (N = 187), 69 were identified for eligibility assessment, of whom 46 were found ineligible for participation
3. Was recruitment successful?	The recruitment target was not met.	We initially aimed to recruit 8-10 dyads. This was subsequently reduced to 5 dyads. We were able to recruit 5 dyads over approximately 3 months.
4. Did eligible participants consent?	25% of participants identified as eligible consented to the intervention.	18 dyads identified as eligible declined to participate.
5. Were participants successfully randomized and did randomization yield equality in groups?	NA	
6. Were blinding procedures adequate?	NA	
7. Did participants adhere to the intervention?	Yes, adherence was good overall with some limitations noted.	All survivors adhered well to all aspects of group sessions. Dyads reported reading multiple take-home sheets, with the exception of one caregiver who reported not reading any take-home materials. Key limitations to adherence were: - Caregivers did not consistently read take-home sheets and complete take-home activities with stroke survivors
8. Was the intervention acceptable to the participants?	Yes, the intervention was largely acceptable to participating dyads with some limitations reported.	Key limitations to acceptability were: - Some stroke survivors reported finding the cognitive level of sessions either too complex or too simple. - Group location due to distance from carpark, heating and acoustic properties (not optimized for people with hearing impairment).

9. Was it possible to calculate intervention costs and duration?	Yes	Estimated intervention cost = £464.69 - £481.49 or £92.94 - £96.30 per dyad over 4 weeks. - £305.60 - £ 322.40: NHS Band 6 facilitator time depending on experience, and - £143.59: Parking and refreshments. - £15.50: Printing Duration of recruitment to interview completion: 24/05/24-01/10/24, approximately three months.
. 10. Were outcome assessments completed?	Partly	Acceptability interviews assessments were completed and analysed. Online TFA questionnaire data were not completed due to technical difficulties.
. 11. Were outcomes measures those that were the most appropriate outcomes?	Yes	The Framework for Acceptability, used in Framework Analysis of post-intervention acceptability interventions has been used previously in a feasibility trial with a similar cohort (Western, 2023).
. 12. Was retention to the study good?	Yes	All dyads completed the intervention with one exception of a dyad that left the trial and was uncontactable. Two dyads missed the last week of sessions, one of whom arranged this before consenting to the trial.
. 13 Were the logistics of running a multicentre trial assessed	No	The feasibility of the pilot was being investigated rather than the feasibility of a feasibility RCT.
. 14. Did all components of the protocol work together?	No Survivors adhered more strongly to the protocol than did caregivers.	Survivors participated in all in-session activities, but caregivers reported not reading all take-home sheets or supporting survivors with homework activities.

Figure 5

Participant Flow Diagram ADePT



Suggestions to Aid Feasibility and Acceptability

Figures 6 and 7 show how the ADePT framework was applied to assess suggestions to aid the feasibility and acceptability of research on sCST.

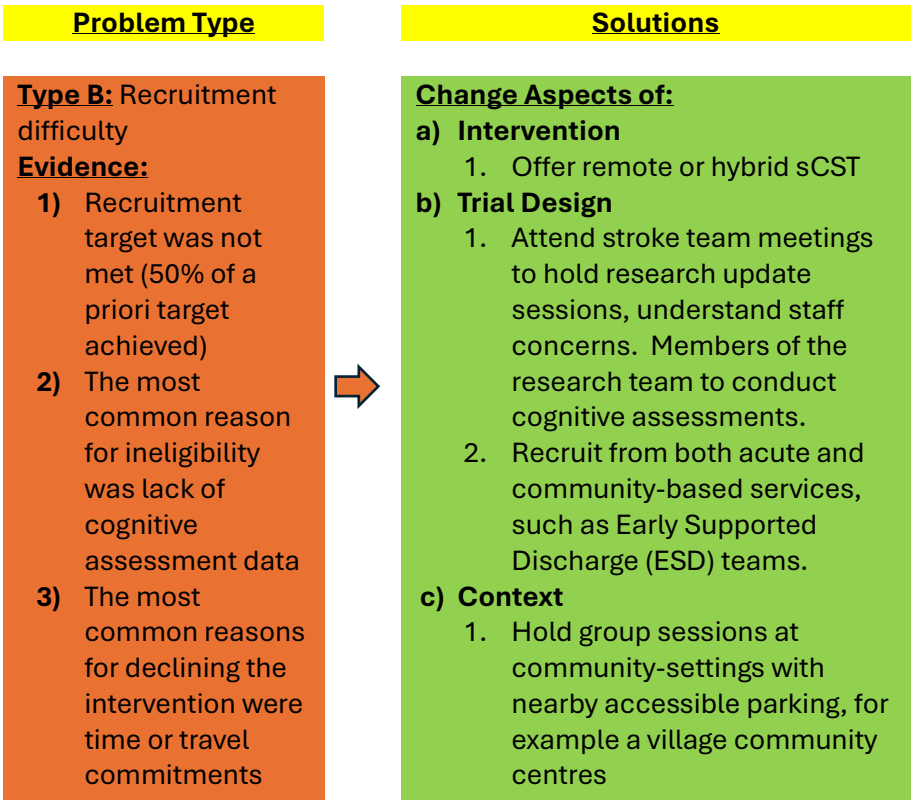
The pilot encountered feasibility limitations related to recruitment and acceptability to dyads, not reaching the a priori recruitment target as detailed in figure 6. and receiving feedback suggesting a need for locations nearer community settings. A potential solution of using hybrid teleconferencing and in-person group provision in community settings to reduce the amount of travel to an in-person group was considered. Another potential solution to include closer liaison with recruiting sites and add local Early Supported Discharge (ESD) services as recruiting sites was also considered. Closer liaison with clinical staff and expansion of recruitment sites to the local ESD services might support identification of potential participants and facilitate the use of community settings to reduce travel. These suggestions were judged likely to be effective and feasible in the context of a future multicomponent feasibility RCT and clinical settings and could be implemented together.

Acceptability limitations detailed in figure 7 included limited engagement with take-home sheets and activities, uneven gender split of group session members, features of the group location and variable responses to group content with some finding it challenging and others not sufficiently challenging. Potential solutions we evaluated included carrying out further PPIE with consultant dyads including pre-frail stroke survivors with cognitive impairment, reviewing group content and activities to understand how they can be further adapted to cater for variability in cognitive abilities, and reviewing the readability of take-home materials. As caregivers reported that the intervention was perceived as too easy for some participants but too hard for others, it may be best suited to people with mild to moderate cognitive impairment and further adaptation to be sufficiently challenging for those with milder levels of impairment. Adapting participant-facing materials may

facilitate recruitment of male stroke survivors. Finally, identifying features that increase accessibility of community-based group rooms (e.g., distance from car park, good acoustics for people hard of hearing, good ventilation) may address acceptability issues related to location. Using the ADePT framework, we assessed these potential solutions and found them likely to be effective, feasible and possible to implement together.

Figure 6

ADePT Recruitment



Assessment of Solutions (Intervention)

Could solution a1 be effective in trial setting?

Yes, if Hybrid

Evidence: virtual CST (vCST) was trialed for patients with dementia during the COVID-19 pandemic. A cross-sectional survey by Fisher (2023) found that 80% of those offering vCST planned to continue to offer vCST as a hybrid model. Staff and participants reported enjoyment, and an increase in confidence in digital ability. Improved accessibility was also reported. Caregivers reported increased confidence from survivors who were able to travel to sCST on their own so this solution may impact this benefit.

Could solution be feasible in trial setting?

Yes, if Hybrid – list in box 1

Evidence: vCST was judged by Fisher (2023) to be a feasible alternative to face-to-face services in the pandemic. However, digital poverty, limited digital literacy, the support needed from caregivers, sensory impairment in engagement and staff time commitment were described as detractors to feasibility. Fisher (2023) advocates that although vCST should not replace CST, a hybrid approach increases accessibility.

Could solution be effective in real world?

Yes, if Hybrid box 2

Evidence: Videoconferencing appeared an effective method to gather acceptability information from dyads in one-to-one interviews, with no confounding difficulties in communication that would appear to affect efficacy of sCST, though this was not measured

Could solution be feasible in real world?

Yes, if Hybrid – box 2

Evidence: Everyone in our current sample was able to use videoconferencing; no activities in sCST required participants to physically manipulate stimuli.

Assessment of Solutions (Trial Design)

Could solution b1 be effective in trial setting?

Yes – box 1

Evidence: In Campbell's (2015) paper synthesizing findings from five trials in acute stroke settings suggestions to overcome recruitment barriers were made. To develop collaborative and trusting relationships with ward staff, they suggest providing research update sessions to solicit and understand staff concerns. Campbell (2015) also suggest assisting with unit tasks as appropriate and within professional confidence, this could include conducting cognitive assessments.

Could solution b2 be effective in trial setting?

Yes – box 1

Evidence: In Abzhandadze's (2021) trial exploring barriers to cognitive screening in acute stroke units, it was reported that a stroke unit with patients with severe strokes was least likely to have performed cognitive screening. Addenbrookes' Hospital has a specialist neurological department and is likely to be the destination for patients who have suffered more severe strokes. Local ESD services provide input to people who have experienced mild to moderate strokes. An ESD service may be able to provide access to a greater number of stroke survivors screened for cognitive impairment.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: Part-time hours impeded consistent stroke team meeting attendance. This could be accounted for in future trials by structuring research site visits to coincide with team meetings. Honorary contracts and clinical supervision could be put in place for researchers to conduct cognitive assessments.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: During the ethical approval stage of the trial, it would be feasible to include the local ESD service as an additional research site.

Could solution be effective in real world?

Yes – box 2

Evidence: Trial and real-world efficacy is likely to be similar, however if the group were run by a ward team, the solution may become unnecessary.

Could solution be effective in real world?

Yes – box 2

Evidence: This solution could be effective in the real world as per Abzhandadze's (2021) findings.

Could solution be feasible in real world?

Yes – box 2

Evidence: In a real-world setting, the group could be run by a ward team and the solution could become a feature of ward meetings.

Could solution be feasible in real world?

Yes – box 2

Evidence: Recruiting from acute and community services may be feasible in the real world, however sCST is likely to be hosted by either an acute hospital service or ESD. Dyads could potentially be referred to the ESD by hospital stroke units to complete sCST.

Assessment of Solutions (Context)

Could solution c1 be effective in trial setting?

Yes – box 1

Evidence: There are typically many community centers in the area covered by acute hospitals, with nearby on-site parking and suitable rooms that can be hired. The distance of car parks to community centers is typically less than the equivalent at a large hospital site, reducing distance to travel and burden for dyads. Some caregivers were conscious that survivors experienced repeated exposure to a hospital environment. This association would likely be decoupled at a community location.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: With careful planning and consideration, rooms in local community centers could be booked for a further trial. This would need to be incorporated into any ethical approval proposal and would involve an appropriate risk assessment.

Could solution be effective in real world?

Yes – box 2

Evidence: The efficacy of this solution is not affected by being in a real world setting and is equally effective in the real world.

Could solution be feasible in real world?

Yes – box 2

Evidence: The feasibility of this solution is not affected by being in a real world setting and is equally feasible in the real world.

Evaluation of Solutions

Box 1: Options that should work in trial context

Stage 1: Options

1. Recruit from ESD in addition to acute hospital services
2. Hold group sessions in nearby community locations
3. Provide hybrid access
4. Attend stroke team meetings to encourage recruitment and complete cognitive assessments

Stage 2: Potential to combine solutions

It would be possible to attend stroke team meetings to encourage recruitment and problem-solve issues while recruiting from acute and ESD services. However, this would complicate this process. Hosting further groups at a nearby community location would be more appropriate for ESD patients who live further from hospital sites. Incorporating hybrid sessions would also be possible, limiting travel burden for dyads. Retaining some in-person sessions may preserve the sense of confidence from some independent travel.

Stage 3: Most cost-effective solution

There are no financial implications of any solution other than c1. With some dyads expressing they would not attend further sessions requiring travel to hospital, and two survivors benefitting from independent travel and group interaction, room hire cost may be justified relative to exploring efficacy and acceptability.

Box 2: Options that should work in real world context

Stage 1: Options

1. Recruit from ESD in addition to acute hospital services.
2. Hold group sessions in nearby community locations
3. Provide hybrid access
4. Attend stroke team meetings to encourage recruitment and complete cognitive assessments

Stage 2: Potential to combine solutions

The integrated community stroke service (Intercollegiate Stroke Working Party; ICSS, 2023) model suggests that important community-based services should support the long-term needs of patients and their families. Joint adoption of sCST by acute hospitals and ESD services may help support the needs of patients and their families in a community setting. While the ICSS model does not explicitly advocate virtual or hybrid working, it supports further investigation of these. Should the sCST group be conducted with hybrid access, this could provide important data. Recruiting to sCST across acute hospital and ESD services would depend on commissioning decisions in the real world.

Stage 3: Most cost-effective solution

As per box 1, room rental will incur a cost, however this is likely justifiable considering potential improvement in efficacy and acceptability.

Box 3: Final assessment of options and tolerance of trade-off between explanatory and pragmatic trial

This is a pragmatic trial, therefore box 2 has higher priority than box 1; however, both arrive at the same conclusion.

Recruiting from ESD and acute hospital services may present commissioning considerations. The hire of a non-hospital location would require risk assessment. However, all options hold potential to improve recruitment to the trial and group if held in the real world. Providing the intervention both remotely and in the community is supported by ICSS guidance (2023). Involvement of MDTs across services would be useful in trial and real-world contexts.

Figure 7

ADePT Acceptability to Content and Delivery

Problem Type	**Solutions**
Type B: Limitations to acceptability of content and delivery **Evidence:** **1)** Caregivers did not consistently read take-home sheets and complete take-home activities with stroke survivors **2)** Some stroke survivors felt the cognitive level was too simple and others found it complex **3)** The uneven gender-split in the group was difficult for some participants **4)** The intervention location was perceived to have limitations (e.g., temperature, acoustics).	**Change Aspects of:** **a) Intervention** 1. Take-home sheets to be modified to be more accessible, with summary paragraph and bullet-point format and take-home session recaps **b) Trial Design** 1. Further PPIE with stroke survivor dyads, including survivors who have registered a cognitive impairment on a standardized measure to gauge level of group content further. Exclude those registering severe cognitive impairment on screening measures. 2. Address lack of males in the group through emphasis on skills-based aspect of sCST in participant information sheets (PIS) **c) Context** 1. Select alternative intervention locations guided by an accessibility checklist drawn up with PPIE input.

Assessment of Solutions (Intervention)

Could solution a1 be effective in trial setting?

Yes

Evidence: Recent adaptations of individualised cognitive stimulation therapy (iCST) have been piloted, with an emphasis on reduction in text, acceptable layout, including bullet-points, and text size, highlighted by patients and caregivers (Rai, 2021). This was shown to be feasible and acceptable with a positive trend in cognitive outcomes for patients (Hui et al., 2024). Investigations have indicated positive preliminary findings when the materials were adapted with an emphasis on increased size and readability (Hui et al., 2024).

Could solution be feasible in trial setting?

Yes– list in box 1

Evidence: The work of Rai (2021) has shown it is feasible to adapt CST materials to a more accessible format, incorporating bullet-points and summaries. While the work of Rai (2021) presented the take-home materials via an app, presenting more options for formatting than physical paper take-home sheets, re-formatting and simplifying the take-home sheets from the current trial is feasible.

Could solution be effective in real world?

Yes – box 2

Evidence: Trials by Rai (2021) and Hui (2024) were conducted in real world settings, suggestions regarding the simplification of materials were made by caregivers and survivors in the present trial who accessed the sheets in their homes. The advice is also commensurate with elements of Stroke Association accessible information guidelines for people with aphasia, demonstrating further effectiveness in a real-world setting.

Could solution be feasible in real world?

Yes – box 2

Evidence: The solution was deemed feasible and acceptable when investigated by Hui (2024) in their trial conducted in a real-world setting, while via an app, the feasibility principles remain the same. It is also encouraged in standard practice for stroke survivors with aphasia, suggesting it is already embedded.

