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Cognitive rehabilitation for dementia

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Chapter 1

The perceptions of people with dementia, their carers, and healthcare staff of cognitive rehabilitation interventions: A qualitative systematic review and thematic synthesis

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Abstract

Dementia is associated with cognitive impairments which affect everyday functioning. Cognitive rehabilitation (CR) is a person-centred, goal-orientated, problem-solving intervention aimed at enabling people with cognitive impairments to manage everyday living and maintain independence. In recent years there has been an upsurge in qualitative studies capturing cognitive rehabilitation experiences of people with dementia (PwD), their carers and healthcare staff. The aim of this review was to synthesise these perspectives to inform future research and the delivery of CR. A qualitative systematic review was conducted. The inclusion criteria for publications were as follows: (1) peer-reviewed qualitative research, (2) studies exploring the experiences of one or more of the following groups: PwD, carers, and healthcare practitioners engaged in CR, (3) an intervention that is characterised by person-centred goals, and cognitive rehabilitation strategies to address these goals, (4) the CR intervention that participants were part of included PwD, carers and healthcare staff (although all three participant groups did not need to be included in the qualitative reporting), and (5) articles in English. The search was completed in July 2024. Six studies were included and rated as high or moderate quality. From the studies included, four domains of themes were derived. These were: i) positive experiences of CR, ii) negative experience of CR, iii) barriers to CR, and iv) how to make CR better. Seven themes populated these domains including: “Feeling better able to cope with dementia”; “Valuing the social component of CR”; “Appreciating the individualised approach”; “Uncertainty about the long-term benefit of CR”; “Good intention to deliver an intervention is not enough”; “Participant difficulties”; and “Recommendations to support the intervention’s success”. The review highlights the need for personalised, and flexible approaches to dementia care. These insights aim to refine CR practices, improving the quality of intervention/care for PwD and their carers and healthcare staff.

Keywords: Cognitive rehabilitation; dementia; carers; healthcare staff; qualitative systematic review

The perceptions of people with dementia, their carers, and healthcare staff of cognitive rehabilitation interventions: A qualitative systematic review and thematic synthesis

Dementia is among the most feared conditions in adults aged over 55 in the UK (Alzheimer's Research UK, 2014) and poses a significant economic burden to healthcare systems (Hurd et al., 2013; Wimo et al., 2011). There are calls for an increase in psychosocial models of care, which along with medical intervention, can support those with dementia to live well with the condition (Alzheimer's Society, 2013; Oyebode & Parveen, 2019; Raphael et al., 2021).

Cognitive rehabilitation (CR) is a "person-centred, goal-oriented, problem-solving therapy aimed at managing or reducing functional disability, mitigating excess disability, and maximising engagement and social participation" (Clare et al., 2019, p. 710). Evidence suggests that CR is particularly useful when supporting people with dementia (PwD) with specific and personally meaningful functional goals (Clare et al., 2019; Garrido-Pedrosa et al., 2017). CR has been recommended by the National Institute for Health and Care Excellence (NICE) to support functional ability in PwD (NICE, 2018). A recent Cochrane review (Kudlicka et al., 2023) included six RCTs and found high-certainty evidence of large positive effects of CR on participant self-ratings of goal attainment, informant ratings of goal attainment, and self-ratings of satisfaction with goal attainment, relative to an inactive control condition. There was also high-certainty evidence showing a small positive affect of CR on self-efficacy and immediate recall reported.

One of the eminent studies within the CR in dementia literature is the GREAT trial (Clare et al. 2019). The authors carried out a large, multisite randomised controlled trial (RCT) comparing CR and treatment as usual (TAU) with TAU alone (N = 475). Participants developed meaningful goals relating to everyday activities. Those in the experimental group received CR for 10 weekly sessions over three months. At three months, there were statistically significant large positive effects for participant-rated goal attainment (d = 0.97). The observed gains related to goals directly targeted in the intervention.

There have been several qualitative studies capturing the perspectives of those who engage with CR, which report positive feedback of the CR intervention for those with dementia (Chester et al., 2022; Warmoth et al., 2022). Qualitative research is considered particularly suited to study the caring professions (DeMauro et al., 2019), and facilitates a more nuanced exploration of the participants' experiences (Christopher et al., 2011). This is particularly useful with a heterogeneous clinical population whose experiences of interventions would not otherwise be detected in quantitative research (Junge et al., 2020). Within CR research, quantitative studies typically assess goal attainment, but the standardised measures used do not capture how participants experience the process of identifying and obtaining goals, nor do they capture what participants consider barriers/facilitators to CR interventions. Qualitative studies can derive some of this information. This is important data to consider when trying to improve the processes and usability of CR clinically. This systematic review included a thematic synthesis of the qualitative feedback about the perceptions of PwD, their carers and healthcare staff about these programmes. The aim was to help inform the development and delivery of future CR interventions.

Method

A qualitative systematic review provides a way of synthesising research findings in a systematic, transparent, and reproducible way (Grant & Booth, 2009; Snyder, 2019). It captures 'themes' or 'constructs' that lie in, or across, individual qualitative studies. This review is structured by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for reporting systematic reviews (Page et al., 2021; see Appendix A for reporting checklist). The aim was to review the qualitative feedback of the perspectives of PwD, their carers, and healthcare staff relating to CR interventions which meet pre-specified eligibility criteria. A qualitative design was believed to be appropriate and considered the best fit epistemologically for a subject matter that deals with subjective perspectives. The review protocol was pre-registered on PROSPERO (https://www.crd.york.ac.uk/prospero/).

A critical realist perspective was adopted, combining the idea that reality exists with the understanding that our interpretation of it is shaped by our subjective viewpoints (Braun & Clarke, 2022; Maxwell, 2012). The author has experience of delivering CR with older adults with mild-to-moderate dementia, which provides clinical awareness of the approach.

Scope of Study

The PICOS mnemonic/search tool (Methley et al., 2014) was used as an organising framework to list terms by the main concepts in the search question (see Table 1).

Table 1

PICOS search tool including main concepts

Population	PwD, their carers, and healthcare staff
Intervention	Cognitive rehabilitation
Comparison	Not Applicable
Outcomes	All outcomes
Study Design	Qualitative studies

Inclusion/Exclusion Criteria

Eligibility criteria are provided in Table 2.

Table 2

Journal article selection criteria

Inclusion criteria	Exclusion criteria
Qualitative research and qualitative data extracted from mixed methods research.	Quantitative research only.
Peer-reviewed articles.	Non-peer-reviewed articles.
Studies investigating the perspectives of one or more of the following groups about CR: PwD; carers; healthcare practitioners.	Studies not capturing perspectives of PwD, carers, or healthcare practitioners engaging in a CR intervention.
CR intervention is characterised by: the development of person-centred goals; cognitive rehabilitation strategies to address these goals; the inclusion of a carer (18+ years old) and healthcare professional in its delivery.	Interventions that do not include all the core CR characteristics described.
Studies written in English language.	Studies written in a language other than English.
Studies published up until July 2024.	Studies published after July 2024.

Search Strategy

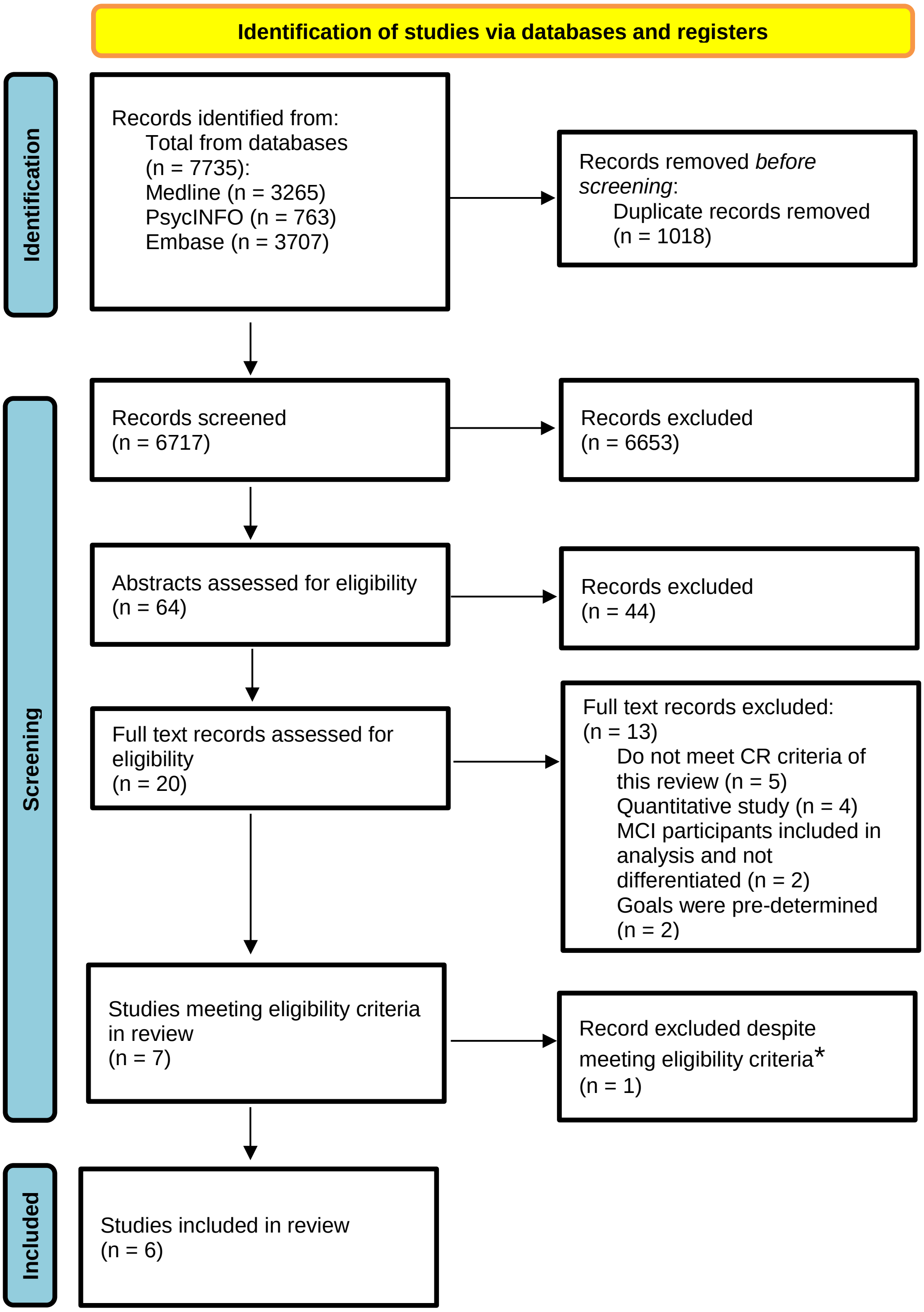
MEDLINE, PsycINFO, and EMBASE were searched. Initially, scoping searches were conducted using a combination of keywords which provided an overview of the literature, some estimation of the volume of relevant papers, and identified key issues (Boland et al., 2017). Thereafter, PROSPERO was screened to ensure no reviews responding to this research topic had been registered. A University of Glasgow academic librarian provided consultation for the proposed electronic search strategy. The search terms used included interventions similar to CR (i.e., cognitive stimulation therapy, cognitive training) where inconsistent and incorrect terminology can be used and therefore the findings may be relevant to this review (Kudlicka et al., 2023). See Appendix B for the search strategies that were used to retrieve reports of studies from MEDLINE, PsycINFO, and EMBASE.

Screening

While the author reviewed all the titles and abstracts for eligibility a second reviewer independently screened 10% of the titles. Titles considered suitable by both reviewers for further screening were retained. The two reviewers then independently reviewed the full texts of 10% of the articles which were retained. There was 100% agreement between the reviewers for both screening stages so further discussion to come to a consensus was not required. EndNote (Clarivate Analytics, 2021) was used to facilitate the screening process and organise references. This review follows the PRISMA four-phase flow method, which presents transparent and comprehensive reporting of the study selection process (Liberati et al., 2009; see Figure 1). Seven papers fulfilled the inclusion criteria. This many studies falls within the "preferred number" (6- 14) as discussed by Booth (2016).

Figure 1

PRISMA flow diagram for the selection of articles in the systematic review



*See data extraction section of review

Data Extraction

Participant characteristics and study design information were extracted from the full text versions of the eligible studies. This information included the Title, Authors & Year of Publication, Geographical location, Setting - Environment/context, Phenomena of interest/research question/s, Research study design/Qualitative approach, methodology, and Data collection and analysis methods (see Appendix C).

One study that was not included in this review despite meeting the eligibility criteria was by Clare et al. (2019). The study's authors explicitly stated that "Findings are presented only briefly [in their article] but will be reported more fully in a separate paper." (p. 712) They provided a short summary of the thematic analysis which was presented in the Warmoth et al. (2022) and Morgan-Trimmer et al. (2021) papers. Although the same trial data was used by Warmoth et al. (2022) and Morgan-Trimmer et al. (2021), they conducted different analyses (i.e., complexity-informed thematic analysis and thematic analysis) and included different quantities and types of participants qualitative data, therefore offering nuanced accounts of the dataset. They were also found to be of high-quality using the CASP checklist (see Table 3).

The full results data and any related appendices of the studies included was inputted into the NVivo software package to manage the data (NVivo, 2002).

Quality Assessment

The methodological quality of included studies was reviewed against the Critical Appraisal Skills Program (CASP) Qualitative Studies Checklist (Critical Appraisal Skills Programme, 2018). The CASP is the most used tool for quality appraisal in health-related qualitative evidence syntheses, with endorsement from the Cochrane Qualitative and Implementation Methods Group (Sekhon et al., 2024). This tool assesses the quality of the selected studies and assesses the contribution of different quality studies to the final synthesis

(Buccheri & Sharifi, 2017). Butler et al.'s (2016) reviewer guidelines were used to assist with the scoring and interpretation of the CASP. Appraisal results are presented in a risk of bias table below (see Table 3). Each study was scored based on a positive evaluation of 10 domains. A third of the studies were also evaluated by a co-rater and there was only disagreement in scoring the researcher/participant relationship item, however this was discussed, and a score agreed for each item. All studies scored 8.5 or above which demonstrates that the review was made up of high and moderate-quality papers. The domains where studies received negative and unclear scores were related primarily to the researcher/participant relationship (five studies).

Table 3

Response to CASP Qualitative Checklist, questions 1-10

	Chester et al. (2020)	Clare et al. (2023)	Morgan-Trimmer et al. (2020)	Oksnebjerg et al. (2019)	Irazoki et al. (2021)	Warmoth et al. (2022)
1. Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y
2. Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y
3. Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y
4. Was the recruitment strategy appropriate for the aims of the research?	Y	Y	Y	Y	Unclear	Y
5. Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y
6. Has the relationship between the researcher and the participants been adequately considered?	N	Y	Unclear	N	N	N
7. Have ethical issues been taken into consideration?	Y	Y	Y	Y	Y	Y
8. Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y
9. Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y
10. How valuable is the research?	Y	Y	Y	Y	Y	Y

Note. Y = Yes and N = No.

Data Synthesis

Thomas and Harden's (2008) thematic synthesis approach was used for the transformation of data into analytical themes. Codes were identified inductively, and constantly compared and regrouped into themes. Descriptive themes were further developed into analytical themes. The derivation of themes was an inductive process where data informed the analysis rather than previous research findings, theories, or conceptual frameworks regarding

CR (Armat et al., 2018). Deriving themes from the raw data using the inductive approach mitigates the possibility of a researcher forcing a pre-determined result (Azungah, 2018). Themes were derived by the author; the themes and evidence for the themes was discussed in research supervision. NVivo software was used to facilitate the thematic synthesis as well as mind mapping software (MindManager, 2020).

Results

From the thematic synthesis seven themes were developed. These could be categorised under four overarching domains (see Table 4). There were three themes under the category of positive views of CR. These included “Feeling better able to cope with dementia”, “Valuing the social component of CR” and “Appreciating the individualised approach”. There was one theme under the domain of the negative views of CR. This was “Uncertainty about the long-term benefit of CR”. There were two themes relating to barriers to CR. These were “Good intention to deliver an intervention is not enough” and “Participant difficulties”. There was one theme around how to make CR better, namely “Recommendations to support the intervention’s success”.

Table 4

Themes identified across the qualitative studies of CR for dementia

Domain	Theme
Positive views of CR	Feeling better able to cope with dementia
	Valuing the social component of CR
	Appreciating the individualised approach
Negative views of CR	Uncertainty about the long-term benefit of CR
Barriers to CR	Good intention to deliver an intervention is not enough
	Participant difficulties
How to make CR better	Recommendations to support the intervention's success

The themes were developed based on the comments from several sources. From which group these comments were made are detailed in Table 5.

Table 5

Sources of evidence for each theme based on current position of research

	Chester et al. (2020)	Clare et al. (2023)	Morgan-Trimmer et al. (2021)	Oksnebjerg et al. (2019)	Irazoki et al. (2021)	Warmoth et al. (2022)
Feeling better able to cope with dementia		PwD, C, S	C	PwD, C	PwD	PwD, C
Valuing the social component of CR		C, S	C, S	PwD, C		PwD, C
Appreciating the individualised approach		S, SS		PwD		PwD, C
Uncertainty about the long-term benefit of CR						PwD, C
Good intention to deliver an intervention is not enough		S, SS				
Participant difficulties	S	S	S			
Recommendations to support the intervention's success	S	S, SS	S	C		S

Note. The inclusion of PwD, C (carer), S (healthcare staff delivering the intervention), SS (senior healthcare staff) demonstrates that the respective participant group has contributed to a theme.

Positive views of CR

Feeling better able to cope with dementia. ***"I don't feel … as if there isn't a future … .I'm not frightened of going out on me own".*** Five studies reviewed described at least one participant group (i.e., PwD, carers, and/or healthcare staff) profiting from gaining knowledge and skills to help them manage dementia-related difficulties (Clare et al., 2023; Irazoki et al., 2021; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). The information and explanations that staff gave about dementia to PwD and their carers was considered beneficial. Although there was little description of the specific CR strategies employed by healthcare staff, the carers and PwD referred to improvements in the PwD's daily functioning during the intervention. Most studies reported that PwD, carers, and healthcare staff felt more confident in helping people manage the condition after engaging in CR (Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). Half of the studies also reported there was greater acceptance of dementia's poor prognosis as participants felt better able to manage the condition (Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022).

Valuing the social component of CR. **"*that therapeutic rapport, which I think actually counts for a lot, but I think it largely goes unmeasured in a way, what we bring as people".*** Most studies spoke about the capacity of CR to generate supportive relationships between the participant groups (Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). Two studies described the relationship between staff delivering the intervention and the PwD and carers as a lynchpin of the intervention (Morgan-Trimmer et al., 2021; Warmoth et al., 2022). The relationship was described as beneficial for supporting CR and non-CR specific experiences including motivating engagement in the intervention, providing a person-centred intervention, and social and emotional support (Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). A few studies described this relationship as therapeutic and noted it resulted in positive outcomes for all participant groups (Morgan-Trimmer et al., 2021; Warmoth et al., 2022). A therapist described:

> the pleasure of seeing people try and do well, even if they're not achieving their goals, it's the other things that they're getting from it, the social interaction, the time to talk about their condition, the dementia, and it not being hushed away and in the cupboard (Therapist 7; Morgan-Trimmer et al., 2021, p. 7)

The group CR intervention detailed by one study (Oksnebjerg et al., 2019) provided opportunities to interact with more people with dementia, which led to PwD and carers feeling less isolated.

Appreciating the individualised approach. ***"I felt I was getting better with [therapist], you know … Cos I felt as if she was, she understood me".*** Half of the studies reported that participants valued the person-centredness of the intervention (Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). Both practitioners and senior staff within these four studies thought that CR provided the opportunity to be flexible, adaptable, and creative when supporting people with dementia. This allowed for individual needs and preferences to be well accommodated. The increased autonomy which was core to CR was enjoyed by a therapist who said that the intervention "allowed creativity in my work, was brilliant. I loved it, and I still do, and if I had the chance I would do a lot more of it" (CRP008-05; Clare et al., 2023, Appendices p. 17).

Negative views of CR

Uncertainty about the long-term benefit of CR. ***"You know I can't say that they're being sustained 100% like I hope they would be … but I think this is, er, the nature of the condition, not the programme".*** This theme was evident in the study by Warmoth et al. (2022) who completed interviews over three sites in the UK with participants nine months post-intervention, which gave participants some experience of the long-term impact of CR. This study and the one by Morgan-Trimmer et al. (2021) were the only studies included in this review to analyse follow-up data. A few PwD and carers said that although the intervention had been useful, the PwD's performance on their selected goal had declined since the end of the intervention. One carer mentioned: "I think it did for a while, it did improve. But you know, we'd never get back to the number that it was originally". (Carer 3, p. 276) "…the number that it was originally" in the quote refers to the goal attainment rating provided at the post-intervention assessment. There were several quotes from carers and PwD that queried the influence of dementia and the limitations of the intervention on their decline in performance on their goals. One carer illustrates this in their response:

> Now, we come onto the issue of … the problem of Alzheimer's itself, so that, to be honest, is very, very difficult to answer … Certain things have slipped away, but is that the fault of the programme or the fault of the condition? And so it's really difficult to equate what the programme has done and what the condition has not allowed it to do. (Carer 6, p. 276)

The study reported that some of the participants' views of managing the negative symptoms of dementia had changed positively due to the intervention, however, they still acknowledged that they were pessimistic about their future due to the condition. For example:

> what they've told me is enough … for me to work along now … The future will have to sort itself out. ……. I'm not looking forward to the future … You know, just thinking, you know won't it be nice, and all that sort of thing. Cos I know it won't be. (PwD 10, p. 277)

Barriers to CR

Good intention to deliver an intervention is not enough. ***"There was a... a lot of goodwill to start the project. But in reality, you know, there were some difficulties and some challenges".*** This theme was derived in a study by Clare et al. (2023) which was the only study exploring the views of staff delivering CR and senior-level staff within several healthcare organisations. Despite many staff members expressing good intention to deliver CR, there was pessimism around the capacity for organisations to sustain delivery. One primary reason cited by staff delivering the intervention was the over prioritisation of diagnosis, medical (e.g. medication) interventions, and crisis management and the under prioritisation of psychosocial interventions like CR. There were also views held by some senior staff which contradicted the goodwill which was cited to be generally present within senior staff groups. One senior staff manger cited “nihilistic” (Appendices p. 11) views of dementia within some organisations which posed a barrier to securing funding for psychosocial interventions. Another senior staff member suggested that CR could be seen as a “luxury” (Appendices p. 12) compared to other interventions. The differing views of senior staff demonstrates some ambiguity within this group about the delivery of CR within their services. The lack of consistent support from more senior staff, as well as high staff turnover, COVID-19, organisational changes, resulted in some clinicians not feeling they had the resources to deliver CR. Clare et al. (2023) stated that “Resource limitations made it difficult to devote the time needed to get to know the person and design a personalised intervention, and created conflict boundaries between providing CR and routine work” (Appendices. p 18). One participant also shared that there was “some confidence issues” amongst staff delivering the intervention. However, this participant also mentioned that she was not sure if it “held people back” from actually delivering CR.

Participant difficulties. ***“where the carers have taken over an awful lot of the tasks...getting a goal in that situation can be quite challenging”.*** There were some challenges which staff encountered with PwD and carers which made the intervention more difficult to deliver. Half of the studies in this review cited ways in which carers could pose a barrier to delivering CR (Chester et al., 2020; Clare et al., 2023; Morgan-Trimmer et al., 2021). Carers may have compensated for the PwD’s difficulties by taking over tasks for them which influenced PwD’s not appreciating the extent of their difficulties and sometimes reduced motivation to resume responsibility or independence. One study stated that some carers viewed CR as additional work and resisted involvement (Clare et al., 2023). Another study noted that PwD and their carers goals could differ (Chester et al., 2020). A staff member commented on a conflictual marital relationship and that they took on a role of attempting to reduce this conflict to support the intervention's success:

> I do find that it's about the nature of the relationship as well. And often you do find, like you're doing a couple's intervention, it's not just about the dementia, it's often about the dynamics that have probably gone on through their whole relationship but the situation is highlighting it, and that's really quite difficult to manage, isn't it? (Therapist 2; Morgan-Trimmer et al., 2021, p. 6)

Participants from two studies (Chester et al., 2020; Morgan-Trimmer et al., 2021) highlighted that those with greater cognitive impairment had greater difficulty coming up with goals. Some reasons cited were lack of insight into their loss of function, inability to set an appropriate goal, lower levels of motivation, and being more withdrawn during sessions. Another barrier to PwD setting goals was having a reluctance to report or address areas of difficulty (Chester et al., 2020).