Assessment of Solutions (Trial Design)

Could solution b1 be effective in trial setting?

Yes – box 1

Evidence: PPIE in stroke research is valuable, but often poorly reported according to da Cruz Peniche (2024) with limited evidence of PPIE from stroke survivors with cognitive impairment. Stroke survivors with cognitive impairment and their caregivers were, however, involved in this pilot, and proposed suggestions for improvement. PPIE for this trial did not include stroke survivors with cognitive impairment but our results suggest that cognitive difficulties would not limit effectiveness of PPIE contributions. Utilising further PPIE will promote a suitable cognitive level for group activities which is further standardised with the exclusion of those registering severe cognitive impairment.

Could solution b2 be effective in trial setting?

Yes – box 1

Evidence: Gough and Novikova (2020) suggest that interventions can be more effective in engaging males if incorporating pragmatic language. It would be possible to further emphasise the skill-building elements of sCST and real-world applicability of these techniques. These elements of the activities were suggested as acceptable to a proportion of, the mostly male, stroke caregivers, emphasising the appeal of pragmatic, skills-based interventions.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: PPIE involvement presents fewer barriers to feasibility for dyads and researchers than attending the group, due to the potential to meet remotely or at the homes of PPIE consultants

Could solution be feasible in trial setting?

Yes – box 1

Evidence: Changes to the Participant Information Sheet are feasible, as these will be re-drafted for other iterations of the group.

Could solution be effective in real world?

Yes Box 1

Evidence: This is relevant to a real world setting also as PPIE can inform whether sCST suits the service in which it is being used.

Could solution be effective in real world?

Yes – box 2

Evidence: The changes to the Participant Information Sheet can be implemented in any materials advertising the group once established.

Could solution be feasible in real world?

Yes Box 1

Evidence: PPIE has been used in action research to develop stroke services (Jones et al., 2008).

Could solution be feasible in real world?

Yes – box 2

Evidence: Changes to the Participant Information Sheet could be implemented in any materials advertising the group once established.

Assessment of Solutions (Context)

Could solution c1 be effective in trial setting?

Yes – box 2

Evidence: Park (2020) found that location features influence learning; for example, the physiological impact of increased heat inhibits learning in academic settings for learners and teachers but good ventilation and air conditioning may mitigate the effect.

Could solution be feasible in trial setting?

Yes – box 2

Evidence: Many rooms for hire in the local area have good ventilation and acoustic properties as they have been designed to function as conference rooms.

Could solution be effective in real world?

Yes – box 2

Evidence: The efficacy of this solution is not affected by being in a real world setting and is equally effective in the real world.

Could solution be feasible in real world?

Yes – box 2

Evidence: The feasibility of this solution is not affected by being in a real world setting and is equally feasible in the real world.

Evaluation of Solutions

Box 1: Options that should work in trial context

Stage 1: Options

1. Take-home sheets to be in more accessible format, with summary paragraph and bullet-point format and take-home session recaps
2. Further PPIE with stroke survivor dyads, including survivors who show cognitive impairments on standardised measures, to gauge level of group content further, following exclusion of those with severe cognitive impairment
3. Address lack of males in the group through emphasis on skills-based aspect of sCST
4. Select an intervention setting with good ventilation, acoustic properties and sound system

Stage 2: Potential to combine solutions

B1 combines well with all other solutions, however while there is a potential that other solutions may not be acceptable for PPIE, this would not be known until PPIE feedback is received. Emphasising the skills-based aspect of sCST in the Participant Information Sheet will combine with the further clarity and bullet-point point style of the take-home sheets, but with careful consideration to not patronising survivors and caregivers. C1 can be easily combined with the above and will not be confounded by any other solutions.

Stage 3: Most cost-effective solution

There are no financial implications of any solution other than c1, however these are important changes for group feasibility and acceptability.

Box 2: Options that should work in real world context

Stage 1: Options

1. Take-home sheets to be in more accessible format, with summary paragraph and bullet-point format and take-home session recaps
2. PPIE to establish acceptability of sCST in the clinical service, following exclusion of those with severe cognitive impairment
3. Address lack of males in the group through emphasis on skills-based aspect of sCST
4. Select an intervention setting with good ventilation, acoustic properties and sound system

Stage 2: Potential to combine solutions

All options can be combined as per box 1.

Stage 3: Most cost-effective solution

As per box 1, room rental will incur a cost, as will an effective sound system. However, an effective sound system may be a feature of a local conference room. The cost is likely justifiable considering potential improvement in efficacy and acceptability.

Box 3: Final assessment of options and tolerance of trade-off between explanatory and pragmatic trial

This is a pragmatic trial, therefore box 2 has higher priority than box 1, however option 2 doesn't impinge on real world context solution. PPIE is an important pillar of stroke research (da Cruz Peniche, 2024) and should be utilised while sCST is investigated further. The importance of an appropriate intervention location is not only useful for acceptability but also an important reasonable adjustment for stroke survivors with aphasia or hearing difficulties; it does not interfere with other elements of the group. Being able to promote access to support for male stroke survivors is potentially beneficial for their mental health, an important area that should be considered carefully (Gough and Novikova, 2020) and take-home sheets should be as accessible as possible.

Further minor limitations to intervention acceptability and solutions are discussed in Appendix V. An initial session including both members of the dyad, an initial preferences questionnaire, development of a stroke survivor workbook, and increased budget for refreshments are solutions proposed to address these minor limitations.

Discussion

This study provides the first application of the ADePT framework to the evaluation of a dyadic post-stroke cognitive intervention feasibility pilot. We conducted a pragmatic, non-randomised, single arm, pilot feasibility trial of a novel adaptation of CST for pre-frail stroke survivors supported by family caregivers (stroke CST, or sCST). Feasibility of the intervention was examined in the context of Shanyinde's (2011) 14 methodological issues for feasibility research. Solutions to improve the acceptability and feasibility of the intervention were assessed using Bugge's (2013) ADePT framework.

The design of the sCST intervention demonstrated strengths in acceptability reported elsewhere (Bramley et al. 2025; Livsey et al. 2025) and summarized here. All stroke survivors reported enjoying sessions and were positively receptive to the intervention (Livsey et al., 2025). Three of four caregivers indicated they would attend further sessions if these were held at a community location. Participating dyads reported benefitting from the intervention, with caregivers reporting a sense of comfort and satisfaction from seeing an increase in confidence or enjoyment on the part of the stroke survivors they support. Dyads also reported increased knowledge of useful cognitive strategies. In contrast, however, the location of the intervention detracted from sCST acceptability due to the need to travel to a hospital site and features of the group room. Other limitations to acceptability were inconsistently expressed across dyads. Group size was perceived as too small for some stroke survivors but acceptable for caregivers and other stroke survivors. Cognitive level of group content was perceived to be easy by some stroke survivors but complex by others. Caregivers did not consistently engage with the take-

home activities, with stroke survivors reporting that the role of the caregivers was unclear at times, as reported in related acceptability papers (Bramley et al., 2025; Livsey et al., 2025).

The sCST feasibility pilot demonstrated several strengths in feasibility. Stroke survivors showed good adherence to all group activities. This was aided by prior consultation with a stroke survivor and caregiver dyad, with PPIE recognised as valuable to effective stroke research (da Cruz Peniche, 2024). Good retention was observed, with only one dyad leaving the trial. Providing session dates in advance may have aided retention (Johnson et al., 2023). The group was generally well attended, but as it was held over the summer period following recent stroke, attendance reduced in the final week when two dyads were unavailable either due to holiday or a hospital appointment. The cost of the intervention was easily calculable. The use of the Framework of Acceptability (Sekhon et al., 2022) as an analytic framework and topic guide for framework analysis of post-intervention acceptability interviews (Gale et al., 2013) was found to be feasible and acceptable, and yielded rich acceptability data. A key limitation to intervention feasibility, however, was difficulty achieving the recruitment target. The most common reason for non-recruitment was lack of cognitive screen or assessment.

The ADePT framework (Bugge et al., 2013) supported generation and evaluation of solutions for the feasibility and acceptability limitations identified from this initial pilot of sCST, for future trials and real-world settings. This is important given that the intervention was adapted from an intervention for people with dementia (CST, Spector et al., 2003) for pre-frail stroke survivors. While CST has been trialed in dementia and similarities exist between dementia and stroke populations, both predominantly occurring in later life, the real-world clinical settings, nature of services and nature of condition onset differ markedly. Unlike the insidious progression of many forms of dementia, stroke is a sudden onset medical emergency, requiring hospital admission and the transition from family member to family caregiver is often sudden and unexpected (Lutz et al., 2017).

Limitations to the study and findings should be acknowledged. First, there were missing data regarding some reasons for ineligibility and demographic and clinical characteristics of some eligible participants approached to participate. This limits the conclusions that can be drawn from further analysis of the recruitment process to understand the extent to which our eligibility criteria may disadvantage stroke survivors who, for example, may not have a family caregiver but are in receipt of paid care. The ADePT framework (Bugge et al., 2013) is not designed for dyadic feasibility trials. While solutions to feasibility and acceptability limitations could be identified and appraised, the framework does not take into account whether solutions are feasible and effective for stroke survivors, caregivers, or both. This limits what can be learned about the degree to which both members of the dyad have been considered to some extent. Further dyadic research evaluated using the ADePT framework (Bugge et al., 2013) may benefit from considering evidence that proposed solutions are likely effective and feasible for stroke survivors and caregivers separately.

This pilot is positioned in the early stages of complex intervention development (Skivington et al., 2021) and would benefit from further adaptation and evaluation to test the proposed solutions to identified feasibility and acceptability limitations. Future iterations of sCST should consider the adaptations proposed to improve the feasibility of recruiting to the intervention and improve acceptability of the intervention to dyads.

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Chapter 5 - Critical Appraisal and Discussion

Word count: 3580

Critical Appraisal and Discussion

This thesis portfolio focuses on the acceptability, feasibility and benefits of dyadic cognitive interventions after stroke, particularly for stroke caregivers. The impact of dyadic cognitive interventions on psychosocial wellbeing outcomes for caregivers is synthesized in Chapter 2 systematic review. The caregiver acceptability of a new adaptation of cognitive stimulation therapy (sCST) for dyads of pre-frail stroke survivors and caregivers is explored in a framework analysis of semi-structured interviews after a small-scale pilot, presented in Chapter 3. The use of the ADePT model (A process for Decision-making after Pilot and feasibility Trials; Bugge et al., 2013) to guide the systematic identification and appraisal of sCST feasibility and acceptability limitations and decisions regarding potential solutions to address these in clinical research and practice is presented in Chapter 4. This final chapter summarises the findings presented in the portfolio and appraises these in relation to wider research and theory. Following this, the strengths and limitations of the portfolio are considered. Finally, a summary of clinical and theoretical implications is outlined with suggestions for future research.

Overview of Results

This thesis portfolio presents a systematic review and two empirical papers. The systematic review (Chapter 2) synthesized research from randomized controlled trials with post-stroke cognition and caregiver psychosocial wellbeing outcomes, to identify the outcome measures and cognitive interventions used, the nature of caregiver involvement, and any evidence of psychosocial wellbeing benefits for stroke caregivers. The most common outcome measures were the memory domain of the Stroke Impact Scale (Duncan et al., 2003), and the Carer Strain Index (Robinson, 1983) for stroke survivors and caregivers respectively. Three dyadic trials were found to have targeted stroke survivor cognition and to have invited both stroke survivors and caregivers in at least one component of intervention. Of these, one reported a significant improvement in psychosocial outcomes for caregivers (Siponkoski et al.,

2022). This trial focused on dyads of stroke survivors with aphasia and their caregivers. It reported a long-term reduction in caregiver burden index following a multicomponent singing group intervention (Siponkoski et al., 2022). This suggests that dyadic cognitive interventions can have potential benefits for caregiver psychosocial wellbeing, although overall, the methodological quality of the dyadic trials identified was found to be limited, as most failed to report blinding of either participants or those delivering treatment or to report effect sizes.

The first empirical paper (Chapter 3) aimed to understand caregiver perspectives on the acceptability of a new adaptation of cognitive stimulation therapy for stroke (sCST) which encouraged caregiver involvement. A pragmatic, non-randomised, single arm, feasibility pilot of a novel adaptation of CST was conducted with five pre-frail stroke survivors supported by family caregivers (stroke CST, or sCST) recruited from a hospital stroke service. Stroke survivors were invited to attend eight sessions of sCST over four weeks, supported by caregivers who received session summaries, psychoeducation and suggested home-based activities in take-home sheets. Following the pilot group sessions, semi-structured interviews were conducted with caregivers to explore their perspectives on intervention acceptability. Interviews were analysed using Framework Analysis guided by the Theoretical Framework of Acceptability (TFA; Sekhon et al., 2022). Subthemes relating to six of the seven domains of acceptability, a theme of general acceptability and another theme of possible improvements were identified. All caregivers described psychosocial benefits of the group, with some reporting feeling comforted or satisfied by a perception of increased confidence or enjoyment in the stroke survivors they supported. Increased insight into stroke was also reported. Caregiver-perceived barriers to acceptability included the location of the group. Caregivers also reported difficulty in response to challenges with anxiety, motivation or frustration on the part of the stroke survivors they supported. Take-home sheets and group content were perceived to be too complex for some and not complex enough for others. Three of four caregivers reported they would attend a full course of sCST if it could be held at another location rather than a hospital setting.

The second empirical paper (Chapter 4) considered facilitators and barriers to the acceptability and feasibility of sCST using Shanyinde's (2011) 14 methodological issues for feasibility research. Solutions to perceived intervention feasibility and acceptability barriers were explored using the ADePT framework (Bugge et al., 2013). Three key feasibility barriers were identified relating to recruitment. Four key acceptability barriers were identified related to group gender-split, cognitive level, group location and take-home materials. Pragmatic solutions to aid feasibility that were evaluated included: the provision of hybrid virtual and in-person groups; alternative conference room locations with closer parking; the addition of community-based Early Supported Discharge teams as recruitment sites; increased research team presence at stroke team meetings with the team conducting cognitive screening for the group. These potential solutions were assessed to likely be effective and feasible in both trial and real-world environments. Potential solutions considered to aid perceived acceptability included: an emphasis on the problem-solving skills-based elements of sCST in recruitment materials; use of simplified summaries and bullet point format to take-home sheets; further patient and public involvement and engagement (PPIE) with dyads affected by post-stroke cognitive impairment; and hosting the group at suitable community settings with good accessibility. These potential solutions were assessed as likely to be effective and feasible in trial and real-world settings.

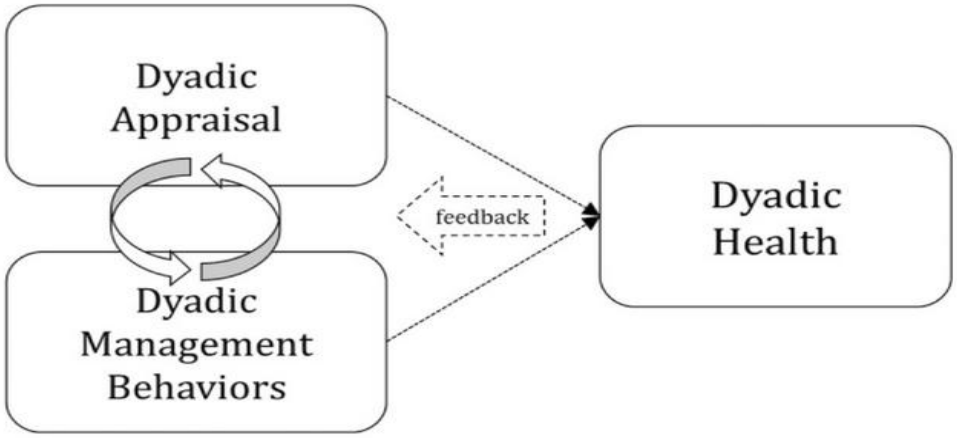
Discussion

The systematic review findings that relate to the efficacy of cognitive interventions actively involving both members of a dyad cannot be credibly aligned to clinical or theoretical models due to the lack of trials meeting this criterion (k3). However, further research in this area will be important to explore potentially relevant clinical and theoretical models.