How to make CR better

Recommendations to support the intervention's success. ***"We had too little time to just talk...but the education shouldn't be shorter. Perhaps the meetings should be longer".*** Most studies illustrated ways participants felt the intervention could be best delivered (Chester et al., 2020; Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). Some emphasised the utility of certain components of the intervention outlined in the procedure and others that were 'add-ons' (Chester et al., 2020; Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et 2al., 2019). Staff participant groups in these studies cited they wanted more time for the following activities: identifying and setting goals, engaging and supporting carers, and providing social interaction. There was some consideration of ways to improve the PwD's engagement in CR by staff members by increasing the flexibility in the language they used to conceptualise goals and strategies (Chester et al., 2020; Morgan-Trimmer et al., 2021). For example:

> Therapist 7: The 'restorative' and 'compensatory', that's too jargon-y, and too heavy for the person, not all, but some of the people with dementia… Therapist 2: Yes, I've had to change the words to 'methods', because 'strategies' just scares them. (Morgan-Trimmer et al., 2021, p. 5)

Discussion

From this systematic review, four domains of themes were derived. These were the positive experiences of CR, negative experience of CR, barriers to CR, and how to make CR better. Seven themes included in the domains were: "Feeling better able to cope with dementia"; "Valuing the social component of CR"; "Appreciating the individualised approach"; "Uncertainty about the long-term benefit of CR"; "Good intention to deliver an intervention is not enough"; "Participant difficulties"; and "Recommendations to support the intervention's success".

The theme, "Feeling better able to cope with dementia" illustrated an increase in confidence managing the condition. This relates to the concept of self-efficacy and there is evidence showing a small positive effect of CR on self-efficacy as reported by PwD (Kudlicka et al., 2023). Participants valued the social component of CR. Older people often have reduced socialisation opportunities than younger people (Ten Bruggencate et al., 2018) and dementia can further impact engagement in social activities and spending time with friends and family (MacRae, 2011; Phinney et al., 2013). It was found in several studies within this review that PwD and their carers often treated the sessions with the practitioners as socialisation opportunities. A primary need of people, no less older adults, is good social relationships and a weekly meeting with a health care practitioner can support this need (Ten Bruggencate et al., 2018). The flexibility and person-centredness of the CR approach resulted in adaptations to the CR protocol to manage problems. This is detailed within the GREAT trial CR protocol (Clare & Kudlicka, 2015 as cited by Morgan-Trimmer et al., 2021), which stated that "some flexibility will be needed as participants will have varying needs and preferences and will progress at different rates" (p. 39). Morgan-Trimmer et al. (2021) reported that the staff delivering CR managed different problems which arose during the intervention, such as relationship conflict between the PwD and carer. Managing relational conflict was not an explicitly defined component of CR and therefore required the staff member to go beyond the manualised delivery of the intervention. The flexibility of the protocol may lead to a practitioner being more likely to support other participants' needs in the pursuit of the person achieving their goals.

Warmoth et al.'s (2022) article described a salient negative experience of the CR intervention in that a few PwD and carers felt that the CR intervention would not lead to sustained long-term goal attainment. This study and the one by Morgan-Trimmer et al. (2021) were the only articles which analysed data from interviews which were completed nine months post-intervention. Other included studies that interviewed participants shortly following their intervention did not derive this theme. Although assessing the long-term implications of CR certainly has its merits, a potential consequence is that PwD could find it more difficult to recall their experiences of the intervention (Hubbard et al., 2003).

The barriers to CR were organisational and relating to the PwD and carers. Clare et al.'s (2023) study was the only one to incorporate interviews of senior level management staff. This can be helpful when trying to understand organisational level factors in the implementation or interventions. They found that generally practitioners delivering the intervention and senior level staff had good intentions to deliver CR. However, there were several factors that hindered the delivery of the intervention. Organisational level factors such as resource constraints, poor leadership and managerial support were raised as issues by staff, and are also cited in the literature on implementing evidence-informed dementia care in the community (Dugmore et al., 2015; Lourida et al., 2017; Raphael et al., 2021). CR can be delivered in conjunction with pharmacological interventions, which may ease the tension that some senior staff and multi-disciplinary team members may have about the delivery of CR (Amieva et al., 2016; Clare et al., 2010; Clare et al., 2019; Thriverge et al., 2014). In most of the studies included in Kudkicka et al.'s (2023) review finding large positive effects of CR on goal attainment, the majority of participants were also prescribed a pharmacological medication.

Working with PwD and carers brought up some other barriers to delivering CR. Those PwD who were in the more advanced stages of moderate dementia were found to have more difficulty setting goals and less motivation to engage in CR (Chester et al., 2020; Morgan-Trimmer et al., 2021), similar findings have been reported in other studies involving goal setting with PwD (Jogie et al., 2021). Some carers were found to resist the CR intervention, viewing it as additional work. Most carers for PwD are family members and partners (Wimo et al., 2013). A high proportion of carers feel carer burden (experiencing caregiving as negative for their health) and between 10-31% of carers have been found to meet the criteria for clinically significant depression or anxiety (Collins & Kishita, 2020; Mahoney et al., 2005). Overburdened carers may naturally resist further demands. When delivering CR it is important to try to spend time thinking about how to support carer investment in the programme and reduce carer burden so as to mitigate possible resistance.

Several recommendations were made by PwD, carers, and staff about how to improve upon the CR intervention. Additional time for tasks and activities was cited in four studies

(Chester et al., 2020; Clare et al., 2023; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019). Persons with greater cognitive dysfunction may experience a greater benefit from additional time than those with less cognitive impairment (Hugo & Ganguli, 2014; Valiengo et al., 2016). Also, additional thought around the language used was mentioned by staff participants in two studies (Chester et al., 2020; Morgan-Trimmer et al., 2021), as important to facilitate engagement. Marital conflict was mentioned in the analysis that contributed to a therapist thinking they were offering a couple's intervention. Couples who experience dementia within the dyad have described this as a "time of confusion and uncertainty because of the ambiguous nature of the losses and the fuzzy boundaries between marriage and widowhood" (Evans & Lee, 2014, p. 347). Staff training in CR may benefit from incorporating skills in managing interpersonal difficulties, to ensure staff are well equipped to manage should such difficulties arise in CR work.

The studies included in this review were considered to be of high to moderate quality using the CASP checklist. They were also relatively recent studies published in or after 2020. Despite the high quality of papers, there was a dearth of information related to the researcher/participant relationship. There can be issues arising if the researcher interviewer does not appreciate their influence over the data collection process (Breen, 2007; Buddharaska, 2010; McConnell-Henry et al., 2010; McDermid et al., 2014). Pre-existing relationships with the participants can influence the quality of what is shared during an interview and participants may share less negative feedback as to try not to damage the relationship (McDermid et al., 2014). Future research would benefit from authors detailing the research interviewer and participant relationship. Despite their quality, some studies did not contribute much to the thematic synthesis. For example, Irazoki et al.'s (2021) study was focused on evaluating their assistive technology (AT) which supported CR. As a result, the feedback was rather limited to participant views of the AT.

Limitations

Despite there being enough studies included in this SR to fall within the “preferred number” range (Booth, 2016), there were some themes which were limited by the fact that they were only identified in one study. Research in this area is relatively new and further qualitative research with different methods of data collection could help further develop some of the themes generated in this review. As such, it is difficult to draw firm conclusions based on the literature available and this limits the generalisability of the findings.

When drawing conclusions from the literature one must consider that PwD can have problems with insight into several domains, including social functioning (Howorth & Saper, 2003). There are several studies demonstrating a large discrepancy between patients and proxy ratings of quality of life (Novella et al., 2001; Trigg et al., 2011). This can reduce the cohesion of findings when participants have differing capacities to reflect on an intervention and make different conclusions on it. Furthermore, older people are found to have a preference toward processing positive information, for instance, they show sustained attention and improved memory for positive events (Mather & Carstensen, 2005). Chester et al. (2020) reported that a barrier to PwD setting goals was having a reluctance to report or address areas of difficulty. Problems with insight, reluctance to discuss areas of difficulty, and preference towards processing positive information may have affected the content of the interviews.

All studies were conducted in Western countries (Britian, Denmark, and Spain). There was also likely to be a lack of ethnic diversity in the participants included in the reviewed studies as the only three studies who reported information about the ethnicity of their participants (Chester et al., 2020; Clare et al., 2023; Warmoth et al., 2022) reported between 89% to 100% of them were white. This, together with the exclusion of non-English language papers, is a key limitation. There is increasing ethnic diversity within Western countries (McAuliffe & Triandafyllidou, 2021; Mirza & Warwick, 2022), so future research should endeavour to study the perspectives of those from a greater range of ethnic minority backgrounds.

The author conducted the thematic synthesis on their own. However, this synthesis was conducted in partial completion of the Doctorate and so the author had access to academic and clinical supervision throughout. This provided an opportunity for others to review/endorse the themes derived.

Practical Implications/Recommendations

There are several recommendations that can be made based on the feedback captured within this review. The following five recommendations are made for the future delivery of CR to PwD:

1. Ensure there is sufficient time for identifying and setting goals, engaging and supporting carers, and providing socialisation opportunities for PwD.
2. Be mindful of the verbal and written language used with participants and adapt it to a participant's individual preferences and level of comprehension. For example, replacing phrases like 'compensatory strategies' with 'strategies that will help you manage your difficulties'.
3. Include a relational component to CR training to enable staff conducting CR to be able to manage interpersonal difficulties that may occur within PwD and carer dyads.
4. Pursue organisational investment in CR to support engagement and resources to support intervention.

5. Maintenance sessions could be provided in months/years after the completion of the original CR intervention which may sustain improvement, especially in the context of future cognitive decline.

Conclusions

This systematic review sheds light on the multifaceted experiences of CR for PwD, carers, and healthcare staff, highlighting both positive and negative aspects, barriers, and recommendations for improvement. The findings emphasize the importance of a personalised, flexible approach in CR, which appears to contribute significantly to the positive feedback from participants. However, the review also uncovers critical barriers, such as organisational constraints, carer burden, and challenges faced by PwD.

Overall, the studies included in this review provide valuable insights and have led to actionable recommendations to refine CR practices, ultimately aiming to improve the quality of life for PwD and their carers. By considering these findings, practitioners and researchers can work towards more effective, inclusive, and supportive CR programmes that address the unique needs and challenges of PwD.

Declaration of Conflicting Interests

The author declares no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Chapter 2

The efficacy of a cognitive rehabilitation in dementia intervention: A single case experimental design study

Prepared in accordance with the author requirements for Dementia;

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Plain Language Summary

Title

The efficacy of a cognitive rehabilitation in dementia intervention: A single case experimental design study.

Background

Cognitive rehabilitation (CR) is an approach that teaches strategies to people with cognitive problems which helps them accomplish tasks which they find challenging. It is found to be helpful for many People with Dementia (PwD) who are still able to learn new procedures for completing tasks they find difficult. NHS Education for Scotland (NES) have developed a workshop and staff resource that aims to provide health and social care staff in Scotland with the knowledge, skills, and resources to use CR with PwD in a consistent and evidence-based way. The resources developed by NES are based on the CR in dementia evidence base. However, the usefulness of this programme for Scotland's health services has not been investigated.

Aims and Questions

Using Single Case Experimental Design (SCED) methodology, the aim of this study was to investigate whether PwD could accomplish a personal goal and feel more confident managing dementia-related difficulties through participating in the NES CR programme. This study is part of a larger research project that covers both efficacy and user experience of CR for PwD. The experience of participating in the programme for staff, PwD, and their carers is explored in a parallel study.

Methods

Five PwD who were referred to Older People's Community Mental Health Teams (OPCMHTs) or the Young Onset Dementia (YOD) service in NHS Greater Glasgow and Clyde (NHSGGC) were included in the study. Three participants completed the intervention. They developed their own goal related to everyday activities. Their achievement with these goals was measured multiple times before and during a CR intervention. The researchers then investigated if they had been better at meeting their goal after they were given support from staff. Participants also completed a measure to assess their confidence in managing dementia-related difficulties during the study and their scores were compared before and after the introduction of the programme.

Ethics

Ethical approval was obtained.

Findings

The participants' goal achievement varied. Participant 1 had a moderate improvement in their goal attainment, but this may have occurred by chance rather than the intervention. Participant 2's performance improved following the CR intervention, unlikely due to chance. Participant 3 initially experienced a decline in their goal achievement, but their intervention was disrupted by a hospitalisation, and post-admission they experienced increasing success with their goal achievement. Self-efficacy changes were mixed, with Participants 1 and 3 experiencing declines, while Participant 2 showed improvement. The factors which could be associated with these findings are addressed in the paper. The study adhered to best practice recommendations but there were some limitations.

Conclusions

The study's approach, allowing personalised goal setting and inclusivity of a diverse clinical population, aligns with the flexible nature of CR. These findings suggest potential benefits of CR interventions for some people, though replication of this SCED study is needed to generate more trust in these findings and further appreciate their usefulness across different clinical settings.

Dissemination

The researcher will submit this paper for publication. The participants were also given the option of receiving a summary sheet of the findings of the study.

Abstract

Dementia is becoming increasingly common in the population as more people live longer and are diagnosed sooner. Cognitive Rehabilitation (CR) is a recommended intervention to help people with dementia (PwD) achieve their personal rehabilitation goals. There is mixed evidence that CR can also improve self-efficacy. NHS Education for Scotland (NES) has developed a training package that aims to provide health and social care staff in Scotland with the knowledge, skills, and resources to apply CR strategies for PwD in a consistent and evidence-based way. This study aimed to investigate whether staff-assisted use of NES CR resources leads to improved goal attainment and self-efficacy for PwD. A multiple-baseline across participants, single-case experimental design (SCED) was used. Participants were PwD who have been diagnosed with a mild/moderate dementia and assessed as eligible for CR. Participants also had a carer who was able to support the intervention and collect data. Five participants were recruited and randomised, three of whom completed the intervention. Goal attainment outcomes varied. There was a medium positive effect of the CR intervention on Participant 1's performance on their laundry-related goal but this was non-significant. Participant 2 experienced a statistically significant improvement in independent use of a mobile phone for texting. Participant 3 showed unexpectedly high goal attainment during the baseline phase, with some decline during the initial period of the intervention phase, subsequently returning to higher levels of goal attainment. Self-efficacy changes were mixed, with Participants 1 and 3 experiencing significant declines, while Participant 2 showed significant improvement. These findings suggest potential benefits of CR interventions for some people but should be considered along with the limitations of the paper. Replication of this SCED study is needed to verify and increase the generalisability of these results.

Keywords: Cognitive rehabilitation, dementia, goal attainment, self-efficacy, single-case experimental design

The efficacy of a cognitive rehabilitation in dementia intervention: A single case experimental design study

As people live longer and with increased awareness of dementia, more people are diagnosed with dementia at the early stages of the neurodegenerative condition (Olazarán et al., 2010). Worldwide there was an estimated 47 million people living with dementia in 2015, projected to reach 130 million in 2050 (Prince et al., 2015). There are several types of dementia, each with their own profile of cognitive changes. However, a common experience for those with the condition is the difficulty managing everyday living tasks.

Cognitive Rehabilitation (CR) is a "person-centred, goal-oriented, problem-solving therapy aimed at managing or reducing functional disability, mitigating excess disability, and maximising engagement and social participation" (Clare et al., 2019, p. 710). CR is an individualised intervention with people choosing everyday activities they would like to have greater success with, which become the specific goals of the intervention. Rehabilitation strategies are then designed to address these goals. The intervention is for those with mild-to-moderate dementia because of their retained cognitive and behavioural capacities, which enables them to benefit from strategies that draw on these capacities to compensate for severe cognitive impairment in other areas (Bahar-Fuchs et al., 2013). CR has been recommended by the National Institute for Health and Care Excellence (NICE) to support functional ability in PwD (NICE, 2018).

A recent systematic review of randomised controlled trials (RCTs) comparing CR with control conditions found high-certainty evidence of large positive effects of CR on self- and informant-ratings of goal attainment, and self-ratings of satisfaction with goal attainment at the end of treatment and at medium-term follow-up (Kudlicka et al., 2023). Qualitative feedback from CR studies has described PwD, carers, and healthcare staff profiting from gaining knowledge and skills to help them manage dementia-related difficulties (Chester et al., 2020; Clare et al., 2023; Irazoki et al., 2021; Morgan-Trimmer et al., 2021; Oksnebjerg et al., 2019; Warmoth et al., 2022). The experience of achieving goals and improving everyday function could increase feelings of self-efficacy. This may be therapeutic to people with dementia and lead to positive health outcomes and reduced carer stress (Tang & Chan, 2016). Kudlicka et al. (2023) found high-certainty evidence showing a small positive effect of CR on self-efficacy as reported by PwD.

The current study

NES has developed a workshop and staff resource that aims to provide health and social care staff in Scotland working at the Enhanced and/or Expertise practice level (as outlined within the Promoting Excellence framework; NHS Education for Scotland, 2021) with the knowledge, skills, and resources to apply CR strategies for PwD in a consistent and evidence-based way. The resources developed by NES are based on the CR in dementia evidence base. However, the clinical utility of the NES resources has not been formally investigated.

This study is part of a larger research project that covers both efficacy and user experience of CR for PwD. The aim of this study is to investigate whether staff assisted use of the CR resources leads to improved goal attainment and self-efficacy for PwD. The acceptability of the programme for staff, PwD, and their carers will be explored in a parallel study.

Method

Design

A multiple baseline across participants, Single Case Experimental Design (SCED) was applied (Harvey et al., 2004). This design eliminates the need to return to baseline, which is more suited to interventions with long-lasting effects (Krasny-Pacini & Evans, 2018) and more favourable to participants as the intervention is not removed whilst still being able to have experimental control (Byiers et al., 2012). Participants were repeatedly assessed during a baseline phase (phase A) and an intervention phase (phase B). Phase A acted as a control and was therefore compared with phase B. Baseline phase length was randomised (i.e., 3, 4, 5-weeks) using an electronic randomiser programme (http://www.randomizer.org) by a researcher not involved in recruitment. Data collection was conducted non-concurrently, which is typical of research conducted in applied clinical settings (Slocum et al., 2022).

The study was designed with reference to the Risk of Bias in N of 1 Trials (RoBiNT; Tate et al., 2016; see Appendix D) with the aim of maximising internal and external validity. Reporting follows The Single-Case Reporting Guideline In Behavioural Interventions guidelines (SCRIBE; Tate et al., 2016; see Appendix E). A study protocol was developed (Appendix F), and ethical approval was obtained from the NHSGGC West of Scotland REC 5 (23/WS/0144; Appendix G) with R&I approval from the NHSGGC (UGN23NE239, Appendix H). The SCED trial was registered with Clinicaltrials.gov (identifier: NCT06069882) prior to starting recruitment.

Participants

Staff working in NHSGGC Older People's Community Mental Health Teams (OPCMHTs) or the Young Onset Dementia (YOD) services were informed of the study and the inclusion and exclusion criteria (Table 6). These services offer input across a range of geographical areas and to people from a range of socioeconomic backgrounds. When a patient meeting eligibility criteria was identified by a team member, they introduced the study to them and provided study information (Appendix I). Their carer and staff member who could deliver the intervention were also provided with information about the study and what would be involved (Appendix J, K). If the patient and carer were interested, contact information was passed to the researcher using a ‘consent to contact’ form (Appendix L). The primary researcher then discussed the study with them and there were several days where they had the opportunity to think about the study and ask questions. If they still wished to participate, they were asked to sign their respective consent form (Appendix M, N). Following this, the staff member signed their respective consent form if in agreement with their role in the study (Appendix O).

Table 6

Inclusion/exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Person with dementia (PwD):	
• People within OPCMHTs or YOD service in NHSGGC who have been diagnosed with a mild/moderate dementia and have been assessed by members of the service as eligible for CR. • Non-professional carer who is able and willing to support the intervention. • Those who are taking dementia-specific medication need to have been receiving a stable dose for at least one month, with no expectation of change during the trial. • Those who have a comorbid mental health disorder, brain injury, or other significant neurological disorder, where dementia is still considered by the patient's clinical team to be the primary presenting difficulty. • Proficiency in the English language.	• Lack of capacity to consent. • Those with severe/advanced dementia. • Those who do not have a non-professional carer to participate in the study.
Nominated person:	
• They must live with the PwD. • They must be willing to take part in the intervention. • They must be able to provide informed consent. • Proficiency in the English language.	• Lack of capacity to consent.
Staff participant:	
• Part of the clinical team. • Have health care degree which qualifies them for their post within the clinical team. • Proficiency in the English language. • They must have access to clinical supervision to support their implementation of CR.	• They are not part of the clinical team.

Measures

An adapted version of the Goal Attainment Scaling (GAS; Turner-Stokes, 2009) was used to monitor intervention outcome. On a weekly basis goal achievement status was recorded by carers using the following GAS categories: (0) at baseline level/no change; (1) partially achieved - some progress from baseline but goal not achieved; (2) goal achieved; (3) more than expected change. In addition, (-1) referred to deterioration from baseline (see Appendix P). Goals were developed with participants and written using the SMART (Specific, Measurable, Achievable, Realistic, and Timely) format. This approach measures the attainment of goals through quantifiably defined levels of expected achievement (Malec, 1999), which makes it easier to compare success within and across participants.

The Memory Loss Self-Efficacy Scale (Kurasz et al., 2021) was developed to assess persons with mild cognitive impairment's confidence in performing activities made challenging due to known cognitive deficits (Appendix Q). The items on this scale assess self-efficacy for daily activities and managing disease in general, for example "How confident are you that you can do all the things necessary to manage your memory/cognitive difficulties on a regular basis?". Each item is scored on a 10-point scale, from 1 being "Not at all Confident" to 10 being "Totally Confident". The measure has good criterion and construct validity and internal and test-retest reliability (Kurasz et al., 2021). This scale provided some evidence as to whether participants felt confident transferring strategies learnt in relation to specific goals to other everyday activities.

Intervention

The CR intervention followed the programme outlined within the NES Cognitive Rehabilitation in Dementia resources. Staff delivering CR helped the PwD devise personal rehabilitation plans with their carers (nominated persons) to achieve a goal using evidence-based rehabilitative methods. These methods included some of the following: environmental adaptations and prompts, introduction of compensatory strategies (i.e., memory aids), procedural learning of skills, and methods for learning or relearning relevant information (Kudlicka et al., 2023). The personal rehabilitation plan was put into practice for six weeks during the intervention phase of the study. Over the six weeks there was a one hour-long session delivered by the staff member each week either in person or on the phone, depending on the participants preference. By having a carer involved in monitoring and supporting the intervention, there were opportunities for in-between session practice. Other studies have provided more or less than six sessions of CR (Kudlicka et al., 2023). The sessions involved assisting the PwD and their carer by providing clear explanations about the various intervention approaches (aforementioned CR methods) for their goal; choosing intervention options and carrying out the intervention (i.e., practicing this within and between sessions); and training the carer in supporting the intervention where appropriate. This is illustrated in the fidelity measure developed by the research team, which includes the initial developers of the NES Cognitive Rehabilitation in Dementia learning resource (Appendix R). This was provided to the person delivering the intervention and their supervisor to ensure that the NES programme was used as intended. Those delivering CR received supervision from a clinical psychologist who has had previous training and experience with CR.

Data Collection

Staff facilitated a goal setting session with PwD and their nominated person at the start of the baseline phase of the study. Goal attainment was assessed daily and self-efficacy was measured at three time points within the baseline and intervention phase (six total).

A study investigating the impact of goal development, intentionality, monitoring, and attainment has shown that frequent goal monitoring may promote behaviour change (Harkin et al., 2016). To mitigate the impact of monitoring on goal attainment, carers were asked not to do anything they did not ordinarily do with the PwD to support goal attainment before the CR intervention, and carers were asked to complete goal attainment measures rather than PwD, as administration of measures could act as prompt and potentially increase goal attainment.

Baseline cognitive functioning data was assessed using the Addenbrooke's Cognitive Examination-III (ACE-III; Hsieh et al., 2013). This is a valid and reliable cognitive screening test for the detection of dementia. Scores on the ACE-III are associated with problems with ADLs (Giebel & Challis, 2017).

Analysis

The analysis involved both a visual analysis and statistical analysis of the data.