The findings of the thesis portfolio more broadly support the theory of dyadic illness management (Lyons & Lee, 2018). Lyons and Lee (2018) suggest chronic illness is often managed dyadically. How dyads appraise an illness together affects which behaviours they enact to manage the illness together, which in turn continues to affect how the illness is appraised, both affecting dyadic health (figure 8; Lyons & Lee., 2018).

Figure 8

Theory of Dyadic Illness Management (Lyons & Lee., 2018)



Subthemes identified in caregiver interviews support the notion of dyadic appraisal and dyadic health (Lyons & Lee, 2018). For example, the *Dyadic Benefit* subtheme relates to the impact of the stroke survivor's perceived gains from the group on positive emotions for the caregiver, such as comfort and satisfaction. This reflects how joint appraisal can shape their emotional wellbeing or health, further encouraging group attendance, a dyadic management behaviour.

The dyadic illness management model (Lyons & Lee, 2018) is further supported by reports of caregiver insight more closely matching stroke survivor insight. When the dyads participated in sCST, caregivers reported that both members of the dyad could gain an understanding and context from the materials and other stroke survivors in the group, shaping their appraisal:

"*It makes me feel as though it's worth, it's worth it's weight in gold really it's to to to help alleviate some of the understanding of what they have to go through every day.*" (P2)

Dyads were also given the tools to change their dyadic management behaviours, including "top-tip" skills in the take-home materials to manage cognitive difficulties following stroke. Some dyads were able to change post-stroke anxiety-related behaviours, for example, enabling the stroke survivor to begin to travel independently. One caregiver reported that by the third session, the stroke survivor they supported was able to travel to the group independently despite their anxiety, representing a change in their dyadic management behaviours as the caregiver was no longer needed to facilitate travel.

Finally, both empirical papers contribute to research on frailty interventions. The empirical paper in this portfolio exploring accessibility for caregivers provides an insight into the experience of the pre-frail dyad during a dyadic cognitive intervention. This is particularly important as frailty is associated with aging (Zampino, Ferrucci, & Semba., 2020) and the spousal caregivers are more likely to fit the criteria for frailty or pre-frailty. And due to this, caregivers may have benefitted from the cognitive stimulation (Ng et al., 2015), though this was not assessed.

Strengths and Limitations

The systematic review and first empirical paper sought to explore an area of research that has received little attention, the psychosocial wellbeing benefits for informal caregivers of dyadic cognitive interventions after stroke and caregiver perspectives on the acceptability of a potential new dyadic cognitive intervention for stroke.

The theory of dyadic illness management (Lyons & Lee, 2018) maps well on to dyadic cognitive interventions for stroke caregivers. The methodological approaches of both empirical papers enabled exploration of the feasibility and acceptability of sCST. The Theoretical

Framework for Acceptability (Sekhon et al., 2022) was used to guide Framework Analysis (Gale et al., 2013) of caregiver perspectives on the acceptability of sCST and the 14 methodological issues of feasibility of Shanyinde et al. (2011) informed assessment of intervention acceptability and feasibility, and the ADePT framework (Bugge et al., 2013) supported assessment of potential solutions to perceived acceptability and feasibility barriers to research on sCST. The method of FA (Gale et al., 2013) utilising the TFA (Sekhon et al., 2022) to explore acceptability is in its infancy but shows promise as a rigorous and transferable method. It was valuable when exploring what participants experienced as key facilitators and barriers to intervention acceptability. The application of the ADePT framework (Bugge et al., 2013) was useful in evidencing the decision-making processes when evaluating acceptability and feasibility adaptations. This is important for later iterations of sCST. The delineation of whether a solution was effective and feasible in a trial or real-world setting was useful to support decision making that considers sCST as a further research trial as well as a potential clinical intervention. Another methodological strength of the acceptability paper was that stroke caregivers were interviewed separately. Individual interviews allowed caregivers to speak without fear of judgement of other caregivers and to speak freely, without fear of upsetting or alienating the person they support (Kellmereit, 2015). Individual interviews also promoted caregiver engagement as they could not defer to stroke survivors as would be possible in a dyadic interview.

A strength of the systematic review was that the trials included were not limited to the western world. While trials were still largely western, this is a reflection on the available literature, not the scope of the review. Another strength of the systematic review was the inclusion of self-report cognitive measures in addition to neuropsychological testing. The inclusion of self-report cognitive measures introduced greater heterogeneity to the review, but allowed a wider exploration of a broader field, beyond what can be known from objective neuropsychological testing alone.

One limitation of the acceptability study is that interviews were conducted by one of the sCST group facilitators. This could potentially result in acquiescence bias (Graeff, 2005), with participants feeling as though they cannot describe negative experiences fully, for fear of offending or disappointing the interviewer. This was considered when promoting methodological rigour and sensitivity to context. In consideration of Yardley's (2000) guidelines for rigour, a reflexive statement (appendix P) was written, conscious of the role as both group facilitator and interviewer. Previous discussions with stroke survivors, caregivers and professionals and correspondence with a research team who used the same analysis to explore the acceptability of a frailty pilot intervention (Western et al., 2023) were also considered. Transparency and coherence were promoted in the compilation of TFA framework matrix and the charting process (Gale et al., 2013). Another limitation of the intervention pilot and acceptability study was that caregivers did not consistently report which activities they completed. While caregivers were asked about the completion of take-home sheets and activities during follow-up interviews, the lack of monitoring during the trial period resulted in a loss of acceptability and feasibility data. Information about the feasibility of completing the optional activities could have been gathered to permit richer information about the acceptability of individual take-home materials.

While the systematic review benefitted from a wide breadth of trials, this also presented limitations. The inclusion of self-report measures of cognition meant there was substantial heterogeneity in measures used. A single trial was identified that targeted cognition, with active participation of both stroke survivors and caregivers and an improvement in caregiver psychosocial wellbeing outcomes. As this trial focussed on dyads affected by post-stroke aphasia its findings may not generalise to non-aphasic stroke survivors. Further research is needed in this area to investigate whether these results can be generalised, particularly as the responsibilities of caregiver of people with aphasia can differ from those of stroke survivors without aphasia (Shafer, Shafer, & Haley, 2019).

Implications for Future Research

The findings of the systematic review suggest that to improve understanding of caregiver benefits from dyadic cognitive interventions after stroke, it will be necessary to improve trial reporting, include more neuropsychological screening measures as outcomes, and explore in-person dyadic interventions. The systematic review found that 10 of 13 trials either did not blind participants or were unclear about whether participants were blinded. Further trials can benefit from more robust and well-reported blinding procedures to mitigate against the threat to internal validity from participants being aware of whether they are in treatment or control groups. Further trials may benefit from clearer reporting of the nature and degree of caregiver involvement. Analysing which caregivers attended the intervention and how it affected their psychosocial outcomes will be important to understand to what extent improvements in psychosocial outcomes reflect the impact of dyadic interventions. Future dyadic cognitive trials for stroke survivors and caregivers may also benefit from greater inclusion of neuropsychological screening measures in addition to self-report measures of cognition. Further research should also investigate the effects of dyadic group-based cognitive interventions in comparison to individual dyadic cognitive interventions, as the group setting was often reported to be a strength for both members of the dyad in the first empirical paper.

The research presented in chapters 3 and 4 suggests that to improve the acceptability and feasibility of sCST in research, it will be important for future pilots or feasibility trials to re-assess acceptability and feasibility after changing the location of the intervention to a community location with close accessible parking, good ventilation and acoustic properties that has facility to provide hybrid online access. Recruitment should also involve local Early Supported Discharge teams and researchers should have increased presence at stroke team meetings, as well as emphasising the problem-solving skills-based aspects of sCST in recruitment materials. Finally simplified and more accessible take-home materials should be

designed following more specific PPIE which involves stroke survivor dyads who have experience of cognitive impairment. Further research may also benefit from gathering more information about the survivor dyads to include better knowledge of caregiver determinants and mediators as described by the ICIM (Gérain & Zech, 2019), including self-report questionnaires on social environment such as informal and professional support available, in addition to sociodemographic, physical factors and emotional regulation. This will provide more pragmatic information on what works for whom.

Implications for Clinical Practice and Theory

LeLaurin and colleagues (2019) suggest caregiver research should specify its underpinning theoretical basis, though this is scarcely ever reported (Aldehaim et al., 2016). The empirical paper supports the dyadic theory of illness (Lyons & Lee, 2018) as a framework to understand dyadic stroke survivor and caregiver interventions, for pre-frail individuals and for individuals without pre-frailty. Caregivers reported benefits from the increased confidence, enjoyment, and purpose survivors derived from sCST but also reported elements of discomfort, stress or embarrassment when survivors were themselves frustrated with feeling frustrated or resistant to elements of sCST. This highlights how appraisals are dynamically shaped by the dyad, potentially influencing dyadic health (Lyons & Lee, 2018). The dyadic theory of illness can be described as more appropriate for dyadic research than the stress and coping model of Lazarus and Folkman (1984) often cited in caregiver research (LeLaurin et al., 2019). This is due to its focus on the dyadic nature of appraisal. The research presented in this portfolio positions stroke caregivers in the context of dyads, rather than as individual caregivers alone and portfolio findings appear to support the dyadic theory of illness (Lyons & Lee, 2018).

Considering the results of the empirical paper and the dyadic theory of illness (Lyons & Lee, 2018), it is suggested that caregivers should continue to be involved in cognitive interventions after stroke, in both their design and implementation. Perceived logistical

barriers, commitment and burden from the point of view of the caregiver should be considered in the development of cognitive interventions. The acceptability paper in this portfolio suggests that these factors affect whether both members of the dyad feel they can access the interventions. This should also be considered in the context of the small pilot sample.

This portfolio suggests overarching implications for Clinical Psychologists working in stroke and pre-frailty. Both the systematic review and empirical papers suggest the benefits of involving caregivers in the professional support of the stroke survivor, pre-frail or otherwise, highlighting the importance of dyadic insight into cognitive changes following stroke. The Clinical Psychologist with specialist training in neuropsychological assessment, formulation and intervention, can include caregivers in formulation of stroke survivor needs with appropriate psychoeducation to shape dyadic appraisals. They can also include caregivers in supporting the survivor to learn cognitively stimulating strategies so they can both be empowered in dyadic illness management behaviours (Lyons & Lee, 2018). Clinical psychologists may hold a role in supporting dyads to recognise their abilities and empower them to jointly perform meaningful and stimulating activities, beneficial to the health of the dyad as a whole. It is hoped that Clinical Psychology remains actively involved in the development and further piloting of sCST.

Conclusions

This thesis portfolio focuses on caregiver perspectives on, and outcomes of, dyadic cognitive interventions after stroke, as a member of the dyad. It presents research that explores the importance of caregiver involvement in cognitive interventions for pre-frail stroke survivors, as any intervention is inherently dyadic, despite this rarely being acknowledged in frailty research to date. The research presented provides a novel contribution to current knowledge on dyadic stroke cognitive interventions through the application of the Theoretical Framework of Acceptability (Sekhon et al., 2022), ADePT Framework (Bugge et al., 2013) and Framework

Analysis (Gale et al., 2013) to explore the feasibility and acceptability of a new adaptation of an intervention for pre-frail stroke survivors and their caregivers.

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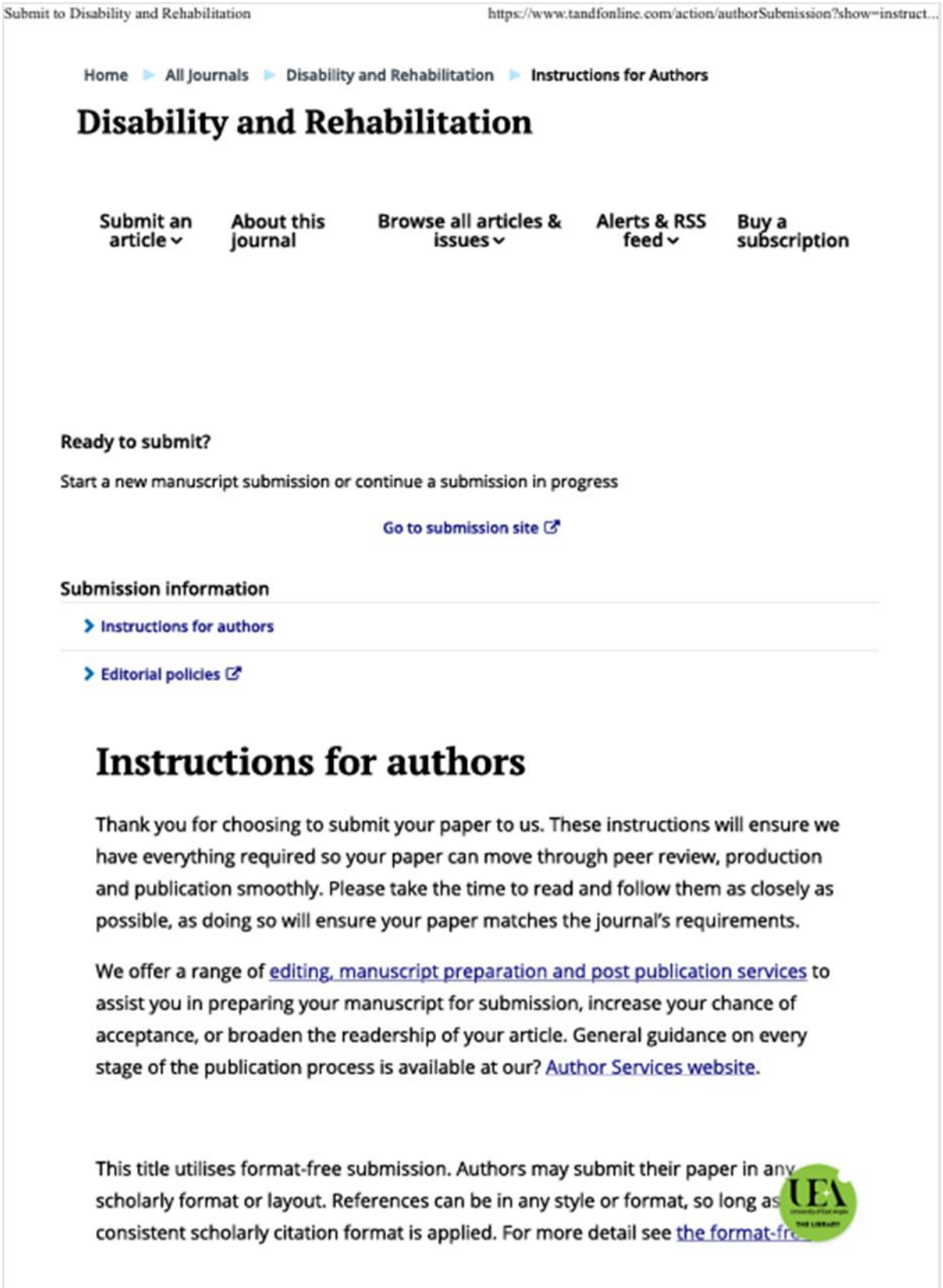

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Disability and Rehabilitation

the producers of the data set(s).

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Appendix B- PROSPERO Protocol

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

Interventions Measuring Post-Stroke Cognition and Informal Stroke Caregiver Outcomes: A Systematic Review

Maximilian Bramley, Sophie Livsey

Review methods were amended after registration. Please see the revision notes and previous versions for detail.

Citation 1 change
Maximilian Bramley, Sophie Livsey. Interventions Measuring Post-Stroke Cognition and Informal Stroke Caregiver Outcomes: A Systematic Review. PROSPERO 2024 CRD42024539798. Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42024539798.