Visual analysis allows researchers to evaluate changes in data patterns within and across conditions using several outcome measure features outlined by Kratochwill et al. (2013). The "Level" relates to the change in levels within and between phases (see Lane & Gast, 2014 for how to calculate level change); "Trend" refers to the slope of the best-fitting straight line for the measures within and between phases (see Lane & Gast, 2014, for description and interpretation of split-level trend); "Variability" corresponds to the range, variance, or standard deviation of the outcome measures about the best-fitting line, whether linear or curvilinear [a stability envelope was developed using the https://manolov.shinyapps.io/ website tool to assess variability; interquartile range (IQR) measurements were used for ordinal goal attainment data]; "Immediacy of effect" refers to the change in level between the last three data points in one phase and the first three data points of the next, and "Overlap" relates to the proportion of data from one phase that overlaps with data from the previous phase [this relates to the nonoverlap of all pairs score (NAP; Parker & Vannest, 2009) and Tau-U value (Parker et al., 2011)].

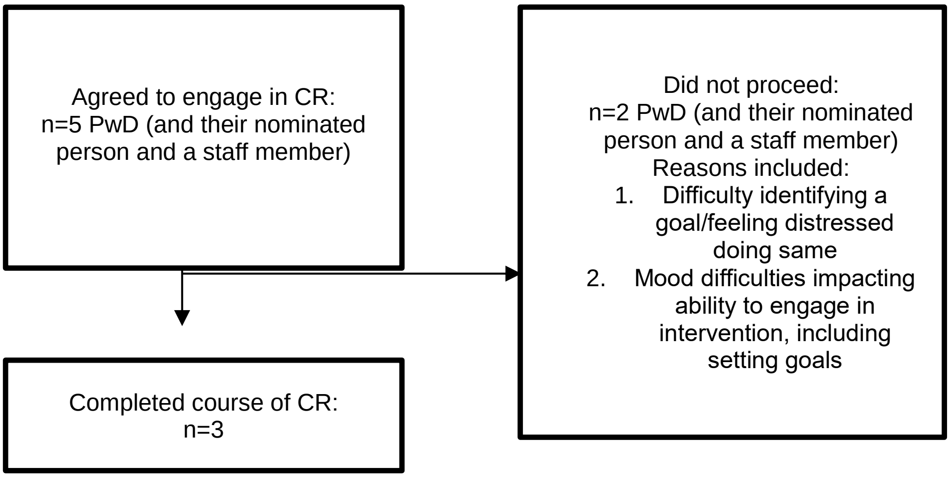
The Tau-U and NAP statistical test examines data overlap between phases to provide an overall effect size using aggregated data across phases for participants (Manalov & Tanious, 2024; Parker et al., 2011). Non-overlapping data is an indicator of performance difference between phases, it is included in standards for evaluating SCED's (Horner et al., 2005). The baseline trend was assessed after inputting the data into Tarlow's (2016) Tau Calculator (http://www.ktarlow.com/stats/tau). Parker et al. (2014) states that Tau-U reliably detects medium and large effect sizes in small sample sizes and Clare et al. (2019) reported a large effect size in a study of CR in PwD. The statistical analysis was conducted via the website: http://singlecaseresearch.org/ and https://manolov.shinyapps.io/.

Results

The flow of participants through the trial is shown in Figure 2. Recruitment took place between November 2023-April 2024. Replication of the original three participants experiment was planned due to SCED design quality appraisal tools (Tate et al., 2013), but unable to be completed.

Figure 2

Flowchart of participant engagement



Five participants were randomised to one of three baseline lengths (see Table 7 for three study schedules). Of the three that completed the study, two participants had the same baseline of three weeks, whilst the other had a baseline of five weeks.

Table 7

Schedule of assessments

		Phase A (Baseline)					Phase B (Intervention)					
Time schedule 1	GOAL 1	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**		
	Self-Efficacy	**1**	**2**	**3**	4	5	6	**7**	**8**	**9**		
Time schedule 2	GOAL 1	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	
	Self-Efficacy	1	**2**	**3**	**4**	5	6	7	**8**	**9**	**10**	
Time schedule 3	GOAL 1	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
	Self-Efficacy	1	2	**3**	**4**	**5**	6	7	8	**9**	**10**	**11**

Note. Bolded numbers denote the weeks when each of the variables were to be assessed.

Sample Characteristics

Demographic and clinical characteristics of the PwD and nominated persons are summarised in Table 8. The Scottish Index of Multiple Deprivation (SIMD) is a relative measure of deprivation (Scottish Government, 2020). The SIMD looks at the extent to which an area is deprived across seven domains: income, employment, education, health, access to services, crime, and housing. SIMD provides a 'Decile' ranking for data areas from 1-10 with 1 being the most deprived and 10 being the least deprived.

Each participant had a diagnosis of dementia. Most of the five participants were diagnosed with the Alzheimer's type, some with young/early onset (diagnosed prior to the age of 65). Alzheimer's is typically identified by a gradual and steady regression in memory and executive functions, followed by impairment in other cognitive functions (Hugo & Ganguli, 2014). The condition is also associated with mood problems like depression, apathy, irritability, and agitation. One participant had a diagnosis of vascular dementia which is characterised more often by an acute stepwise pattern of cognitive changes (Hugo & Ganguli, 2014). Cognitive decline is usually seen in the domains of complex attention and executive functions. Other common features include gait disturbance, incontinence, and personality or mood changes. As can be seen from the ACEIII scores within the table, the participant diagnosed with vascular dementia had a higher memory subscore than those diagnosed with Alzheimer's. Their fluency and attention subscore was also higher than the other participants.

A table of participants GAS scales are included in Appendix S. No adverse events occurred for any participant due to the study. There was a hospitalisation during the intervention phase for Participant 3, however this was not due to the intervention. This resulted in the extension of their intervention for 5/6 weeks due to their admission and inability to engage in the intervention.

Table 8

Demographic and clinical participant information

	PwD 1 (Participant 1)	***PwD 2 (Participant 2)***	***PwD 3 (Participant 3)***	***PwD 4 (Participant 4)***	***PwD 5 (Participant 5)***
Age range of participant*	60-64	55-59	70-74	65-69	70-74
Sex	Female	Male	Female	Male	Male
Ethnicity	White Scottish	White Scottish	White Scottish	White Scottish	White Scottish
Primary language	English	English	English	English	English
Marital status	Married	Married	Married	Married	Married
Years of education - range*	15-19	20+	15-19	15-19	15-19
Occupational status	Retired	Retired	Retired	Retired	Retired
Dementia diagnosis type	Alzheimer’s with early onset	Alzheimer’s with early onset	Vascular dementia	Alzheimer’s with early onset	Alzheimer’s
Scottish Index of Multiple Deprivation	10	9	3	7	4
Addenbrooke’s Cognitive Examination-III score	46/100	63/100	82/100	61/100	53/100
Attention Subscore	8/18	13/18	17/18	11/18	9/18
Memory Subscore	4/26	9/26	17/26	6/26	7/26
Fluency Subscore	6/14	5/14	13/14	6/14	7/14
Language Subscore	21/26	24/26	25/26	26/26	19/26
Visuospatial Subscore	7/16	12/16	10/16	12/16	12/16
Staff participants delivering the intervention	Assistant Psychologist	Trainee Clinical Psychologist	Assistant Psychologist	Trainee Clinical Psychologist	Trainee Clinical Psychologist
Time schedule	3 weeks baseline	3 weeks baseline	5 weeks baseline	5 weeks baseline	4 weeks baseline
Session number, duration, and periodicity	6 weekly sessions; approximately 1 hour	6 weekly sessions; approximately 1 hour	6 weekly sessions; approximately 1 hour	Withdrew following goal setting session	Did not proceed with goal setting session
Setting of sessions	Home visits (3 sessions) and telephone (3 sessions); no distractions	Home visits (6 sessions); some distraction from pet during some sessions	Home visits (5 sessions) and telephone (1 session); no distractions		

*****For confidentiality reasons, exact age/years of education are not provided.

Visual and Statistical Analysis Summary

Participant 1.

Goal Attainment. Participant 1's goal was to complete the laundry more independently. The CR strategy employed was a checklist to remind them of the sequence of the laundry that involved both washing and drying. A graph of their goal attainment across the days they completed the laundry is shown in Figure 3. During baseline phase (phase A) there was an accelerating therapeutic change shown using the split-middle method of estimating the trend (see Appendix T, for split-method trend graphs). However, the data were variable (less than 80% data falling within the IQR stability envelope), and a measure of the relative and absolute level change showed no change during the baseline phase. The variability of the data during the baseline phase may be due in part to the initial hesitancy expressed by the participant in engaging with the study as reported by the staff member delivering the intervention. During the intervention phase (phase B) there was a contra-therapeutic trend shown by deceleration of the upwards trend shown during the baseline phase. However, relative level improvement was demonstrated over the intervention phase. Phase B data were calculated to be stable with more than 80% of data falling within the IQR.

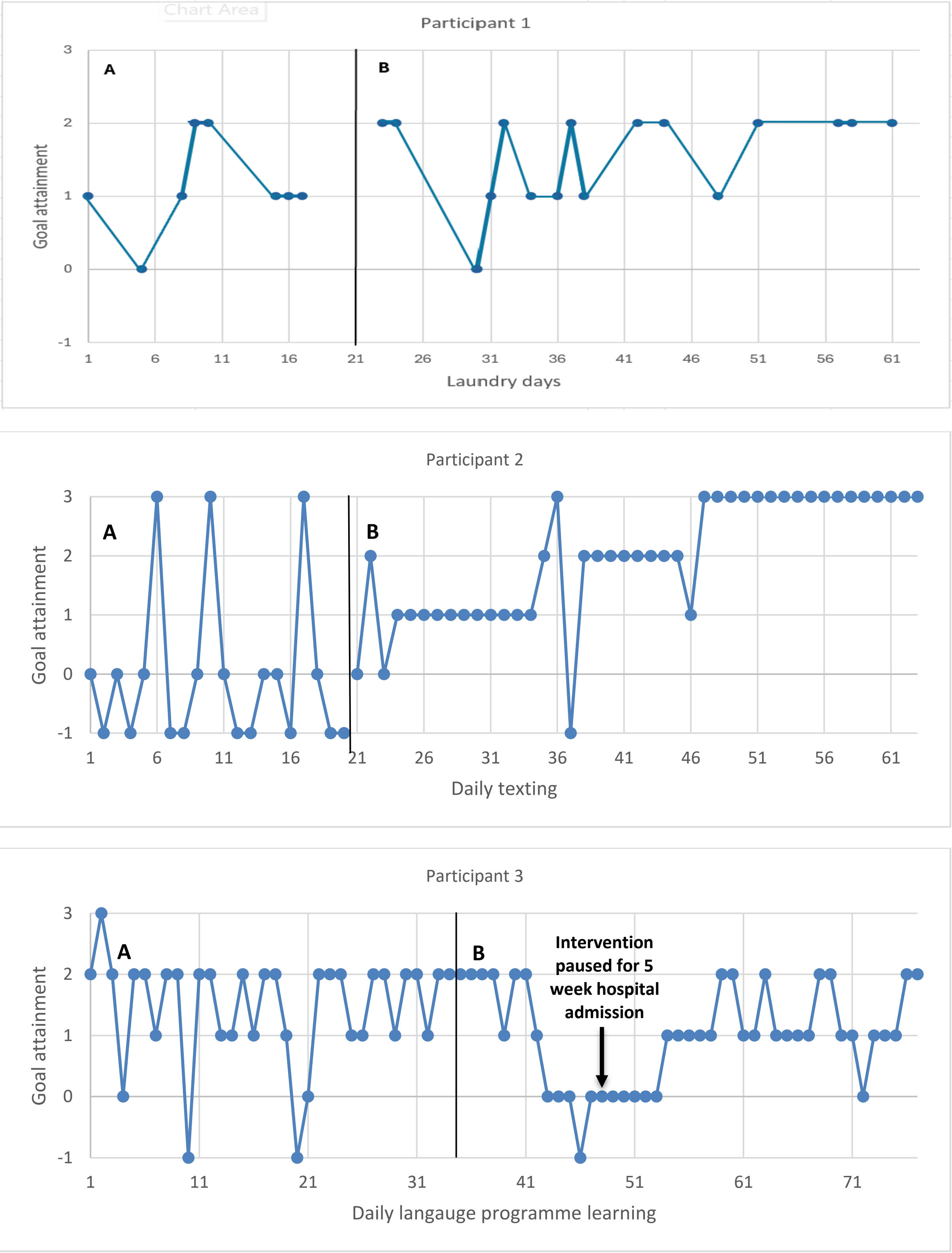
Between-phase visual analysis revealed a positive (improving) mean, median, relative and absolute level change from phase A to B. There was an immediate abrupt change shown following the introduction of the intervention. The graph shows the percent of non-overlapping data points between A and B phases was 0.71, indicating that the intervention had a medium effect (Parker & Vannest, 2009). The Tau-U analysis was used to determine performance change between phases A and B and revealed a non-significant improvement in the independent completion of the participants laundry-related goal [(Tau-U $_{\text{A vs B}}$) = .42, p = .09)].