REVIEW TITLE AND BASIC DETAILS

Review title 1 change
Interventions Measuring Post-Stroke Cognition and Informal Stroke Caregiver Outcomes: A Systematic Review

Review objectives 1 change
1. Have trials with stroke survivor and informal carer outcomes included measures of cognition and caregiver strain and if so using which measures?
2. How many of these trials tested interventions that targeted cognition after stroke and if so using what types of interventions and how were carers involved?
3. What evidence is there that these trials targeting cognition after stroke have psychosocial gains for informal caregivers?

SEARCHING AND SCREENING

Searches 1 change
A predetermined search string, developed in consultation with a specialist librarian, of 'stroke', 'dyadic' and 'intervention' and their synonyms will be used.
We will search the following electronic bibliographic databases: MEDLINE Ultimate; PsycINFO, Scopus, CINAHL Ultimate; ESBCOvia the University of East Anglia Library search.
Filters will be applied to limit publications to those published from 2000 onwards.
Reference lists of specific systematic reviews of stroke dyadic interventions will be searched for additional research articles.

Study design 1 change
Randomised Controlled Trials
Inclusion criteria:
• Studies that measure outcomes across a dyad
• Studies published in full in the English language
• Studies classified as a randomised control trial
• Studies that include a psychosocial outcome measure for carers e.g., Carer Burden Scale
- Studies that include a cognitive outcome measure for stroke survivors e.g., Mini-Mental State Examination
Exclusion criteria:
• Conference abstracts search results
• Unpublished data search results
• Report search results
• Commentaries without the original data search results
• Study protocols
• Single time point designs
• Any study that is not described as a randomised control trial
- Studies with only qualitative outcome for the outcomes identified

ELIGIBILITY CRITERIA

Condition or domain being studied
Stroke

Population 1 change
Stroke survivor and informal carer
Inclusion criteria:
• 18 years old and above
• Carers are informal carers, family members or friends, their relationship with stroke survivor is not in a paid professional relationship (carer's allowance benefit does not constitute a paid professional relationship for the purposes of this review)
Exclusion criteria:
• Carers are not described as having a neurological diagnosis such as dementia or a stroke themselves
• Stroke survivors are not described as having any other neurological diagnosis in addition to stroke e.g., Dementia

Intervention(s) or exposure(s) 1 change
All interventions will measure outcomes in both the stroke survivor and informal carer. This review looks to identify interventions that measure a cognitive outcome for stroke survivors and a psychosocial outcome for informal stroke caregovers, looking at all non-pharmacological or surgical interventions.
Exclusion criteria:
- Interventions that have a pharmacological component
- Interventions that do not meet participant or study inclusion criteria

Comparator(s) or control(s) 1 change
The comparator will be treatment as usual, standard care, or other control conditions. Randomised-Controlled-Crossover Designs are also included.

OUTCOMES TO BE ANALYSED

Main outcomes 1 change
• Outcomes:
Psychosocial carer outcome measures e.g., Carer Burden Scale, wellbeing scales, scales measuring social isolation

Cognitive stroke survivor outcomes measures e.g., Mini-Mental State Evaluation, Addenbrookes Cognitive Examination, Stroke Impact Scale - Memory and Thinking Subscale

Additional outcomes 1 change
Cognitive Measures used by studies
Psychosocial Measures used by studies
Level of Caregiver involvement (attended intervention together; attended intervention in parallel; caregiver intervention only; caregiver informant; parallel caregiver intervention e.g., carer support group; caregiver skills training)
Interventions targeting cognition type (broad types: cognitive rehabilitation; cognitive stimulation strategies; cognitive training; psychoeducation related to cognition; cognitive assessment feedback; or where the intervention is postulated to improve cognition)

DATA COLLECTION PROCESS

Data extraction (selection and coding) 1 change
Data Extraction
A form will be developed and piloted to extract data from the study for study quality and data synthesis. Data will be extracted and recorded on the following.
• Study characteristics
- First author and date (Study ID)
- Country
- Setting (stroke unit, rehabilitation unit, other hospital setting, community stroke service)
- Sample size and attrition
• Participant characteristics
- Age (Mean and SD) of stroke survivors and carers
- Sex of stroke survivors and carers
- Ethnicity of stroke survivors and carers
• Intervention characteristics
- Details of intervention
- Details of control

- Profession of clinicians delivering intervention and control conditions
- Duration of intervention and control conditions
- Number and duration of sessions for intervention and control conditions
- Delivery mode of intervention and control conditions (to each member of dyad individually, to each member of dyad separately in a group, to both members of dyad together, to both members of dyad together in a group, combined delivery modes, other mode not specified)
- Delivery format of intervention and control conditions (teleconferencing, face-to-face, audio-recording, video, written or pictorial instructions, other)
- Sample size
- Attrition rate

Risk of bias (quality) assessment 1 change

Study quality will be assessed using the Revised Joanna Briggs Institute Critical Appraisal tool for appraisal for the assessment of risk of bias in randomised controlled trials, this tool has been selected as it has been used in similar Systematic Literature Reviews (Pucciarelli et al, 2021).

PLANNED DATA SYNTHESIS

Strategy for data synthesis 1 change

A narrative synthesis will be conducted following guidance by Popay et al. (2006). The synthesis will be structured around cognitive intervention type, cognitive outcome measures, psychosocial outcome measures, level of caregiver involvement, and caregiver outcomes. The main elements of the data synthesis will be:
- Developing a theoretical model of how the interventions work, why they work, and for whom do they work. These theoretical models will be presented via a mixture of narrative and diagrammatical form.
- Developing a primary analysis, this will be preliminary only to identify factors involved in why the interventions have reported the results that they have reported and to test the robustness of the results of the preliminary synthesis. In the primary synthesis I will group cognitive and psychosocial outcome measures used, I will also group level of caregiver involvement and type of cognitive intervention.
- Exploring the relationships in data, this will be an observation of the factors that may account for patterns in direction and size of effect when looking across the different studies to examine the evidence that trials targeting post-stroke cognitive outcomes have psychosocial gains for informal caregivers.
- Examining the robustness / certainty of the synthesis product, this will be assessing whether the evidence is strong enough to draw conclusions about size and direction of effect, and whether results can be generalised to different contexts.

Heterogeneity will be explored across the types of intervention grouped according to type as detailed above, intervention characteristics will also be detailed as per the explanation in question 26.
Data will be presented in tabular and narrative form with the expectation of developing a theoretical model which may utilise diagrammatical presentation where useful. Tables will summarise context as described in question 26 (study, participant, and intervention characteristics). Tables will also be utilised to present/aid a narrative synthesis of the degree to which consistant outcome measures have been used, description of different types of cognitive intervention reported in studies, types of caregiver involvement reported in studies, and results of psychosocial outcomes in studies that have targeted cognition.

Analysis of subgroups or subsets

Not applicable

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Mr Maximilian Bramley, University of East Anglia
- Miss Sophie Livsey, University of East Anglia

Review affiliation

University of East Anglia

Funding source

The University of East Anglia

Named contact

Maximilian Bramley. Department of Clinical Psychology & Psychological Therapies, Norwich Medical School, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich NR4 7TJ
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TIMELINE OF THE REVIEW

Review timeline
Start date: 24 May 2024. End date: 10 March 2025

Date of first submission to PROSPERO 1 change
24 April 2024

Date of registration in PROSPERO 1 change
01 May 2024

CURRENT REVIEW STAGE

Publication of review results
The intention is not to publish the review once completed.

Stage of the review at this submission 1 change

Review stage	Started	Completed
Pilot work	✓	✓
Formal searching/study identification	✓	✓
Screening search results against inclusion criteria	✓	✓
Data extraction or receipt of IP	✓	✓
Risk of bias/quality assessment	✓	✓
Data synthesis	✓	✓

I am amending this, as though this protocol has not changed since my initial amendment application on the 24th Novemeber 2024, I have been asked to clarify the reasons for my changes in February 2025. At the time that my amendment was made I had began the formal screening of search results against eligibility criteria but now I have completed data analysis. No further amendments have been made between Novemeber 2024 and February 2025.

Review status
The review is currently planned or ongoing.

ADDITIONAL INFORMATION

Additional information 1 change
Recent reviews of interventions that benefit stroke survivors and informal caregivers have been published recently including a review registered by Pucciarelli et al on Prospero in 2018 and published in 2021, however no review looks specifically at post-stroke interventions that quantify both post-stroke cognition and caregiver psychosocial outcomes.

PROSPERO version history 1 change

- Version 1.1, published 24 Feb 2025
- Version 1.0, published 01 May 2024

Review conflict of interest
None known

Country
England

Medical Subject Headings
Caregivers; Cost of Illness; Humans; Quality of Life; Randomized Controlled Trials as Topic; Stroke; Survivors

Revision note 1 change
This amendment was originally made in November 2024 but further clarification was sought in February 2025 and so I am providing this now. Following discussion the research team, it was decided to narrow the focus of the research questions to interventions that involved cognitive stroke survivor outcomes and psychosocial caregiver outcomes as this is a key area in which there are currently no systematic reviews, whereas there are multiple systematic reviews considering dyadic interventions for stroke survivors and their caregivers more generally, with

recent additions to this Pucciarelli (2021), Zhao (2022), Bakas (2022), this necessitated updates to the review question, types of study to be included, intervention/exposure, outcomes, and while narrative synthesis will still be used it will now focus on the updated outcomes so as to appropriately fit the new research questions.Caregiver wellbeing has been found to interact with stroke survivor cognition, but no systematic review has examined this in context of cognitive interventions.

Appendix C – PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	24
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	25
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	26-27
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	27
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	28-29
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	28
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix D
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	29
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	29-30, Appendix B

Section and Topic	Item #	Checklist item	Location where item is reported
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Appendix B
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	29 Appendix B
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	30
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	29
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	29
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	29

	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Appendix B
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	30
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	35
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	31
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	NA
Study characteristics	17	Cite each included study and present its characteristics.	33-34
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	37-39
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	43-47
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	33-34 and 37-39
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and	40-47

		measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	37-39
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	49-50
	23b	Discuss any limitations of the evidence included in the review.	50-51
	23c	Discuss any limitations of the review processes used.	50-51
	23d	Discuss implications of the results for practice, policy, and future research.	52-53
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	28
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	28
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Appendix B
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	24
Competing interests	26	Declare any competing interests of review authors.	24
Availability of data, code and other	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	NA

materials			

Appendix D – Search Strategies

CINAHL, MEDLINE, PsychINFO	
S1	(MH “Stroke+”)
S2	(MH “Intracranial Hemorrhages+”)
S3	(MH “Cerebrovascular Trauma+”)
S4	Stroke*
S5	“Intracranial hemorrhage*”
S6	“Cerebrovascular trauma*”
S7	“Transient ischemic attack*”
S8	TIA
S9	“Cerebral infarction*”
S10	“Ischemic attack*”
S11	Infarct*
S12	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11
S13	(MH “Caregivers”)
S14	Carer*
S15	Caregiver*
S16	“Informal care*”
S17	“Family care*”
S18	Wife
S19	Husband
S20	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
S21	(MH “Randomized Controlled Trials+”)
S22	“Randomized control* trial*”
S23	“Randomised control* trial*”
S24	“RCT”
S25	S21 OR S22 OR S23 OR S24
S26	S12 AND S20 AND S25
Scopus	
((TITLE-ABS-KEY(stroke)) OR (TITLE-ABS-KEY(intracranial hemorrhage*”)) OR (TITLE-ABS-KEY(“cerebrovascular trauma*)) OR (TITLE-ABS-KEY(“transient ischemic attack*”)) OR (TITLE-ABS-KEY(tia)) OR (TITLE-ABS-KEY(“cerebral infarction*”)) OR (TITLE-ABS-KEY(“ischemic attack*”)) OR (TITLE-ABS-KEY(“infarct*))) AND (TITLE-ABS-KEY(carer*)) OR (TITLE-ABS-KEY(caregiver*)) OR (TITLE-ABS-KEY(“informal care*”)) OR (TITLE-ABS-KEY(“family care*”)) OR (TITLE-ABS-KEY(wife)) OR (TITLE-ABS-KEY(husband))) AND (TITLE-ABS-KEY(“randomized control* trial*”)) OR (TITLE-ABS-KEY(“randomised control* trial*”)) OR (TITLE-ABS-KEY(“RCT”)))	

Appendix – E Email to Author

From: Maximilian Bramley (MED - Postgraduate Researcher) <M.Bramley@uea.ac.uk>
Sent: Sunday, December 8, 2024 19:03
To: sharon.k.ostwald@uth.tmc.edu <sharon.k.ostwald@uth.tmc.edu>
Subject: Question regarding Home-based psychoeducational trial for stroke dyads (2014)

Hello,

I am conducting a systematic review of stroke research that includes both stroke survivor outcomes and stroke carer outcomes, where cognitive outcomes have been included for the stroke survivor.

I came across your trial:

"Home-based psychoeducational and mailed information programs for stroke-caregiving dyads post-discharge: a randomized trial" (Ostwald et al., 2014).

My apologies as I am sure you are busy, but I am emailing to ask whether cognitive changes after stroke were discussed in any of the 39 content-based guidelines provided to dyads? I was wondering whether your content-based guidelines on "Right-Brain Issues" under the heading of "Special Problems" included information about cognitive changes?

It would be brilliant if you could confirm this for me, your work really seems very valuable, and I would like to include it in my systematic review if you discussed any type of cognitive changes after stroke.

Kind regards and thank you in advance,

Max Bramley

Trainee Clinical Psychologist

Postgraduate Student (ClinPsyD)
Faculty of Medicine and Health Sciences
University of East Anglia

Appendix F – Intervention Characteristics

Author and Date	Intervention [Profession]	Control [Profession]	Duration	Number of Sessions and Length of Sessions	Delivery Mode and Format
Bertilsson (2014)	Client-centered activities of daily living (CADL) incorporate person-centered activities and goal setting when rehabilitation activities of daily living (ADL) tasks. CADL involved learning a global problem-solving strategy, i.e. a goal–plan–do–check meta-cognitive strategy inspired by Polatajko and colleagues (Polatajko et al., 2012). [Occupational Therapist]	No specific ADL intervention was prescribed, and it varied according to occupational therapists at the rehabilitation units who participated. Other non-ADL rehabilitation was provided as needed. [Occupational Therapist]	T: Mean 53.9 days ranging from 7-90 days C: Mean 45 days ranging from 1-90 days	T: Mean number 19.3 ranging from 1-52 Mean length NR C: Mean number 13.4 ranging from 1-91 Mean length NR	Dyad and Individual with face-to-face and telephone sessions
Bunketorp-Käll (2017)	Rhythm-and-Music Therapy (R-MT) Involved performing rhythmic, cognitively demanding hand and foot movements in beat to music. This was done in a multisensory environment encompassing rhythm to stimulate and improve motor and cognitive functions (attention, concentration, and memory). [R-MT Therapist] Horse-Riding Therapy (H-RT) Horse-riders engaged in exercises individually tailored to their physical needs and horse-riding ability, performed while moving. Targeted outcomes. This was done in a multisensory environment to stimulate and improve motor functions, strength, endurance, cognitive functions (attention and concentration) and psychosocial outcomes. [Physiotherapist and Occupational Therapist, plus 2-4 support staff to ensure safety relative to disability]	R-MT 1 year after inclusion [R-MT Therapist]	T: 12 weeks C: 12 weeks	T: Number 24 Length R-MT 90; H-RT 240 C: Number not applicable Length not applicable	Individual with face-to-face sessions

Fjaertoft (2004)	Extended Stroke Unit Service (ESUS) supporting discharge from stroke unit with follow up rehabilitation program and mobile stroke team, promoting earliest possible discharge: (1) collection of basic information (2) visiting home/making plans (3) discharge from unit (4) follow up rehab; (5) outpatient clinic 4 weeks post discharge; (6) information meeting 3 months post discharge. [nurse, physiotherapist, occupational therapist, part-time services of physician]. In addition to control (OSUS).	Ordinary Stroke Unit Service (OSUS) consisted of a standardised medical program and focus on early mobilisation (first 1-2 weeks) with further follow-up arranged by primary healthcare. No mobile stroke team access provided. [Stroke nurse, physiotherapist and physician].	T: Within 72 hours of admission to stroke unit to 3 months after discharge C: NR	T: Number NR Length NR C: Number NR Length NR	Dyad and individual with face-to-face sessions
Forster (2013)	London Stroke Carers Training Course (LSCTC) involving systematic assessment of 14 competency components (skills and knowledge, including individual cognition-specific changes) to care for stroke survivors. Delivered in in-patient setting with a follow up session post-discharge. [staff in rehabilitation setting].	Usual care as recommended in national guidelines including information and advice, goals for rehabilitation and discharge planning. [Not recorded].	T: Not specified (however caregivers must be assessed as competent in six key components) C: NR	T: Number not specified Length NR C: Number NR Length NR	Individual to caregiver with face-to-face sessions
Kashyap (2023)	Hatha Yoga includes breathing exercises, strengthening exercises, asanas, pranayama, and meditation and yoga lecture on first session. [Intervention clinician not recorded but supervised by Yoga instructor]. Follow-up supervised tele-yoga via a recorded video telecast on the Google Meet platform, in addition to control.	Described as standard rehabilitation for stroke. [Not recorded].	T: 25 weeks (12 weeks supervised and three months encouraged practice) C: NR	T: Number Minimum 16 sessions supervised, and 68 sessions encouraged home practice. Length 60 minutes C: Number NR Length NR	Stroke survivor group then individual with face-to-face sessions, to telerecordings to unsupervised practice.