Self-efficacy. Within-phase visual analysis showed no real change (see Figure 4 for visual summary of self-efficacy data). It can be seen from the line graph that there was no change in the trend during phase A or B (see Appendix T, for split-method trend graphs). The self-efficacy data were considered stable as 80% of data fit within 25% of the median.

Between-phase visual analysis revealed a worsening mean, median, relative and absolute change from phase A to B. Tau-U analyses revealed a significant decline in reported self-efficacy between baseline and intervention phases [(Tau-U $_{A \text{ vs } B}$) = -1, $p < .05$)].

Figure 3

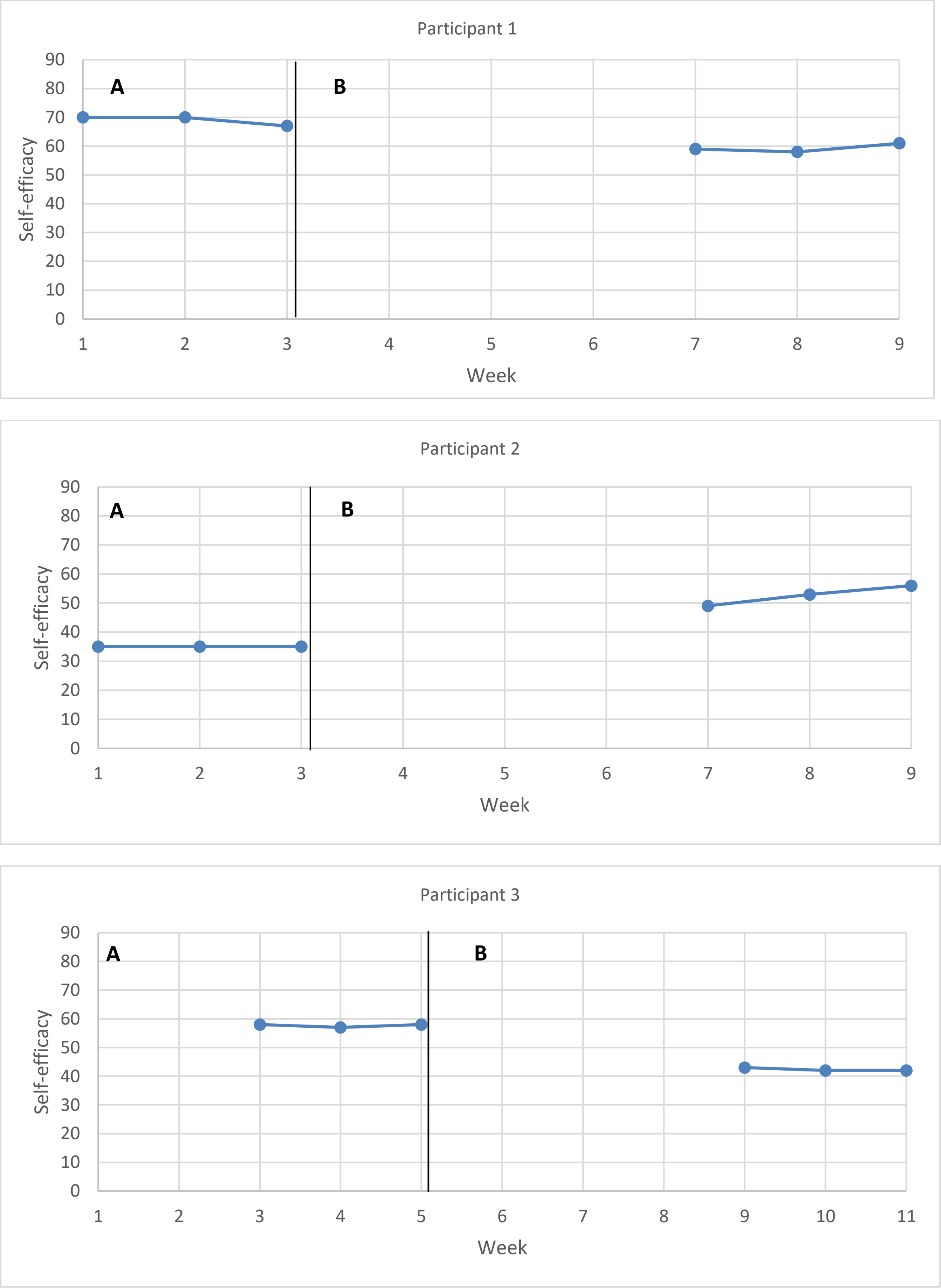
Three graphs summarising the goal attainment data from each participant



Note. Graphs are separated into phase A and B. Raw data for graphs are included in Appendix T.

Figure 4

Three graphs summarising the self-efficacy data from each participant



Note. Graphs are separated into phase A and B. Raw data for graphs are included in Appendix T.

Participant 2.

Goal attainment. Participant 2's goal was to send text messages independently. A visual summary of their data is included in Figure 3. CR techniques employed were verbal prompts from the nominated person to remind them to practice sending a message and written prompts via the production of a checklist on how to text, as well as vanishing cues to help with spelling and grammar. Within-phase analysis shows a clear oscillatory pattern demonstrated by a deteriorating relative and absolute level change and an accelerating contra-therapeutic trend during the baseline phase. This data was assessed to be stable (see Appendix T for split-middle IQR stability envelope graph). Within the intervention phase, there was an improving relative and absolute level change demonstrated and an accelerating therapeutic trend.

Between-phase analysis revealed a mean, median, relative, and absolute level change indicating an improving change from phase A to B. There was an abrupt change seen following the introduction of the intervention. The percent of non-overlapping data between A and B phases was 0.86, indicating that the intervention had a medium effect (Parker & Vannest, 2009). Tau-U analyses revealed a significant improvement in reported goal-attainment related to developing independence with text messaging between baseline and intervention phases [(Tau-U $_{\text{A vs B}}$) = .72, p < .05)].

Self-efficacy. The visual summary of the self-efficacy data for Participant 2 is included in Figure 4. Within-phase analysis showed no relative or absolute level change during phase A but a slight accelerating therapeutic trend. This therapeutic trend became more accelerated in phase B and there was a positive relative and absolute level change during this phase (see Appendix T for visual trend). The data was assessed to be stable.

Between-phase analysis revealed an improving mean, median, relative, and absolute change from phase A to B. Tau-U analyses revealed a significant improvement in reported self-efficacy between baseline and intervention phases [(Tau-U $_{\text{A vs B}}$) = 1, $p < .05$)].

Participant 3.

Goal attainment. Participant 3's goal was to learn to use a language programme to facilitate/assist communication with a relative (Figure 3 for visual summary of data). CR techniques employed were spaced retrieval and errorless learning. The within-phase analysis revealed no relative or absolute level change during the baseline phase and a zero-celerating trend (see Appendix T for visual trend data). This trend was calculated to be stable. In phase B there was an improvement demonstrated by a positive relative level change and an accelerating therapeutic trend. After approximately two weeks of the intervention this participant was admitted to hospital. The intervention was paused whilst they were in hospital for five weeks. Several days before the admission there was no change in goal attainment. Furthermore, after a period of three days to recover post admission the intervention was restarted and there was a period of no change recorded in goal attainment. The trend data were calculated to be stable.

Between-phase analysis demonstrated a worsening mean, median, and relative level change from phase A to B, despite an improvement within phase B. There was a delayed change following the introduction of the intervention. The percent of non-overlapping data between A and B phases was 0.32, indicating that the intervention had a weak effect (Parker & Vannest, 2009). Tau-U analyses revealed a significant decline in reported goal-attainment related to learning signs between baseline and intervention phases [(Tau-U $_{\text{A vs B}}$) = -.36, $p < .05$)]. There was some missing data (three daily measurements during the baseline phase). The data was considered 'missing at random' and was replaced using the minimum-maximum method (Peng & Chen, 2021). This is a conservative estimate method and can be used in conjunction with a visual analysis.

Self-efficacy. The visual summary of the self-efficacy data for Participant 2 is included in Figure 4. Within-phase analysis showed no relative or absolute level change in phase A and a zero-celerating trend. In phase B, there was a worsening relative and absolute level change and slight accelerating contra-therapeutic trend (see Appendix T for visual trend data). The data were stable.

Between-phase analysis revealed a worsening mean, median, relative, and absolute level change from phase A to B. Tau-U analyses revealed a significant decline in reported self-efficacy between baseline and intervention phases [(Tau-U $_{\text{A vs B}}$) = -1, p < .05)].

Discussion

This study aimed to investigate whether a CR intervention could support those with mild-to-moderate dementia to achieve their personal goals, and whether participants would feel more self-efficacious with regard their general confidence in completing tasks made more challenging by their memory/cognitive difficulties.

Goal attainment

The SCED design is particularly adept at assessing the outcomes of a personalised intervention based on a person's characteristics, personal, and environmental factors (World Health Organisation, 2007). The design provided the scope for assessing a heterogeneous sample with varied goals, levels of cognitive function, and CR approaches to support goal attainment (Krasney-Pacini & Evans, 2018). Goal attainment data was highly variable and aggregating these findings and assessing their generalisability would be less meaningful than interpreting the participants data individually.

There was a medium positive effect of the CR intervention on Participant 1's performance on their goal, but it was revealed by a Tau-U calculation to be non-significant. This finding could be due to several factors. Firstly, this could be related to the hesitancy that this participant had in taking part in CR which was reported by the staff member delivering the intervention. Literature shows that taking part in an intervention could place further pressure on a person who is already finding it difficult managing a condition (Grindley, 2008) and can make them confront their limitations (Kudlicka et al., 2023). They were not the only participant to be reluctant taking part in this intervention with one other participant dropping out after becoming stressed coming up with a rehabilitation goal. Also, another participant dropped out due to mood problems that also influenced their capacity to set a goal. This highlights the importance of seeking continued consent for the intervention to take place and considering the wellbeing of people involved in rehabilitation programmes. A second factor implicated in the between-phase analysis is the high baseline scores. A score of one and two on their GAS measure indicated an improvement beyond the initial assessment of performance in relation to the completion of laundry with different amounts of prompting. Therefore, the PwD attempted to do the laundry without the CR strategies and was documented to have some success. A crucial component but also a limitation of this study's design is the development of a goal prior to a baseline phase which can lead to pursuit of that goal prior to the introduction of the intervention. A third factor which may be implicated in the non-significant finding is that this participant had the lowest ACE-III score which implies a lower level of cognitive functioning compared to the other participants. Those with greater cognitive dysfunction are observed to find CR more difficult (Chester et al., 2020; Morgan-Trimmer et al., 2021). A fourth factor to consider is that there were less opportunities for practicing CR strategies compared to other participants due to their goal being related to a task which only took place an average of 2/3 days a week, rather than daily. This patient has a diagnosis of Alzheimer's disease which is associated with more difficulty with memory and learning than other dementias, especially in the initial stages of the condition (Hugh & Ganguli, 2014). Having comparable opportunities to the other participants to practice strategies could have increased their performance.

The introduction of the CR intervention led to a statistically significant medium positive effect on Participant 2's attainment of their goal related to independent texting. From observing the visual data there is a clear accelerating therapeutic trend during the intervention phase of the study. This finding should be considered in the context of the unexpected baseline GAS pattern. The baseline data shows sudden increases from scores of zero or minus one on most days to three (which denotes the sending of a text independently) on three occasions. It is not clear what accounts for the scores of three whilst on the vast majority of baseline days this did not happen. What is clear though is that during the intervention phases there was a marked increase in ability to send text messages independently.

Overlap analysis revealed a significant decline in Participant 3's goal attainment between the baseline and intervention phase. However, this between-phase finding is less meaningful due to a hospitalisation which occurred early in the intervention phase, which prevented the learning of the language programme. This was indicated by a score of zero on the participants GAS recorded around the days of the hospitalisation which indicates that the PwD did not spend at least 30 minutes attempting to learn the language programme. Arguably more meaningful data to interpret the outcome of the intervention is the visual analysis which shows a zero-celerating trend during the baseline and then a therapeutic accelerating trend during the intervention phase. However, this intervention trend was delayed which was likely due to the five-week hospital admission. This trend may be due to a recovery of functionality following the hospitalisation rather than the intervention itself due to the lack of consistent higher GAS scores. A maturation effect is discussed as a threat to the internal validity of SCED designs (Slocum et al., 2022), perhaps another threat to internal validity is the progressive decline associated with dementia. This participant had a vascular dementia diagnosis, therefore, they may have more sudden significant deteriorations in their cognition which may require further adaptation of the CR strategies. Another possible outcome could be that their insight into their daily functioning may become impaired, which may cause them to change their goal entirely. Follow-up sessions of CR may have been beneficial to help carers and PwD adapt to their condition. After the hospital admission, the PwD, nominated person, and staff member were willing to continue the intervention. Similarly to Participant 1, this participant had high baseline scores. A score of one and two on their GAS measure indicated the intentional learning of language programme components and the remembering of them, respectively. Therefore, the PwD attempted to learn components without the CR strategies and was documented to have some success. This again highlights the therapeutic effect of simply setting a goal, even before specific CR interventions were introduced.

Self-efficacy

The self-efficacy data of each individual participant were stable and significant but there were differences between participants. Participants 1 and 3 experienced a significant decline in self-efficacy ratings following the introduction of the intervention. Whereas Participant 2 had a significant improvement in their self-efficacy ratings between the phases. There are several potential causes for these conflicting findings. Firstly, Participant 1 and 3's self-efficacy ratings were higher than Participant 2's rating during the baseline. The intervention may have been quite revealing of their limitations which could have caused the decline in their subjective views of their efficaciousness (Kudlicka et al., 2023). Secondly, Participant 2 had superior goal attainment compared to the other participants which may have further increased their overall confidence. In addition, they were recorded to have better than expected goal attainment for the last two weeks of the intervention which may have provided them an opportunity to practice CR strategies with other goals in that time.

The measure used to assess self-efficacy was adapted for those with mild cognitive impairment and includes items more specific to managing memory/cognitive problems. This may have contributed to the more significant findings compared to a previous study that included a more generalised measure (i.e., General Self-Efficacy Scale; Schwarzer & Jerusalem, 1995) which found non-significant differences between their pre-intervention assessment and three and nine-month follow-up (Clare et al., 2019). A potential limitation of this measure is the length of the items, which may have been difficult for those with cognitive impairment to comprehend. However, the carer would have been able to help scaffold this for the PwD. Furthermore, the measure had good psychometric properties for administration with those with mild cognitive impairment.

Strengths and Limitations

This study was informed by the RoBiNT rating scale (Tate et al., 2013) and SCRIBE checklist (Tate et al., 2016), which provide guidance for the development and reporting of high-quality SCED studies. This study fulfilled many of the items featured in the RoBiNT scale (see Appendix D for checklist and scores) and SCRIBE checklist (see Appendix E for checklist and where information is included in this study).

There were several limitations of this study. The RoBiNT rating scale (Tate et al., 2013; see Appendix D) details elements of the SCED design that were not incorporated. Although staff and their clinical supervisors were provided a fidelity checklist (see Appendix R) to use at least once during the intervention these checklists were not collected, which meant that for treatment adherence the study scored a 0. It was not possible to blind participants and therapists to the phases of the intervention. There was an unsuccessful attempt made to replicate the intervention for three more participants. It was not feasible to obtain a measure of inter-rater reliability of the goal attainment outcome. Despite participants being randomised to the three study schedules when included in the study there was some drop out of participants which caused two participants to follow the same schedule. This reduced the internal validity of the study as a staggered start of the intervention was to help control for extraneous environmental variables and maturation which may influence the data (Slocum et al., 2022).

There was control over the amount of CR sessions provided to the participants but there was less control over the amount of in-between session practice that could occur between the nominated person and participant. Amiva et al. (2017) queried whether the benefits of their CR intervention were due to the content of CR or that this intervention had much greater one-to-one intervention than group interventions. Between session practicing of CR strategies could be recorded in future studies.

There was a small amount of data (three time points) missing from Participant 3's goal attainment data. Missing data met the criteria for minimum-maximum method (Peng & Chen, 2021). This is a conservative estimate method and can be used in conjunction with a visual analysis. Therefore, the impact of this missing data was mitigated.

Applicability

This study adopted a pragmatic, realistic approach given that the inclusion criteria were broad, and the participants were recruited from a clinical service. The intervention was delivered by clinical staff within the NHS based on the training and resources developed by NES (NHS Education for Scotland, 2021). Participants were also provided the freedom to decide what goal they wanted to focus on which fits with the flexibility of the CR approach and the variety of meaningful goals which those with dementia have reported in other studies (Huizenga et al., 2023; Ripley et al., 2024).

As only three participants were included in this study, this limits the generalisability of the findings. However, there is an argument that even Randomised Control Trials (RCTs) with a larger sample size have generalisability issues due to their typically restrictive inclusion criteria that make them difficult to replicate in clinical practice (Romeiser-Logan et al., 2017). Within SCEDs, generalisability is improved based on the heterogeneity of the participants within a study, the richness of the demographic and clinical information provided, and replication of SCED papers

(Krasny-Pacini & Evans, 2018; Kratochwill et al, 2010). Future research could try to replicate this study.

Conclusions

This study examined the effectiveness of a CR intervention in helping individuals with mild-to-moderate dementia achieve personal goals and enhance self-efficacy. The study tailored interventions to participants' unique characteristics and cognitive functions. Goal attainment varied significantly: Participant 1 showed a medium positive but non-significant effect, potentially influenced by hesitancy, lower cognitive function, and limited practice opportunities. Participant 2 experienced a statistically significant improvement in independent texting, though baseline data anomalies which reduce the confidence in the data. Participant 3's significant decline in goal attainment was disrupted by hospitalisation, but post-hospitalisation data indicated a delayed therapeutic trend. Self-efficacy changes were mixed, with Participants 1 and 3 experiencing declines, while Participant 2 showed improvement.

Methodologically, the study adhered to the RoBiNT rating scale and SCRIBE checklist. Despite limitations, the study's pragmatic approach, allowing personalised goal setting and incorporating an inclusive eligibility criteria, aligns with the flexible nature of CR. These findings suggest potential benefits of CR interventions, though replication of this SCED study is needed to validate and increase the generalisability of these results.

Declaration of Conflicting Interests

The author declares no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Appendices

Appendix A

PRISMA 2020 checklist

Section and Topic	Item #	Checklist item	Location where item is reported (Page number)
TITLE			
Title	1	Identify the report as a systematic review.	Pg 12
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pg 13
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pg 15/16
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pg 16
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pg 18
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.	Pg 19
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Pg 19/87
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.	Pg 19

Section and Topic	Item #	Checklist item	Location where item is reported (Page number)
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.	Pg 19
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.	Pg 21
	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.	Pg 21
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.	Pg 21/22/23
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.	N/A
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)).	Pg 19
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Pg 21/23/24
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Pg 21/24/25
	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.	Pg 23/24
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A

Section and Topic	Item #	Checklist item	Location where item is reported (Page number)
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
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.	Pg 20
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Pg 20
Study characteristics	17	Cite each included study and present its characteristics.	Pg 91
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pg 23
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.	Pg 91
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pg 91
	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 measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Pg 24-30
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pg 30-35

Section and Topic	**Item #**	**Checklist item**	**Location where item is reported (Page number)**
	23b	Discuss any limitations of the evidence included in the review.	Pg 35/36
	23c	Discuss any limitations of the review processes used.	Pg 35/36
	23d	Discuss implications of the results for practice, policy, and future research.	Pg 35/36
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.	Pg 17
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pg 17
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Pg 37
Competing interests	26	Declare any competing interests of review authors.	Pg 37
Availability of data, code and other materials	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.	Pg 87

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix B

Search strategies for each database

APA PsycInfo <1806 to July Week 3 2024>

1 (dementia or Alzheimer*).ti,ab. 120956

2 exp Dementia/ 96838

3 ((memory or cognit*) adj3 (rehab* or management or group* or intervention or treatment or remediat* or therap*)).ti,ab. 65337

4 (experience* or perception* or opinion* or satisfaction or perspective* or view or feedback or interview* or qualitative or mixed method*).ti,ab. 1841293

5 cognitive rehabilitation/ or neuropsychological rehabilitation/ or neurorehabilitation/ or occupational therapy/ or psychosocial rehabilitation/ or rehabilitation centers/ or telerehabilitation/ 19064

6 1 or 2 124949

7 3 or 5 81743

8 4 and 6 and 7 820

9 limit 8 to english language 763

Embase <1974 to 2024 July 22>

1 (dementia or Alzheimer*).ti,ab. 397850

2 exp Dementia/ 472363

3 ((memory or cognit*) adj3 (rehab* or management or group* or intervention or treatment or remediat* or therap*)).ti,ab. 87254

4 (experience* or perception* or opinion* or satisfaction or perspective* or view or feedback or interview or qualitative or mixed method*).ti,ab. 4110960

5 exp rehabilitation/ 515048

6 1 or 2 542487

7 3 or 5 591050

8 4 and 6 and 7 3850

9 limit 8 to english language 3707

Ovid MEDLINE(R) ALL <1946 to July 22, 2024>

1 (dementia or Alzheimer*).ti,ab. 290047

2 exp Dementia/ 217607

3 exp Cognitive Dysfunction/ 41949

4 1 or 2 or 3 356003

5 ((memory or cognit*) adj3 (rehab* or management or group* or intervention or treatment or remediat* or therap*)).ti,ab. 61044

6 exp rehabilitation/ or "activities of daily living"/ or cognitive training/ 365723

7 5 or 6 422269

8 (experience* or perception* or opinion* or satisfaction or perspective* or view or feedback or interview or qualitative or mixed-method*).ti,ab. 3139308

9 4 and 7 and 8 3471

10 limit 9 to english language 3265

Appendix C

Participant characteristics and study design information from included studies

Study Title	Authors & year of publication	Geographical location	Setting - Environment / context.	Phenomena of interest / research question/s	Research study design / Qualitative approach, methodology	Data collection and analysis methods
The Dementia Early Stage Cognitive Aids New Trial (DESCANT) intervention: A goal attainment scaling approach to promote self-management.	Chester,H. Clarkson,P. Davies,L. Hughes,J. Islam,M S. Kapur,N. Orrell,M. Peconi,J. Pitts,R. Poland,F. Russell,I. Challis,D. 2020	United Kingdom	Home visits	This study explored the reflections of Dementia Support Practitioners (DSPs) facilitating the cognitive rehabilitation intervention.	Mixed methods	Five semi-structured interviews were completed with data analysed thematically.
Implementing a home-based personalised cognitive rehabilitation	Clare,L. Kudlicka,A. Collins,R. Evans,S. Pool,J.	United Kingdom	Home visits	The aim of this translational study, building on evidence from the GREAT randomised controlled trial, was to develop a foundation for implementing	Mixed methods	Responses to open-ended survey questions were categorised using content analysis.

intervention for people with mild-to-moderate dementia: GREAT into Practice.	Henderson,C. Knapp,M. Litherland,R. Oyebode,J. Woods,R. 2023			the GREAT Cognitive Rehabilitation intervention in community-based services for people with mild-to-moderate dementia.		Framework analysis was used to analyse information from qualitative interviews.
Implementation processes in a cognitive rehabilitation intervention for people with dementia: A complexity-informed qualitative analysis.	Morgan-Trimmer,S. Kudlicka,A. Warmoth,K. Leroi,I. Oyebode,J. R. Pool,J. Woods,R. Clare,L. 2021	United Kingdom	Home visits	This study examines the implementation of the GREAT intervention, where the intervention is conceptualised as a complex intervention designed to incorporate a degree of self-organisation through its person-centred design and requirement to be responsive to the contexts, needs and preferences of people with dementia.	A process evaluation examined experiences of GREAT therapists and participants receiving the intervention, through thematic analysis of a focus group with therapists and interviews with participants	Six therapists took part in a focus group, interviews were conducted with 25 participants and 26 carers, and therapy logs for 50 participants were analysed.

					and their carers.	
Self-management and cognitive rehabilitation in early stage dementia - merging methods to promote coping and adoption of assistive technology. A pilot study.	Oksnebjerg,L. Woods,B. Vilsen,C. R. Ruth,K. Gustafsson,M. Ringkobing,S. P. Waldemar,G. 2019	Denmark	Memory clinic	The aim of the current pilot study was to examine the feasibility and applicability of a group-based goal-oriented rehabilitation programme for people with early stage Alzheimer's disease, and to explore if such a programme can be a suitable and effective way to deploy and adopt AT. In addition, the study also aimed to explore outcome measures that capture the aims of the intervention, to inform planning of future large-scale studies.	The study design is based on the principles of the Medical Research Council (MRC) framework for the development and evaluation of complex interventions.	The qualitative data from the interviews was inductively processed and summarised in emerging themes and subthemes, according to the principles of the Constant Comparison Analysis.
A qualitative study of the cognitive rehabilitation program GRADIOR for people with	Irazoki, E. Sánchez-Gómez, M.C. Contreras-Somoza, L.M. Toribio-Guzmán, J.M.	Spain	Memory clinic	The study aimed to evaluate the new version of GRADIOR (v4.5) based on the experience of people with mild cognitive impairment (MCI), people with dementia (PWD), and healthcare staff.	A qualitative study using the focus group methodology.	Semi-structured and open-ended questions used during focus group discussions. Content analysis.

cognitive impairment: Outcomes of the focus group methodology.	Martín-Cilleros, M.V. Verdugo-Castro, S. Jenaro-Río, C. Franco-Martín, M.A. 2021					
Reflections on a personalized cognitive rehabilitation intervention: Experiences of people living with dementia and their carers participating in the GREAT trial.	Warmoth,K. Morgan-Trimmer,S. Kudlicka,A. Toms,G. James,I. A. Woods,B. 2022	United Kingdom	Community based services	The researchers examined what participants reported were the crucial aspects of the individualised intervention and whether the participants experienced any changes as a result.	Qualitative interview study.	Semi-structured interviews with PwD and their carers. Thematic analysis.