Marsden (2010)	Community Living After Stroke for Survivors and Carers (CLASSiC) including Physical Activity Component followed by education component; education topics included what is stroke, goal setting, risk factors, talking to health professionals, memory, falls prevention, relaxation. [Physiotherapist, social worker, dietician, clinical nurse consultant, speech pathologist, and occupational therapist]	No intervention from the MDT to crossover. [Physiotherapist, social worker, dietician, clinical nurse consultant, speech pathologist, and occupational therapist]	T: Seven weeks C: Seven weeks	T: Number seven Length 150 minutes C: Number Not applicable Length Not Applicable	Dyadic groups face-to-face
McKinney (2002)	Short screening battery of cognitive assessments followed by detailed battery of cognitive assessments to assess specific cognitive functions with provision of recommendations to account for specific deficits, detailed feedback was provided to patient and caregiver if they consented. [Assistant Psychologist].	Short screening battery of cognitive assessments with results not provided to patient or other staff. [Assistant Psychologist].	NR for either group.	T: Number NR Length NR C: Number NR Length NR	Individual for testing, option for dyadic feedback, mode of delivery not reported
Mou (2023)	Family-Focused dyadic psychoeducational intervention that includes three structured face-to-face education sessions pre-discharge and four weekly telephone counselling sessions post-discharge. Stroke rehabilitation techniques are taught and dyads provided with information about stroke care, the recovery process and post-stroke health management. [Registered nurse].	Usual care focused on stroke survivors: medical treatments and care. Dyads also were provided with health education sessions on lifestyle management post-stroke. [doctors, nurses and rehabilitation services].	T: Five weeks C: NR	T: Number seven Length: 60 minutes per session for first three sessions, 30 minutes per telephone counselling session C: Number NR C: Length NR	Individual dyadic face-to-face sessions to telephone sessions
Ostwald (2014)	Includes post-discharge home-visits delivering information following 39 pre-determined protocols for education support, skill training, counseling and signposting. Broken into seven categories: stroke recovery, stress of stroke, promotion of healthy lifestyle, special problems, therapeutic skill training, coping strategies and community networks.	Monthly personalised psychoeducation letters on the signs of stroke, stroke prevention, stress reduction, diet and exercise guidelines, signposting, and leisure activity adaptation tips. Small gift per month, copies of magazine,	T: 6 months C: 12 months	T: Number 16 sessions and 12 letters T: Length 70 minutes C: Number 12 letters	Individual dyadic face-to-face sessions

	[advanced practice nurses, occupational and physical therapists]. In addition to control.	birthday and anniversary cards. [Not reported].		C: Length Not applicable	
Siponkoski (2022)	Multicomponent singing intervention, combining group-based singing and group training using melodic intonation therapy and home training, using tablet-based training application called Singalonger with different training aids contained within it. [Choir conductor and music therapist]. In addition to control.	Standard speech therapy, neuropsychological rehabilitation. Also, physical and occupational therapy are provided in public health care. [Not reported].	T: 16 weeks C: 16 weeks	T: Number 64 Length 90-minute group training; 30-minute home training C: Number NR Length NR	Group with caregivers invited (though a minority did not attend) face-to-face to individual stroke survivors through an online app for home training
van den Berg (2016)	CARE4STROKE exercise therapy program with caregiver. Patient-tailored mobility-goal-based exercises. If the patient was discharged home, the program continued through the CARE4STROKE app, telerehabilitation services via videoconferencing and weekly home visits. Also had a FitBit Zip (Fitbit Inc, San Francisco, CA) as an activity monitor to motivate participants through real-time feedback). [Physiotherapist]. In addition to control.	Usual care following Australian clinical guidelines for stroke management (addressing mobility impairment, sensorimotor impairment, dysphagia or communication difficulties, upper limb activity, activities of daily living, "cognition etc."). [Not reported].	T: Eight weeks C: NR	T: Number Minimum 40 sessions Length 30 minutes C: Number NR Length NR	Individual dyadic online with face-to-face weekly evaluation
Vloothuis (2019)	CARE4STROKE Program involving exercise therapy executed with caregiver. Exercises were patient-tailored mobility-goal-based. [Physical therapist]. In addition to control.	Usual care following Dutch Rehabilitation guidelines. Guidelines specify exercises are recommended to improve functional outcomes such as standing balance, physical condition and walking competence. [Not reported].	T: 12 weeks (including four weeks control) C: 12 weeks	T: Number Minimum 40 sessions Length 30 minutes C: Number NR Length NR	Individual dyadic online through an app with participants encouraged to speak to a physiotherapist using online platform

Wolfe (2000)	Community rehabilitation includes assessment at home for rehabilitation needs, with goals set for therapy. One daily visit from each therapist maximum for a maximum of three months plus home care as available for all participants in local area (maximum three one-hour visits daily by "home help" for personal care, "meals on wheels" and a community nurse for specific tasks). [Physiotherapist, occupational therapist, speech and language therapist and therapy aide].	Community care control included home care as available for all participants and access to outpatient resources in district including hospital-based stroke clinic, geriatric day hospital, generic domiciliary physiotherapy and "usual community resources". [Not reported].	T: Three months C: NR	T: Number NR Length NR C: Number NR Length NR	Individual face-to-face

T = test group; C = control group; NR = not reported.

Appendix G – The Theoretical Framework of Acceptability (Sekhon et al., 2017)

Theoretical Framework of acceptability (TFA)	Definition
Ethicality	The extent to which the intervention has good fit with an individual's value system
Affective Attitude	Anticipated Affective Attitude: How an individual feels about the intervention, prior to taking part Experienced Affective Attitude: How an individual feels about the intervention, after taking part
Burden	Anticipated burden: The perceived amount of effort that is required to participate in the intervention Experienced burden: the amount of effort that was required to participate in the intervention
Opportunity Costs	Anticipated opportunity cost : The extent to which benefits, profits, or values must be given up to engage in the intervention Experienced opportunity cost: the benefits, profits or values that were given up to engage in the intervention
Perceived effectiveness	Anticipated effectiveness: the extent to which the intervention is perceived to be likely to achieve its purpose Experienced effectiveness: the extent to which the intervention is perceived to have achieved its intended purpose
Self-efficacy	The participant's confidence that they can perform the behaviour(s) required to participate in the intervention
Intervention Coherence	The extent to which the participant understands the intervention and how it works

Note. From "Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework" [Supplementary File 6] by M, Sekhon, M. Cartwright and J. J. Francis. Sekhon, 2017, *BMC Health Services Research*, *17*(1):88, (https://doi.org/10.1186/s12913-017-2031-8). CC BY 4.0 (http://creativecommons.org/licenses/by/4.0/)

Appendix H – Topic Guide

	STROKE CARERS
UNDERPINNING THEORIES	**The Theoretical Framework of Acceptability (TFA)** (Sekhon et al. 2022): 7 constructs of acceptability posited (Ethicality, Affective Attitude, Burden, Opportunity Costs, Perceived effectiveness, Self-efficacy, Intervention Coherence)
UNDERPINNING PHILOSPHOPHICAL STANCE	**Pragmatism** - Reality is socially constructed and unlikely to ever be wholly understood / consistent with ontological position of **critical realism** (knowledge is constructed within a particular context) - Knowledge can be generated by understanding what practically works best (or doesn't work) within the specific context (Kaushik & Walsh, 2019) / consistent with epistemological position of **contextualism** ('the environment in which an event occurs intrinsically informs the event and its interpretation')
RESEARCH QUESTIONS	1) Is an adapted Cognitive Stimulation Therapy intervention acceptable to the informal carers of pre-frail stroke survivors? 2) How can the intervention be improved? 3) Is the intervention feasible to use in further research? Is it feasible to recruit and retain the required numbers to run the group intervention to inform the protocol of future research hoping to utilise this intervention.
SAMPLE	Aim = recruit 10 to allow for the possibility of group drop-out. Based on CST manual for group size (between 5-8) and guidelines / literature on qualitative analysis suggesting 6 - 20 participants are sufficient for interview data.
QUANTITATIVE DATA	Feasibility data relating to recruitment success and retention of stroke carers.
QUALITATIVE DATA	1-2 hour semi-structured interviews (change from initial plan to use focus groups) via Teams using Teams recording and transcription with a comfort break as required in weeks soon after last group session. Topic Guide informed by the Theoretical Framework of Acceptability Questionnaire Follow-up pack to be sent with debriefing letter, contact details, token of gratitude.
TOPIC GUIDE FOR CARERS OF PRE-FRAIL STROKE SURVIVORS	*Research goals of the interview:* • How would carers of pre-frail stroke survivors feel about adapted CST as an intervention? • What do carers of pre-frail stroke survivors think about the amount of effort that would be required to participate in an adapted CST intervention for the carers and for the stroke survivors themselves? • What, if any, ethical consequences did carers of pre-frail stroke survivors feel there might be to engaging in an adapted CST intervention for carers and stroke survivors? • What did pre-frail stroke carers see as the potential costs of engaging in an adapted CST intervention?

- How effective do pre-frail stroke carers think an adapted CST intervention could be for pre-frail stroke survivors? What would this mean for the carer if the stroke survivor continued the intervention (e.g., impact for carer of positive/negative effects of the intervention)?
- How confident do carers of pre-frail stroke survivors feel about supporting the stroke survivor to engage in adapted CST? What does that involve? Did they engage in any of the follow up activities on the take-home sheets? If so, what helped with this? If not, what made this difficult/what could help? Overall, how confident were they to engage in follow up activities?
- How well do carers of pre-frail survivors understand the adapted CST intervention and how it works?

Introduction – approximately 10 minutes:

- *Welcome, introduction of the interview*
- *Instructions regarding the interview:* "Thank you for coming and for supporting this research, we have talked before about the important role played by those who support someone after stroke. I am interested in how you felt about the sample sessions of adapted CST and how you would feel about the idea of the person you care for attending a full programme of perhaps 14 weekly sessions. Your views are important to us so please feel free to be honest and candid because your comments will help us to know what works well and what we might need to change in order to make it better. We will take a break halfway through so you can go to the loo or get a drink, but if you need to step out at any point before or after this break, please let me know"

Main questions – approximately 90 minutes:

- The person you support attended 6 sessions, the themes of there were **Current affairs, sounds, using money, faces, categorising objects, orientation.**
- You were also given some take-home sheets with additional optional activities on **the summarising strategy, playlists, budgeting a take-away, mnemonics, categorisation, and visual versus verbal instructions**
- "To start us off, could you please tell me one word that you feel summarises what you thought of the eight sample sessions?"
- "Thank you, let's talk a bit more about how you felt about the sessions you read about in the take-home sheets or learned about from the person you support"
    - **What did you like about the sessions from what you heard or read?**

- What did you not like?
- **Did anything make you uncomfortable or distressed?**
- Was what we asked of you fair?
- **What did you find difficult about the sessions or the process of supporting the person you care for attending the sessions?**
- How did you feel before the first session?
- We gave out some sheets to summarise each session and suggested some follow up activities.
- **Did you feel confident to take part in the take-home sessions? If not why not?**
- Were you able to read the sheets? Were you able to do any of the follow up activities? What did you think about them? Did you find them enjoyable? I have copies of them all with me.
- Did you find the take-home activities enjoyable?
- **What did you think was the purpose of the activities? Was this clear?** (memory and thinking; mental wellbeing; general wellbeing and functioning in context of frailty)
- Do you think that the activities helped the person you support in any way?
- Do you think the activities helped you to support the person you support in any way?
- Do you feel the person you support gained anything from coming to these sessions?
- **Do you feel you gained anything from the person you support attending these sessions?**
- Do you feel there were any negatives to coming to these sessions for the person you support?
- Do you feel there were any negatives supporting the person you support to the sessions?
- **Did the sessions feel relevant to the difficulties the person you support experiences after their stroke?**
- Thinking back to before the sessions, how did you feel about the person you support attending the first one?

~Comfort break – 10 minutes

- Now I would like to ask you a few questions about how you would feel about the person you support attending a full course of sessions like these, perhaps 14 sessions once a week?
  - **Do you think there would be any benefits to attending a full course of this treatment? If so, what do you think the benefits could be?**
  - Do you think there would be any benefits to other carers of stroke survivors in the person they support attending a full course of this treatment? If so, what do

you think the benefits could be?
    - (if not mentioned – do you think this treatment would have any effect on the person you support's ability to complete their usual day-to-day tasks/mood/memory and thinking skills?)
    - Do you think a full course of this treatment would help the person you support to achieve their goals?
    - Do you think the person you support attending a full course of this treatment would help the person you support to achieve your goals?
    - What would be the barriers or challenges involved in the person you support attending a full course of this treatment?
- Finally, I want to ask you about any changes or improvements that might be needed
    - **Is there anything you would change about the general format of the sessions? (e.g. length, frequency, session structure)**
    - **Is there anything you would change to the content/themes of the sessions?**
    - **Is there anything missing that you feel would be helpful?**
    - Is there anything you would change about the types of activities included in the sessions?
    - Is there anything you would change about the types of activities included in the take-home sheets?

Conclusion – approximately 10 minutes:

- *Sum up what has been discussed, mention the positive aspects, compliment and thank the participants*
    - "Is there anything important to you we haven't mentioned?"
    - "If you want to follow any issues you have talked about, you can contact myself or my supervisor via email"

"We will shortly send you a debrief letter which will explain your options about withdrawing from the study, raising concerns, and how you can be updated on the results of the study. You will also receive a £10 shopping voucher."

Appendix I – CONSORT Extension Pilot and Feasibility

Section/Topic	Item No	Checklist item	Reported on page No
Title and abstract			
	1a	Identification as a pilot or feasibility randomised trial in the title	66
	1b	Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials)	67
Introduction			
Background and objectives	2a	Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial	68-69
	2b	Specific objectives or research questions for pilot trial	71
Methods			
Trial design	3a	Description of pilot trial design (such as parallel, factorial) including allocation ratio	67
	3b	Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons	73-74/Appendix N
Participants	4a	Eligibility criteria for participants	74
	4b	Settings and locations where the data were collected	74
	4c	How participants were identified and consented	74

Interventions	5	The interventions for each group with sufficient details to allow replication, including how and when they were actually administered	72-73
Outcomes	6a	Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed	73
	6b	Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons	74/Appendix N
	6c	If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial	NA
Sample size	7a	Rationale for numbers in the pilot trial	74
	7b	When applicable, explanation of any interim analyses and stopping guidelines	NA
Randomisation:			
Sequence generation	8a	Method used to generate the random allocation sequence	NA
	8b	Type of randomisation(s); details of any restriction (such as blocking and block size)	NA
Allocation concealment mechanism	9	Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned	NA
Implementation	10	Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions	NA
Blinding	11a	If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how	NA
	11b	If relevant, description of the similarity of interventions	NA

Statistical methods	12	Methods used to address each pilot trial objective whether qualitative or quantitative	73 & 77
Results			
Participant flow (a diagram is strongly recommended)	13a	For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective	76
	13b	For each group, losses and exclusions after randomisation, together with reasons	76
Recruitment	14a	Dates defining the periods of recruitment and follow-up	73
	14b	Why the pilot trial ended or was stopped	NA
Baseline data	15	A table showing baseline demographic and clinical characteristics for each group	NA
Numbers analysed	16	For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group	78
Outcomes and estimation	17	For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group	NA
Ancillary analyses	18	Results of any other analyses performed that could be used to inform the future definitive trial	NA
Harms	19	All important harms or unintended effects in each group (for specific guidance see CONSORT for harms)	74
	19a	If relevant, other important unintended consequences	NA
Discussion			
Limitations	20	Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility	93-94

Generalisability	21	Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies	95-96
Interpretation	22	Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence	92
	22a	Implications for progression from pilot to future definitive trial, including any proposed amendments	97-98
Other information			
Registration	23	Registration number for pilot trial and name of trial registry	74
Protocol	24	Where the pilot trial protocol can be accessed, if available	NA
Funding	25	Sources of funding and other support (such as supply of drugs), role of funders	74
	26	Ethical approval or approval by research review committee, confirmed with reference number	73

Appendix J – Sample Take-Home Sheet

sCST take-home sheet
Session 1 - Current Affairs

Today we had our first session. We introduced ourselves to each other and we selected a group name and a group song, which we will sing together at the beginning of every session.

We also discussed some recent news headlines.

In today's session on Current Affairs, we practiced our communication and thinking skills by discussing our answers to a variety of questions relating to topics, such as fashion and our most treasured possessions.

Top tip:

Memory difficulties are common after a stroke. There are many strategies that can help to support memory, we will introduce you to a selection of these strategies over the course of the group.

One strategy that can be help with memory is the ***summarising* strategy**:
This is when we convert large amounts of information into a few key points. Using this strategy encourages us to take our time when reading information and to summarise the information into our own words which can help make the information more meaningful.
Also, summarising the information reduces the amount of information we need to remember.

Activity:

At home, find a news story (either from a newspaper or an online news website) and practice summarising it into key points. You can do this together, or if you'd like you could summarise one story each and then have a go at recalling the news story to each other.

You may find it helpful to use the following headings when you summarise the story: Who? What? When? Where? How? Why?

Appendix K Research Ethics Committee Favourable Ethical Opinion

NHS
Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 02071048083

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

27 March 2024

Miss Sophie Livsey
[redacted]

Dear Miss Livsey

Study title:	**Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors: A Non-randomised, Acceptability and Feasibility Pilot Study**
REC reference:	**24/YH/0075**
IRAS project ID:	**335493**

Thank you for your letter recent correspondence, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

Confirmation of ethical opinion

On behalf of the Committee, 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, subject to the conditions specified below.

Appendix L Confirmation of Capacity and Capacity

NIHR | Cambridge Biomedical Research Centre

Cambridge University Hospitals NHS Foundation Trust
Research and Development Department
Box 277
Cambridge Biomedical Campus
Hills Road
Cambridge CB2 0QQ

Direct Dial:
Switchboard: 01223 245151
E-mail: hazel.davies7@nhs.net
cuh.research@nhs.net
www.cuh.nhs.uk

20/05/2024

R&D ref: A096977
Dr Nick Evans
University of Cambridge

Dear Dr Nick Evans

IRAS ID: 335493
Title: Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors: A Non-Randomised, Acceptability and Feasibility Pilot Study
REC Ref: 24/YH/0075
Protocol version: 0.4 dated 27/03/2024

Thank you for sending details of the above named study.

The R&D department has received the HRA Approval letter and reviewed the study documents. The project has been allocated the internal R&D reference number of **A096977**. Please quote this in all future correspondence regarding this study.

Capacity and capability to conduct this study at Cambridge University Hospitals NHS Foundation Trust is confirmed. Any fully approved amendments that have been submitted whilst the project was in set up have been incorporated into our local confirmation of capacity and capability. Recruitment can commence at this site from the date of this letter. At all times the safety of study participants who are continuing or discontinuing on the study protocol is a priority.

We would like to take this opportunity to remind you of your responsibilities under the terms of the UK Policy Framework for Health and Social Care Research, applicable to Researchers, Chief Investigators, Principal Investigators and Research Sponsors. All research undertaken under this approval must comply with the requirements of the applicable laws and relevant guidelines relating to the conduct of research, including legislation on human tissue and personal data. **We would also like to remind you of the conditions of approval for this study detailed at the end of this letter.**

Please note it is a Department of Health aim to enable fast patient access to research and as such we aim to consent the first patient within 30 days of study start.

The Trust is required to report regularly on its research activity and we request that you insert the following phrase into the acknowledgement section of any subsequent publication from this study: **This research was supported by the NIHR Cambridge Biomedical Centre (BRC 1215 20014)**. While this study may not have received funding from the Cambridge BRC, it will have been supported by campus infrastructure funded by it. We are very grateful for your help with this.

I wish you every success with this study. We are keen to support good research at Cambridge University Hospitals NHS Foundation Trust and are pleased that you have decided to conduct your project here.

Yours sincerely

TAssari

Tracy Assari
Research Governance Lead

Appendix M – Confirmation of Sponsorship

Research & Innovation
University of East Anglia
Norwich Research Park
Norwich NR4 7TJ
United Kingdom

www.uea.ac.uk

TO WHOM IT MAY CONCERN

23 February 2024

Study: Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors: A Non-randomised, Acceptability and Feasibility Pilot Study

Chief Investigator: *Sophie Livsey*

This is to confirm that the University of East Anglia shall act as sponsor for the above study.

Further the University of East Anglia and Subsidiary Companies have arranged insurance cover as detailed on the attached Company Public Liability and Professional Negligence Insurance certificates.

The cover is subject to the terms and conditions of the policy. If you require further details, please contact the undersigned.

It is fully expected that UEA shall renew its insurance policies with at least the equivalent cover going forward.

Yours faithfully

Sarah Ruthven
Research Manager
Research and Innovation

E-mail: researchsponsor@uea.ac.uk

Appendix N – Research Ethics Committee Amendment

Amendment Tool

v1.6 06 December 2021

For office use

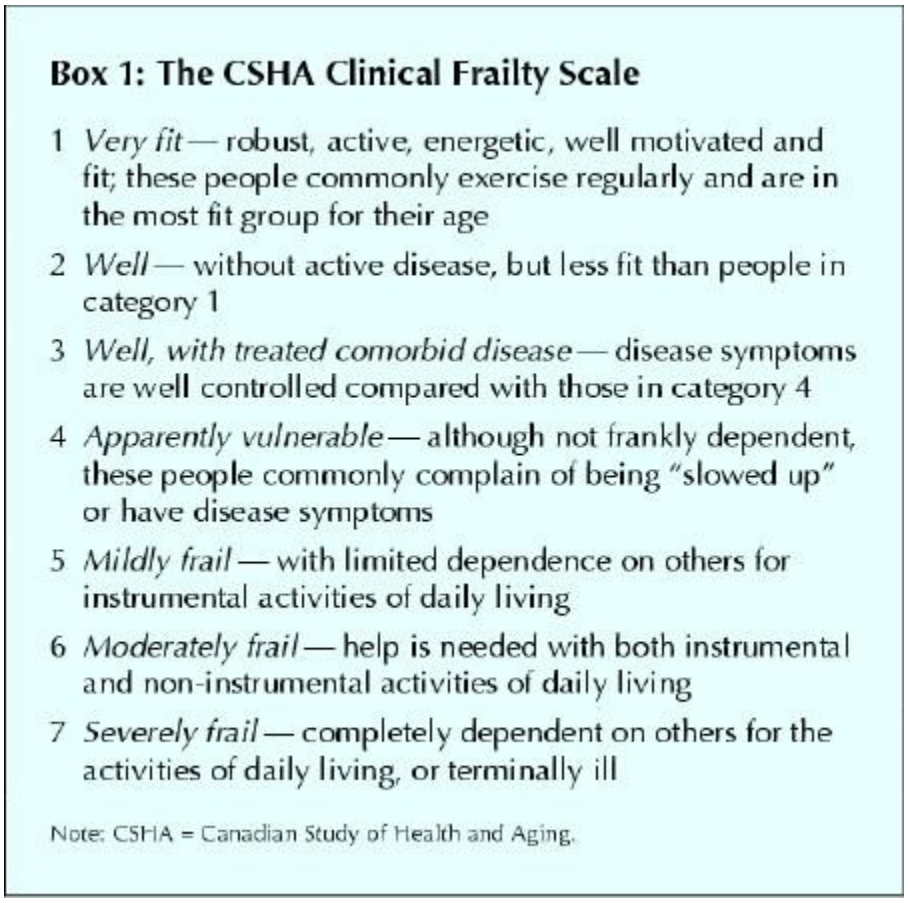
QC: No

Section 1: Project information

Short project title*:	Pilot of Cognitive Stimulation Therapy for Pre-Frail Stroke Survivors
IRAS project ID* (or REC reference if no IRAS project ID is available):	335493
Sponsor amendment reference number*:	Amendment 2
Sponsor amendment date* (enter as DD/MM/YY):	04 July 2024
Briefly summarise in lay language the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study. If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained (note: this field will adapt to the amount of text entered)*:	Change in inclusion criteria and data collection method. Inclusion criteria changes are: stroke survivor participants must now be within 12 months post-stroke, instead of 6 months; stroke survivor participants must show evidence of cognitive decline or impairment on any standardised cognitive screening tool or assessment, instead of just on the Oxford Cognitive Scale; carer participants must provide regular support to the stroke survivor participant, but they are no longer required to live with them). Instead of via focus groups, the data will instead be collected via individual interviews - this will only very minimally change the procedure that each participant experiences and will have no effect on the total time of involvement. These changes are reflected via changes to the protocol, participant information sheets (x2), consent forms (x2), cover letter, letter to GP and letter to recruiters.

Project type (select):	**Specific study**	
	Research tissue bank	
	Research database	
Has the study been reviewed by a UKECA-recognised Research Ethics Committee (REC) prior to this amendment?:	**Yes**	No
What type of UKECA-recognised Research Ethics Committee (REC) review is applicable? (select):	**NHS/HSC REC**	
	Ministry of Defence (MoDREC)	

Appendix O – Clinical Frailty Scale (Rockwood et al., 2005)



Box 1: The CSHA Clinical Frailty Scale

1 *Very fit* — robust, active, energetic, well motivated and fit; these people commonly exercise regularly and are in the most fit group for their age

2 *Well* — without active disease, but less fit than people in category 1

3 *Well, with treated comorbid disease* — disease symptoms are well controlled compared with those in category 4

4 *Apparently vulnerable* — although not frankly dependent, these people commonly complain of being "slowed up" or have disease symptoms

5 *Mildly frail* — with limited dependence on others for instrumental activities of daily living

6 *Moderately frail* — help is needed with both instrumental and non-instrumental activities of daily living

7 *Severely frail* — completely dependent on others for the activities of daily living, or terminally ill

Note: CSHA = Canadian Study of Health and Aging.

Note. From "A global clinical measure of fitness and frailty in elderly people" by K. Rockwood, X. Song, C. MacKnight, H. Bergman, D. B. Hogan, I. McDowell, A. Mitnitski, 2005, *CMAJ*, *173*(5), p. 490 (https://doi.org/10.1503/cmaj.050051) Copyright 2005 by CMA Media Inc. or its licensors

Appendix P – Reflexive Log

I was the primary researcher in this study, conducted as a part of my Doctorate of Clinical Psychology training. I am a 33-year-old, white British, heterosexual, married father of two female children. My experience of working with stroke survivors was gathered from my work in ABI residential rehabilitation and community out-patient rehabilitation settings. Both settings involved working with the individuals and other members of their caregiving dyad. I have worked for a charity supporting unpaid caregivers. I also am related to an informal stroke caregiver in my late grandmother who supported my grandfather after he sustained a stroke shortly before the COVID-19 pandemic, both appeared to show symptoms of frailty which increased. In my work with informal caregivers, I was often reminded by both members of the dyad that caregivers feel forgotten and are under-supported, this influenced my perspective when interacting with the dyads, as I held in mind that the caregivers were likely under-supported and rarely consulted. These experiences informed my research questions as I feel it is important to embrace the experiences of caregivers. My experience also involved caregivers reporting they need to put their needs behind the needs of the stroke survivor. This perspective was supported by the caregiver in the PPIE dyad involved in the trial assuming that the input we sought was purely from the stroke survivor and he was surprised when we asked for his input. This shaped my understanding of the analysis by investigating further when caregivers responded that there was no burden of the intervention and discovering that they reported the contrary when questioned further.

Despite my personal experience, I remained an outsider from those in the caregiving group, I needed to consider that while I am aware of their daily tasks and literature relative to burden, strain and benefits of caregiving, I do not have a similar lived experience, both in role and age. One caregiver commented on holding the same initial reluctance to engage in additional activity as the person they support and described this as influenced by being older, this sharpened my sense of

being an outsider. This caused me to reflect on the relationship between age and frailty and whether participants expected me to be able to understand their experiences but allowed me to be able to explore their responses further from a position of useful ignorance. I recall that I felt the pull to move towards the position of an insider in an effort to validate some of the difficult feelings experienced by the caregivers and our difference in age, and feel less as though I am an intruder. One participant asked me why the project appealed to me and what I wanted to gain from it, I felt the urge to disclose information about my grandparents but resisted this until the interview had finished as I had not provided this information in other interviews.

I was also conscious of power dynamics at play, caregivers were aware that my colleague (SL) and I adapted and facilitated the group and its materials. Caregivers were able to provide input as to the acceptability of the group which they may have felt could result in the pilot not progressing to the next stage of development, or potentially my colleague and I not having the information needed to complete our doctoral research. I was conscious of this and discussed with the project supervisor (CF) the notion that participants may feel they should say they have read the materials when they may not have done this, reflecting on this jointly it was decided to emphasise the importance of reasons for why any sessions were not read, having copies of the materials ready to normalise this. I was also aware of my position relative to attenuation bias more generally with the notion that participants may have hidden perceived limitations to sCST acceptability, I tried to reiterate during interviews that a “frank answer is a good answer” but was aware that a frank answer may carry with it a degree of discomfort for caregivers. I also expressed that I was unsure who would carry on further iterations of sCST and that there were currently no plans for me to be involved in this to separate myself more from the future of sCST in an effort to address attenuation bias. I was watchful for this in analysis and aware that the potential for this bias must be reported, rather than eliminated.

I was aware of my feelings regarding a move from an initial plan to conduct focus groups to conducting individual interviews. My recent experience with focus group interviews felt meaningful and it was initially disappointing that this was not viable due to the number of participants and guidance relative to ideal number of participants in a focus group not being met. I was initially disappointed as I felt the data would lose the naturalistic properties of conversation between participants in focus groups. However, as I began conducting individual interviews it became clear to me that many of the more sensitive answers about the relationship between the caregiver and survivor influencing acceptability would be unlikely to have been voiced to the same extent in a group setting. I became increasingly pleased with the richness of the data, deciding that individual interviews hold many strengths relative to context and would favour these in the future, even if there were adequate numbers for focus groups.

Appendix Q – Consent to Contact Form

CONSENT TO CONTACT FORM

Research Project Title: Acceptability of Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors

IRAS number: 335493

Chief Investigators: Sophie Livsey and Max Bramley of the Norwich Medical School, University of East Anglia

Please complete this form if you are happy for a member of the research team at the University of East Anglia to contact you to discuss your participation in the above research project.

We give permission for the research team for the above study to contact us to discuss the above-named study.

We understand that our personal contact details below will be stored securely, in line with the Data Protection Act and General Data Protection Regulations and shall not be used by the research team for any purpose other than to discuss our participation in the study.

Participation is voluntary, and we can withdraw our interest at any time. If we withdraw our interest and decide not to take part, the research team will destroy any copies of our personal details and the clinical care offered will not be affected in any way.

Name of Stroke Survivor Participant:	Signature of Stroke Survivor Participant:	Date:
Name of Informal Carer Participant:	Signature of Informal Carer Participant:	Date:
Address:		
Telephone number:		
Email address(es):		

Whilst still on the unit, a good day and/or time to come and talk to us is:

_____

When discharged home, our preferred time to be contacted is (please circle): **Morning** **Afternoon** **Evening**

and our preferred method of contact is (please circle): **Phone** **Email**

Version 1 – 29/11/2023

Appendix R – Participant Information Sheet Caregivers

Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors: A Non-randomised, Acceptability and Feasibility Pilot Study

Carer Participant Information Sheet

Summary

We are conducting a pilot research study to test whether a thinking and memory skills therapy group is acceptable to the carers of the people attending. Acceptability is measured against how ethical, relevant, helpful, manageable, and likeable, you as a carer find it to have the stroke survivor you support going to some sample sessions of this group, helping them with small sample optional exercises/games at home, and helping them get to Addenbrookes Hospital.

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

The information pack tells you more about this.

Why have I been given this information sheet?

You have received this sheet, because you support someone who uses Addenbrooke's hospital, your role is important. People in your role are often under-represented in research and the design of NHS services; we hope to begin to address this.

We would like to invite you and the person you support to attend appointments at Addenbrooke's Hospital to participate in our research study.

If you have any questions that aren't covered in this participant information sheet, please let us know and we will be glad to tell you more.
Please take your time to read this information leaflet, **as we do not want you to feel pressured into any decision regarding this study.**

Background and further information

People who have sustained a stroke and have reduced resilience are more likely to have serious negative health and disability outcomes. Not only are these outcomes negative for the person who has survived a stroke, but they can also be difficult for the family or friends who support them at home, as the impact of supporting someone with reduced resilience is often higher due to the additional strain around these outcomes.

An adult with reduced resilience is described as meeting three or more of these criteria:

- Significant unintentional weight-loss
- Exhaustion
- Weakness
- Slowness of walking speed,
- Low physical activity

The person you support has been identified as meeting one or two of these criteria, showing that they are more likely to develop reduced resilience.

Research has suggested that certain types of groups that provide mental stimulation through activities, may be able to help reverse the process of having significantly reduced resilience (frailty).

We are piloting a Cognitive Stimulation Therapy group adapted for people who have a stroke and are developing signs of reduced resilience.

We are seeking feedback on this group before research progresses to clinical trial stage, to see if it could become part of a healthcare programme combining multiple treatments (e.g., exercise, nutritional advice as well as the Cognitive Stimulation Therapy group) for resilience difficulties after stroke.

The perspectives of carers are often missed in research this area; this study aims to address this.

Who can take part?

You can take part if you:	You cannot take part if you:
✓ Are 18+ years old ✓ Regularly support someone who has survived a stroke	û Do not have access to a computer, laptop or tablet from which you can access an online interview

✓ Have the ability to speak and read the English language to engage fully in the CST take-home activities and online interview ✓ Are able to independently make the decision about whether you would like to take part in the study	û Are a professional carer for the person you support û Are being investigated by the safeguarding team

What is involved?

Before the Group:

A member of the research team will arrange a visit to the stroke survivor's homeor to the ward (should the stroke survivor you support still be living there at the time) to talk through this sheet further and answer questions.

They will then talk you through paperwork regarding how we ask you to keep any personal information you have learned in the study confidential and how we will keep your information anonymous unless anyone is at risk of serious harm.

They will also talk you through your right to withdraw your participation from the study and your data at any point during the study, but not after the interview You will then be asked to complete a brief demographic questionnaire.

During the Group:

You will support the stroke survivor to travel to the group one day every week. The weekly sessions will last two hours, and they will be over the period of four weeks in summer 2024. Further information about this is on their separate information sheet.

In the group sessions the stroke survivor will participate in activities (discussions, games, etc.) that are designed to get their brain active. Each session will have a theme and will be structured as follows:

- Introduction
- Group song
- Discussion of recent news stories
- Main activity, for example the "Faces" session where we will ask you to think of different fun ways to help participants remember the names of new people
- Summary of session and handing out take-home sheets

The group will be run by two researchers who have designed this group and run a similar group previously. A medically trained member of the Addenbrooke's Hospital Stroke Team will also be present to support with any risk or emergencies.

After the Group:

You will be invited to a Microsoft Teams interview lasting one-to-two hours on another day in the weeks after the group has finished to discuss feedback. The interview will be recorded using the built-in video and audio recording in Microsoft Teams so that the interviewcan be transcribed

Possible advantages of taking part

- You will be provided with a £10 shopping voucher as a thank you for your time
- You will be helping to develop a group that may help others in the future
- You may be able to forge relationships or a network with other carers if you wish
- You will gain first- hand experience of participating in a psychological research trial

Possible disadvantages of taking part

- You will spend 11 hours of your time committed to this study, this could be tiring
- You will spend time travelling to the study location not included in these 11 hours
- Speaking about your experiences of caring for someone in a feedback group could feel uncomfortable
- Using Microsoft Teams for an interview can be confusing if you are unfamiliar with it
- Unfortunately, **travel costs to and from Addenbrooke's cannot be reimbursed**, but discounted parking at the hospital can be arranged at a rate of £4.80 per day, which can be reimbursed by researchers upon request.

Other Important Information – Q&A

Q - Who is organising and funding this research?

Max Bramley – Trainee Clinical Psychologist at the University of East Anglia (UEA), employed by the NHS

Dr Catherine Ford – Clinical Associate Professor, employed by UEA.

Professor Niall Broomfield – Professor of Clinical Psychology, employed by UEA

Dr Nicholas Evans – Clinical Lecturer in Geriatric and Stroke Medicine, employed by the University of Cambridge and the NHS

Additional support from: **Sophie Livesey**– Trainee Clinical Psychologist at the UEA, employed by the NHS. Max Bramley will be leading this arm of the study as part of his doctoral training to become a Clinical Psychologist; **the project is funded by his training programme as the research sponsor – UEA**, use of 'we' in this sheet pertains to UEA**.**

Q - Who has checked this study?

This study has received a favourable opinion by the NHS Health Research Authority, University of East Anglia, and the Cambridge University Hospitals NHS Trust.

Q - How much of my time will this take?

We estimate that this will take approximately 11 hours of your time, excluding travel. This will be split into:

One hour—spent talking through the study, the information sheet and signing important paperwork around consent and confidentiality.

Four two-hour periods (eight hours)—this is the time the group sessions will take for the person you support who has had a stroke. You do not need to stay in the hospital during the group. There will also be brief take-home exercises/games to try with the stroke survivor you support.

One-to-Two hours – spent providing your feedback about the group via online interview using Microsoft Teams.

Q - What if I don't want to take part anymore?

You can withdraw from the research at any point before the interview. Once the interview has happened, the information will be written up and anonymised so it will not be possible to withdraw your contribution at this point.

You and the stroke survivor you support may want to withdraw at any point before the interview, while there is no need for you to tell us why, it can be really useful for us to know as it may tell us something about the group, so you will still be able to come to the interview if you wish. Their routine care under Addenbrooke's Hospital will not be affected either in participating in the study or withdrawing from it.

If your ability to fully understand, retain and balance information about participating in the study changes, we will speak to you about the possibility of withdrawing from the study.

Q - What are your choices about how your information is used?

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Q - Where can you find out more about how your information is used?

You can find out more about how we use your information by emailing research supervisor Dr Cat Ford on **catherine.ford@uea.ac.uk** or by visiting www.hra.nhs.uk/information-about-patients/

Q - How will you use information collected about me?

We will need to use information from you for this research project. This information will include your

- Full Name
- Contact Details
- Other Demographic Information (age, gender, education, ethnicity)

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. Demographic information will be anonymously reported in the write-up of the study, in order to describe the characteristics of the participant sample. We will write our reports in a way that no-one can work out that you took part in the study.

Any personal identifying data you share during the interview will be altered to preserve your anonymity. Noone will access your medical records.

If there is a revelation of harm or potential harm to the participant or another person, it may be necessary to breach confidentiality and report the matter to the appropriate agencies, however we would always try to discuss this with you first.

Direct quotes may be published from the interview following the CST group, these will all be anonymised, and care will be taken to not use any quotes that could identify you.

Q - Is there anything I should be worried about if I take part?

We don't have any reason to expect specific risks to your wellbeing in relation to this study.

We don't have any reason to expect specific risks to the person who you support. It is possible, however, that you may find discussing your role supporting the stroke survivor emotional or even distressing. I will be available to talk to, should you have any difficulties relating to your participation in this study.

If you have specific worries in relation to your caring role or the one you care for in relation to stroke, that staff at Addenbrooke's Hospital cannot assist with, it may be useful to call one of the lines below:

- **Stroke Association Helpline** (for those affected by stroke including carers) - **0303 3033 100** (open Monday-Friday 9am-5pm; Saturday 10am- 1pm).
- **Samaritans** (confidential emotional support) - **116 123** (open 24/7 365 days a year).

Q - Will the stroke survivor I support no-longer have an impacted level of robustness at the end of this group?

We do not expect this group to affect the stroke survivor you support's level of robustness at this stage.

Q - Where will the group be held?

Addenbrooke's Hospital, more specific information will follow about where on the hospital premises the group will be held.

Q - How secure is my data?

All information that is collected will be stored on a password protected system on a password protected laptop, this is in-line with UK General Data Protection Regulations 2018.

Q - What if I have more questions after the visit to discuss this sheet or complaints about the study?

You can get in touch with me as principal researcher via email on **m.bramley@uea.ac.uk** or my supervisor on **catherine.ford@uea.ac.uk** . To raise a complaint please email Professor Sian Coker, who will be dealing with complaints independently on s.coker@uea.ac.uk

Q - What will happen to the results of this study?

Results can also be shared directly with you, the participant, via email or other preferred contact method if you so wish.

Appendix S – Participant Information Sheet Stroke Survivors

University of East Anglia

NHS Cambridge University Hospitals NHS Foundation Trust

Form version: 7
Date created: 02/07/2024
REC Ref: 24/YH/0075
IRAS Project ID: 335493
Chief Investigator: Sophie Livsey, Trainee Clinical Psychologist
Sponsor: University of East Anglia

Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors: A Non-randomised, Acceptability and Feasibility Pilot Study

Stroke Survivor Participant Information Sheet

Summary

We are recruiting participants who have recently had a stroke to take part in our research study.

The lead researcher of this study, Sophie Livsey, is a Trainee Clinical Psychologist completing their Doctorate in Clinical Psychology at the University of East Anglia. This research project is being conducted as part of their studies.

In this pilot study, we are hoping to test the acceptability of a therapy group that is designed to help people practise and develop their memory and thinking skills. 'Acceptability' is the degree to which the intervention seems ethical, relevant, helpful, manageable and likeable.

In order to do this, you are invited to take part by attending a few sample sessions of an intervention and then giving feedback about your experience.

In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study, we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

The information pack tells you more about this.

Why have I been given this information sheet?

You have received this information sheet because you have had a stroke within the past twelve months and have been identified by members of your clinical team as possibly meeting criteria to take part in this research.

University of East Anglia

NHS Cambridge University Hospitals NHS Foundation Trust

Background and further information

Individuals who have had a stroke are twice as likely to experience frailty than the general population. Frailty can lead to negative health outcomes, such as disability, poorer recovery and lower quality of life.

Some people may not be frail after a stroke but may have lost some of their physical resilience. This is sometimes known as 'pre-frailty' because it can be a sign that frailty is more likely to develop later on.

Some research has shown that frailty can be prevented by offering 'multi-component interventions' – this is when two or more different therapies that aim to help with different aspects of health, happen at the same time. Usually, the combination is physical exercise therapy, memory and thinking skills therapy, and diet education.

The memory and thinking skills therapies that have been used in stroke and frailty research vary greatly—there is no agreement yet on what they should include or how they should be done.

One well-known therapy for memory and thinking is called Cognitive Stimulation Therapy (CST). This was originally designed for dementia and is usually run in groups. It has been found to improve memory and thinking ability, as well as quality of life.

This study hopes to find out whether an adapted version of CST would be an acceptable intervention for people who have had a stroke. Specifically, whether it seems relevant, helpful, manageable and likeable. This will help to inform further research on the prevention of frailty after stroke.

Who can take part?

You can take part if you:

- ✓ Are 18+ years old
- ✓ Had a stroke 12 months ago, or less
- ✓ Are due to be discharged back home before the adapted CST group starts
- ✓ Are experiencing a loss of physical resilience as a result of your stroke
- ✓ Are experiencing some difficulty with your memory or thinking as a result of your stroke
- ✓ Have a family member or friend who regularly supports you and is willing to take part in a connected research study
- ✓ Have the ability to speak and read the English language to participate fully in the adapted CST group and online interview

You cannot take part if you:

- × Have significant difficulties with language, memory or thinking that would make taking part too difficult
- × Are not able to independently make the decision about whether you would like to take part
- × Have a diagnosis of dementia
- × Do not have access to a computer, laptop or tablet from which you can access an online interview

University of East Anglia

NHS Cambridge University Hospitals NHS Foundation Trust

What is involved?

Before the group

A member of the research team will arrange a visit to your home or to the ward to talk through this sheet further and answer questions.

You will be asked to complete a **brief demographic information questionnaire.**

During the group

Attend **eight sample sessions of the adapted CST group intervention**. You will be invited to Addenbrooke's Hospital **once a week for four weeks**. During each visit, two 45-minute sessions will take place back-to-back with a short break in between. **Each 'visit' to the hospital will therefore last up to 2 hours.**

There will be up to twelve people in the sessions: ten stroke survivors and two researchers who will lead the group. The group sessions will start in a few weeks' time, we will be in touch nearer the time to confirm exact dates if you agree to take part.

In the group sessions, you will be asked to participate in activities (discussions, games, etc.) that are designed to get your brain active. Each session will have a theme and will be structured as follows:

1. Introduction – welcome, group song, discussion of recent news stories
2. Main activity - for example, in the 'Faces' session, we will ask you to think about different, fun ways to help you remember the names of new people.
3. Summary of session and handing out 'take-home activity sheets

After the group

You will be asked to complete **a brief online questionnaire** about what you thought of the group sessions. **This should take no more than a few minutes to complete.** Then, a week or two after the group CST sessions finish, you will be asked to attend an **online interview, via Microsoft Teams, for up to two hours.** During this, you will be asked a series of questions about the sessions you attended, which will be discussed as a group. The interview will be recorded using the built-in video and audio recording in Microsoft Teams so that the interview can be transcribed.

Possible advantages of taking part

We cannot guarantee any health benefits to taking part in this research, but:

- Your participation in this study may lead to **further research into the development of new treatments after stroke**.
- You may find it beneficial to **get to know other like-minded stroke survivors** who take part in the study and, possibly, **develop valuable friendships**
- You will be able to receive a **follow-up appointment** with one of the Consultants in Stroke Medicine up to 6 months after the research study has finished, if needed
- You will receive a **£10 shopping voucher** as a thank you for taking part

University of East Anglia

NHS Cambridge University Hospitals NHS Foundation Trust

Possible disadvantages of taking part

- This study will require approximately **11 hours of your time**
- Unfortunately, **travel costs to and from Addenbrooke's cannot be reimbursed**, but discounted parking at the hospital can be arranged at a rate of £4.80 per day, which can be reimbursed by researchers upon request.
- There is a possibility that taking part in this study could **cause adverse effects** (such as increased fatigue) **or exacerbate existing difficulties** (such as anxiety)
- There is also a **chance that you will not get on with all other group members**, although researchers will make efforts to minimise the impact of this

Other Important Information—Q&A

Q: If I have been given this information sheet, do I have to take part?

A: No, participation in this study is voluntary, Please consider all the information in this leaflet and discuss any questions with the researcher before you make your decision

Q: What will happen in relation to my care if I do not wish to take part?

A: If you do not wish to take part, the medical care you receive will not be affected. However, if you think that taking part will interfere with your other medical appointments, please discuss this with the researchers and/or your medical team.

Q: What can I expect during the consent process?

A: You will have at least 24 hours after receiving this information sheet to consider whether you would like to take part in the study. One of the researchers will visit you again soon and you will have the opportunity to ask any questions you may have. If you are willing to take part, then you will be guided through the consent form.

Q: How will you use information about me?

A: We will need to use information from you and your medical records for this research project. This information will include:

- Your full name
- Contact Details
- Other Demographic Information (age, gender, education, ethnicity)

Researchers will use this information to do the research and check your records to obtain information about your stroke and the impact it has had on your health and physical resilience. This is explained further on the next page. Your name and contact details are only required for communication between the researcher and yourself and will be destroyed after communication is no longer needed. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no one can work out that you took part in the study.

University of East Anglia

NHS Cambridge University Hospitals NHS Foundation Trust

We will keep all information about you safe and secure. Your information will be assigned an anonymous participant code, data we collect from you within the study will not be linked to you by name or any other identifying information. Data and other information we collect from you will be held in a secure online server.

Due to the group setting of the CST sessions, you will be expected to share your first name or a preferred nickname with fellow participants. You have a choice in what other information you choose to share with other participants.

Some direct quotes may be published from the interview, however, these will be anonymised and care will be taken to not publish any quotes that may identify you.

There may be some situations in which researchers may wish to share information about you with other appropriate agencies. for example, if there is a revelation of harm or potential harm to you or another person. If possible, researchers will let you know if they feel this is necessary.

As part of the consent process, you will also be asked if you consent to researchers sending a letter to your GP to let them know about the study and that you have decided to take part.

Demographic information will be anonymously reported in the write-up of the study, in order to describe the characteristics of the participant sample.

Q: Will any of my medical data be accessed, and for what purpose?

A: Yes, medical data that is relevant to your stroke and the impact it has had on your health will be collected (e.g. what type of stroke you had, when you had it, score on memory and thinking tests). This information will be anonymously reported in the write-up of this study, in order to describe characteristics of the participant sample. We will write this in a way that no one can work out that you took part in the study.

Q: What are my choices about how my information is used?

A: You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Q: Where can I find out more about how my information is used?

A: You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/, or by contacting one of the research team members. Our contact details are on the first page of this information sheet.

Q: What will happen if I don't want to carry on with the study?

A: You are free to withdraw from the study at any point if you wish to do so. If you withdraw part way through the research, we will retain the information about you we already have but we will not obtain any new information from or about you from that point onwards. If the reason for withdrawal is due to a medical or health reason, you will

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be offered a review appointment with a physician or psychologist within the Addenbrooke's stroke services. You are encouraged to contact a member of the research teams if you have any concerns about the study and your participation.

If you decide that you would not like to continue attending the group CST sessions, you will be given the option to withdraw from the study completely or drop out of the group but remain in the study so that you can still attend an interview to give your feedback. It is important we hear both positive and negative feedback about the CST therapy group to help us develop it further.

If your ability to fully understand, retain and balance information about participating in the study changes, researchers will speak to you about the possibility of withdrawing from the study.

Q: What if something goes wrong?

A: If something happens, such as increased fatigue or distress, you will have the option to discuss your concerns with the researcher to see if adaptations can be made for you or if you need to withdraw. If you, or the researchers, develop any concerns about your health or wellbeing throughout the study we will discuss this with you a follow-up appointment with a physician or psychologist within the stroke services can be arranged. A physician will also be in the room during the group sessions at Addenbrooke's and will be able to assist you should any health events occur.

Q: What will happen to the results of this study?

A: This study will form part of the researcher's thesis for the award of a Doctorate in Clinical Psychology. The results of this study will be shared with researchers within the field and hopefully be published for wider access. Results can also be shared directly with you, the participant, via email or other preferred contact method if you so wish.

Q: Who is organising and funding this study?

A: The lead researcher is Sophie Livsey, a Trainee Clinical Psychologist on the doctoral programme in clinical psychology at the University of East Anglia. The research is funded by the University of East Anglia.

Q: How have patients and the public been involved in this study?

A: An advisory group made of a stroke survivor and their carer was formed for the purpose of this study, they assisted with the design of research, research materials (such as this information sheet) and the adaptation of the intervention.

Q: Who has reviewed this study?

A: This research study has received a favourable opinion by the NHS Health Research Authority, the University of East Anglia and the Cambridge University Hospitals NHS Trust.

be offered a review appointment with a physician or psychologist within the Addenbrooke's stroke services. You are encouraged to contact a member of the research teams if you have any concerns about the study and your participation.

If you decide that you would not like to continue attending the group CST sessions, you will be given the option to withdraw from the study completely or drop out of the group but remain in the study so that you can still attend an interview to give your feedback. It is important we hear both positive and negative feedback about the CST therapy group to help us develop it further.

If your ability to fully understand, retain and balance information about participating in the study changes, researchers will speak to you about the possibility of withdrawing from the study.

Q: What if something goes wrong?

A: If something happens, such as increased fatigue or distress, you will have the option to discuss your concerns with the researcher to see if adaptations can be made for you or if you need to withdraw. If you, or the researchers, develop any concerns about your health or wellbeing throughout the study we will discuss this with you a follow-up appointment with a physician or psychologist within the stroke services can be arranged. A physician will also be in the room during the group sessions at Addenbrooke's and will be able to assist you should any health events occur.

Q: What will happen to the results of this study?

A: This study will form part of the researcher's thesis for the award of a Doctorate in Clinical Psychology. The results of this study will be shared with researchers within the field and hopefully be published for wider access. Results can also be shared directly with you, the participant, via email or other preferred contact method if you so wish.

Q: Who is organising and funding this study?

A: The lead researcher is Sophie Livsey, a Trainee Clinical Psychologist on the doctoral programme in clinical psychology at the University of East Anglia. The research is funded by the University of East Anglia.

Q: How have patients and the public been involved in this study?

A: An advisory group made of a stroke survivor and their carer was formed for the purpose of this study, they assisted with the design of research, research materials (such as this information sheet) and the adaptation of the intervention.

Q: Who has reviewed this study?

A: This research study has received a favourable opinion by the NHS Health Research Authority, the University of East Anglia and the Cambridge University Hospitals NHS Trust.

Appendix T – Consent Form

IRAS ID: 335493
Participant Identification Number for this trial:
Version 5, dated 02/07/2024

University of East Anglia

CARER CONSENT FORM

Title of Project: Acceptability of Adapted Cognitive Stimulation Therapy (CST) for Pre-frail Stroke Survivors – a Carer's Perspective

Name of Researcher: Max Bramley

	Please initial in box
• I confirm that I have read the information sheet dated 02/07/2024 (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
• I understand that my participation is voluntary and that I am free to withdraw at any time before the interview without giving any reason, without my medical care or legal rights being affected, however data already gathered with consent will be retained for the study.	☐
• I consent to the storage and processing of personal information and data for the purpose of this study.	☐
• I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.	☐
• I understand that the information gathered during the study will be treated as strictly confidential and handled in accordance with the EU General Data Protection Regulations 2018. However, if there is a sign that either I or the person who I care for may come to serious harm or may harm others, I understand that this information will be shared with the relevant bodies to keep myself and others safe.	☐
• I understand that should my ability to fully understand, retain and balance information about participating in the study change, researchers will speak to me about the possibility of withdrawing from the study.	☐
• I agree to take part in the above study.	☐

IRAS ID: 335493
Participant Identification Number for this trial:
Version 5, dated 02/07/2024

Optional

- I would like to receive the results of the study upon completion and therefore I give consent for researchers to securely retain my personal contact information until this time. ☐

Name of Participant	Date	Signature
_____	_____	_____
_____	_____	_____
Name of Person taking consent	Date	Signature

Appendix U – Personal Information and Demographics Form

Personal Information and Demographics

University of East Anglia

Pilot of Cognitive Stimulation Therapy for Pre-frail Stroke Survivors

Thank you for agreeing to take part in this research study.
Please take the time to complete the following questions which ask about your contact information and demographic details.

Why do we need this information?

We ask for your contact information so that we can remain in contact with you throughout the course of this research (for example, if we need to cancel a group session due to researcher sickness, and to send you instructions about how to join the online focus group). This information will be destroyed as soon as we no longer need to remain in contact with you.

We ask for your demographic information so that we can anonymously report information about the participants in the write up of the research study. We will write this in a way that no-one will be able to tell that you took part. This might look something like this: "of the 12 participants in the study, nine (75%) were White British, two (17%) were Pakistani and one (8%) was Black British". We will write this in a way that no-one will be able to tell that you took part.

Personal information

Name ☐ DoB ☐

Address ☐

Email ☐

Phone ☐

Demographic information

Gender — Please tick ☑

- Female ☐
- Male ☐
- Other ☐
- Prefer not to say ☐

Highest level of education — Please tick ☑

- No qualifications ☐
- O-Level/GCSE ☐
- Apprenticeship ☐
- A-Level ☐
- Higher education (e.g. BA/BSc, diploma or above) ☐
- Prefer not to say ☐

Ethnicity — Please tick ☑

Asian or Asian British

- Indian ☐
- Pakistani ☐
- Bangladeshi ☐
- Chinese ☐
- Any other Asian background ☐

Black, Black British, Caribbean or African

- Caribbean ☐
- African ☐
- Any other Black, Black British, or Caribbean background ☐

Mixed or multiple ethnic groups

- White and Black Caribbean ☐
- White and Black African ☐
- White and Asian ☐
- Any other Mixed or multiple ethnic background ☐

White

- English, Welsh, Scottish, Northern Irish or British ☐
- Irish ☐
- Gypsy or Irish Traveller ☐
- Roma ☐
- Any other White background ☐

Appendix V – Additional Applications of the ADePT Framework

Problem Type		**Solutions**
Type B: Limitations to acceptability relative to psychosocial, fatigue and engagement factors **Evidence:** **1)** A more homogenous group was preferred by a group member who disliked the group song. **2)** Dyads expressed stress, anxiety or trepidation ahead of group sessions, often citing uncertainty and trouble recalling sessions. **3)** Caregiver role felt unclear for some including survivors and caregivers and few dyads spoke about frailty. **4)** Dyads reported fatigue, with one dyad referencing the time of day as problematic. **5)** TFA data could not be analysed (Sekhon et al., 2022) due to technological issues		**Change Aspects of:** **a) Intervention** **1)** Development of a workbook to be completed at the end of each individual session with summaries of what has been useful, what has been enjoyable, and what has been difficult. **2)** A single session with both members of all dyads to attend to address uncertainty. clarify roles and the purpose of research. **3)** A preferences questionnaire to identify favourite musical genres and common interests, in addition to identifying which times of day may exacerbate fatigue. **b) Trial Design** **c) Context**

Assessment of Solutions (Intervention)

Could solution a1 be effective in trial setting?

Yes – box 1

Evidence: The use of a stroke survivor workbook for group cognitive interventions has been endorsed by Bertisch (2011) who suggest a group note-taking template following cognitive remediation group sessions for those who have experienced an acquired brain injury. This may reinforce strategies suggested in the sessions. The template can be amended to include whether there was an element of the session that was particularly appreciated or should change. This could be incorporated further into the take-home sheets and stimulate conversation in dyads in addition to prompting memory and concretize information from groups (Langenbahn et al., 1999). This could also include TFA questionnaires for the final session.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: Use of a workbook for stroke survivors in a cognitive remediation group was demonstrated to be feasible in Bertisch and colleagues' (2011) trial.

Could solution be effective in real world?

Yes Box 1

Evidence: The efficacy of this solution is not affected by application to a real world setting.

Could solution be feasible in real world?

Yes Box 1

Evidence: The feasibility of this solution is not affected by application to a real world setting, though may incur printing costs, similar to the present trial dependent on method of binding.

Could solution a2 be effective in trial setting?

Yes – box 1

Evidence: Trials by Marsden (2010) and Siponkoski (2022) have included group-based interventions with stroke survivors and their caregivers. Clarity of role and purpose of research was not assessed in these trials and evidence for effectiveness of an initial session to ease stroke survivor stress and anxiety was not established.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: Trials by Marsden (2010) and Siponkoski (2022) show that it is feasible to include both members of a stroke survivor and caregiver dyad in the group room at once.

Could solution be effective in real world?

Yes – box 2

Evidence: Effectiveness of caregivers attending an initial session of a group-based intervention for stroke survivors has not been established.

Could solution be feasible in real world?

Yes – box 2

Evidence: The feasibility of caregivers attending an initial session of a dyadic group cognitive intervention is not posited to be affected by being in a real world setting.

Assessment of Solutions (Intervention)

Could solution a3 be effective in trial setting?

Yes – box 1

Evidence: Further questionnaires or tools to establish patient likes and dislikes and, times of day that are difficult due to fatigue have the potential to carry response burden (Rolstad, Adler & Rydén, 2011). However, Griffin (2021) suggests providing acquired brain injury survivors with a sense of connection and identification within groups is more beneficial than providing structure alone. Griffin (2021) found that hobby groups, including music groups, were some of the most popular groups for acquired brain injury survivors before and after their injury. Effectiveness of a preferences questionnaire has not been investigated.

Could solution be feasible in trial setting?

Yes – box 1

Evidence: The feasibility of a preferences questionnaire at the beginning of a group has not been investigated.

Could solution be effective in real world?

Yes Box 1

Evidence: The efficacy of a preferences questionnaire has not been investigated in a real world setting.

Could solution be feasible in real world?

Yes Box 1

Evidence: The feasibility of a preferences questionnaire has not been investigated in a real world setting.

Evaluation of Solutions

Box 1: Options that should work in trial context

Stage 1: Options

1. Development of a workbook to be completed at the end of each individual session with summaries of what has been useful, what has been enjoyable, and what has been difficult.
2. A single session with both members of all dyads to attend to address uncertainty. clarify roles and the purpose of research.
3. A preferences questionnaire to identify favourite musical genres and common interests, in addition to identifying which times of day may exacerbate fatigue.

Stage 2: Potential to combine solutions

All options combine well together.

Stage 3: Most cost-effective solution

The hire of the room if hosted at a community center will incur an additional cost for the additional initial group session and the printing of the workbook may incur an additional cost to the take-home materials if professionally binded. The printing of one preferences questionnaire per stroke survivor will cost the least amount of money.

Box 2: Options that should work in real world context

Stage 1: Options

1. Development of a workbook to be completed at the end of each individual session with summaries of what has been useful, what has been enjoyable, and what has been difficult.
2. A single session with both members of all dyads to attend to address uncertainty. clarify roles and the purpose of research.
3. A preferences questionnaire to identify favourite musical genres and common interests, in addition to identifying which times of day may exacerbate fatigue.

Stage 2: Potential to combine solutions

All options can be combined as per box 1.

Stage 3: Most cost-effective solution

As per box 1, a3 is the option that will cost the least amount of money.

Box 3: Final assessment of options and tolerance of trade-off between explanatory and pragmatic trial

This is a pragmatic trial, therefore box 2 is higher priority than box 1, however option 2 doesn't impinge on real world context solution.

All options can be combined and all are applicable to both a trial and real world setting. All options are evaluated suitable. However, it should be noted that the effectiveness and feasibility of many of these solutions have not been investigated. Though as they are unlikely to incur substantial financial cost and emotional distress or burden, they are assessed as suitable for further investigation. PPIE input should be sought regarding these proposed solutions in later trials investigating sCST.