Appendix D

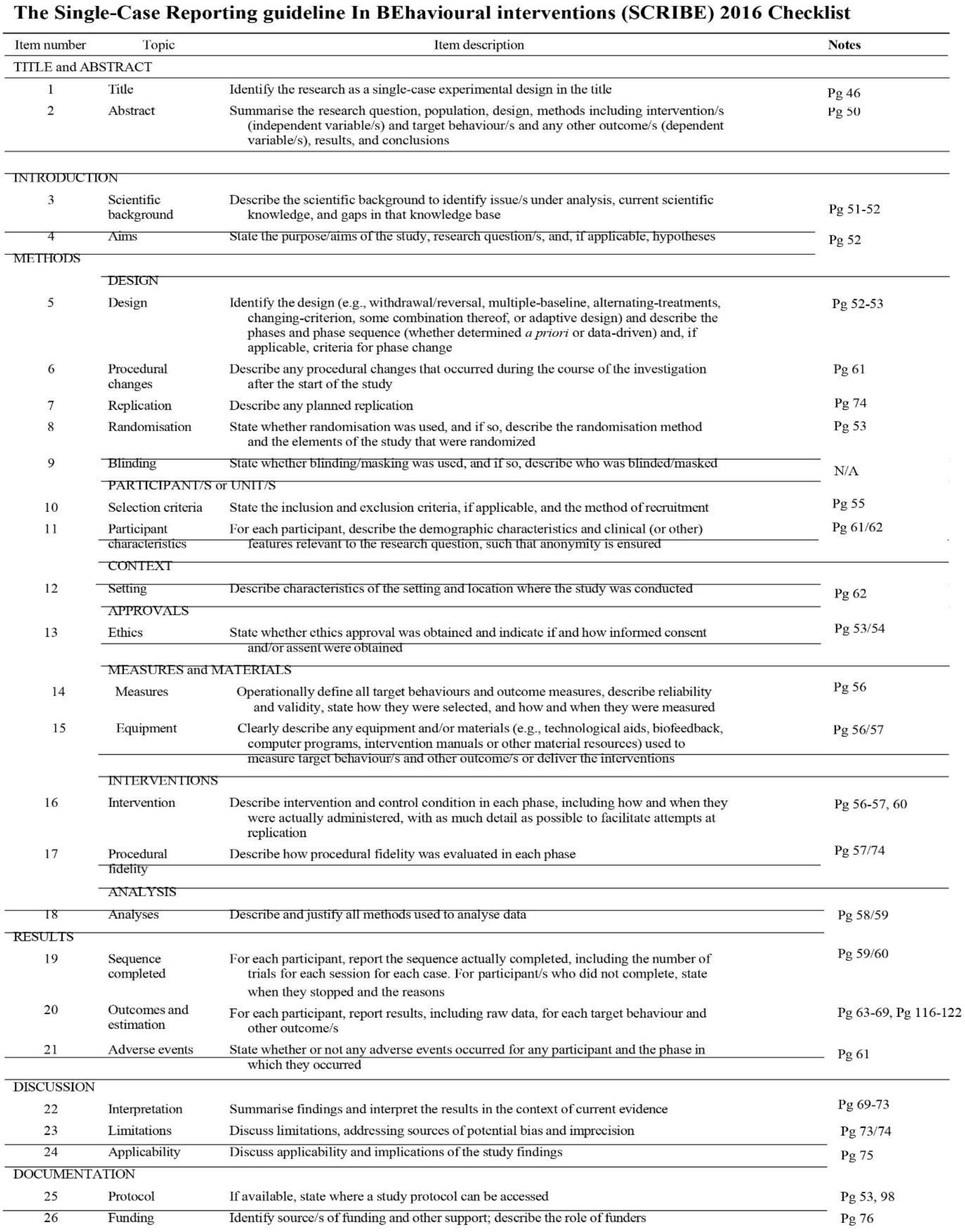
RoBiNT rating scale

Item	Score
1. Design: Score 2 for three demonstrations of treatment effect (e.g. 6-phase multiple-baseline).	**2**
2. Randomisation: Score 2 for randomisation of either sequence and/or onset of all phases.	**2**
3. Sampling of behaviour: Score 2 for 5 data points in every phase. Score 1 for 3/4 data points in every phase.	**1**
4. Blinding patient / therapist: Score 2 for blinding of participants and therapists to phase of intervention.	**0**
5. Blinding of assessor: Score 2 for assessor who is blind to the phase of the intervention. Score 1 for assessor who is independent of the therapist.	**1**
6. Inter-rater reliability: Score 2 or 1 depending on the degree to which there was agreement between measures and the quality of these measures.	**0**
7. Treatment adherence: Score 2 when four criteria are met for treatment adherence (see Tate et al., 2013 for criteria).	**0**
8. Baseline characteristics: Score 2 for baseline conditions and characteristics which serve to maintain behaviour are assessed before intervention and considered in report. Score 1 for evaluation that goes beyond provision of demographic, medical, and functional status variables, or clinical profile of test scores.	**2**
9. Therapeutic setting: Score 2 for information provided about the specific environment the intervention took place.	**2**

10. Target behaviour: Operational definition of target behaviour (Score 1), precise and repeatable measure of behaviour, and specification of what constitutes a correct/incorrect response. Score 2 for all three elements.	**2**
11. Intervention: Score 2 when intervention is described in detail, including number, duration, and periodicity of sessions.	**2**
12. Raw data record: Complete raw data provided versus incomplete data (Score 2 and 1 respectively).	**2**
13. Data analysis: Score 2 for systematic visual analysis. Score 1 for incomplete systematic/aided visual analysis or no rational provided for statistical analysis.	**2**
14. Replication: Score 2 for a full replication of the experiment (i.e., original + 3 replications). Score 1 for one or two replications (i.e., original + 1 or 2 replications).	**0**
15. Generalisation: Score 2 for generalisation measure evaluated throughout all phases of the experiment. Score 1 for evaluating generalisation prior to and at the conclusion of treatment.	**2**
Total score:	**20/30**

Appendix E

SCRIBE checklist



The Single-Case Reporting guideline In BEhavioural interventions (SCRIBE) 2016 Checklist

Item number	Topic	Item description	**Notes**
TITLE and ABSTRACT			
1	Title	Identify the research as a single-case experimental design in the title	Pg 46
2	Abstract	Summarise the research question, population, design, methods including intervention/s (independent variable/s) and target behaviour/s and any other outcome/s (dependent variable/s), results, and conclusions	Pg 50
INTRODUCTION			
3	Scientific background	Describe the scientific background to identify issue/s under analysis, current scientific knowledge, and gaps in that knowledge base	Pg 51-52
4	Aims	State the purpose/aims of the study, research question/s, and, if applicable, hypotheses	Pg 52
METHODS			
	DESIGN		
5	Design	Identify the design (e.g., withdrawal/reversal, multiple-baseline, alternating-treatments, changing-criterion, some combination thereof, or adaptive design) and describe the phases and phase sequence (whether determined *a priori* or data-driven) and, if applicable, criteria for phase change	Pg 52-53
6	Procedural changes	Describe any procedural changes that occurred during the course of the investigation after the start of the study	Pg 61
7	Replication	Describe any planned replication	Pg 74
8	Randomisation	State whether randomisation was used, and if so, describe the randomisation method and the elements of the study that were randomized	Pg 53
9	Blinding	State whether blinding/masking was used, and if so, describe who was blinded/masked	N/A
	PARTICIPANT/S or UNIT/S		
10	Selection criteria	State the inclusion and exclusion criteria, if applicable, and the method of recruitment	Pg 55
11	Participant characteristics	For each participant, describe the demographic characteristics and clinical (or other) features relevant to the research question, such that anonymity is ensured	Pg 61/62
	CONTEXT		
12	Setting	Describe characteristics of the setting and location where the study was conducted	Pg 62
	APPROVALS		
13	Ethics	State whether ethics approval was obtained and indicate if and how informed consent and/or assent were obtained	Pg 53/54
	MEASURES and MATERIALS		
14	Measures	Operationally define all target behaviours and outcome measures, describe reliability and validity, state how they were selected, and how and when they were measured	Pg 56
15	Equipment	Clearly describe any equipment and/or materials (e.g., technological aids, biofeedback, computer programs, intervention manuals or other material resources) used to measure target behaviour/s and other outcome/s or deliver the interventions	Pg 56/57
	INTERVENTIONS		
16	Intervention	Describe intervention and control condition in each phase, including how and when they were actually administered, with as much detail as possible to facilitate attempts at replication	Pg 56-57, 60
17	Procedural fidelity	Describe how procedural fidelity was evaluated in each phase	Pg 57/74
	ANALYSIS		
18	Analyses	Describe and justify all methods used to analyse data	Pg 58/59
RESULTS			
19	Sequence completed	For each participant, report the sequence actually completed, including the number of trials for each session for each case. For participant/s who did not complete, state when they stopped and the reasons	Pg 59/60
20	Outcomes and estimation	For each participant, report results, including raw data, for each target behaviour and other outcome/s	Pg 63-69, Pg 116-122
21	Adverse events	State whether or not any adverse events occurred for any participant and the phase in which they occurred	Pg 61
DISCUSSION			
22	Interpretation	Summarise findings and interpret the results in the context of current evidence	Pg 69-73
23	Limitations	Discuss limitations, addressing sources of potential bias and imprecision	Pg 73/74
24	Applicability	Discuss applicability and implications of the study findings	Pg 75
DOCUMENTATION			
25	Protocol	If available, state where a study protocol can be accessed	Pg 53, 98
26	Funding	Identify source/s of funding and other support; describe the role of funders	Pg 76

Appendix F

Study protocol

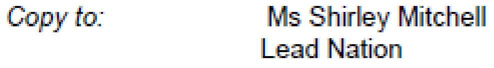
Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix G

Ethics Approval Letter

the letter, pages 99-102 has been removed due to confidentiality issues.



Copy to: Ms Shirley Mitchell
Lead Nation

Appendix H

R&I Management Approval Letter

The approval letter, pages 103-104 has been removed due to confidentiality issues.

Appendix I

PwD Information Sheet

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix J

Nominated Person Information Sheet

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix K

Staff Participant Information Sheet

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix L

Consent to Contact Form

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix M

PwD Consent Form

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix N

Nominated Person Consent Form

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix O

Staff Participant Consent Form

Available via Open Science Framework:

https://osf.io/7fyk3/?view_only=43e6f9c6eac04b96b0415ed38d5544e0

Appendix P

Goal Attainment Form

IRAS ID: 326759 Version: 2 Date: 04/08/2023

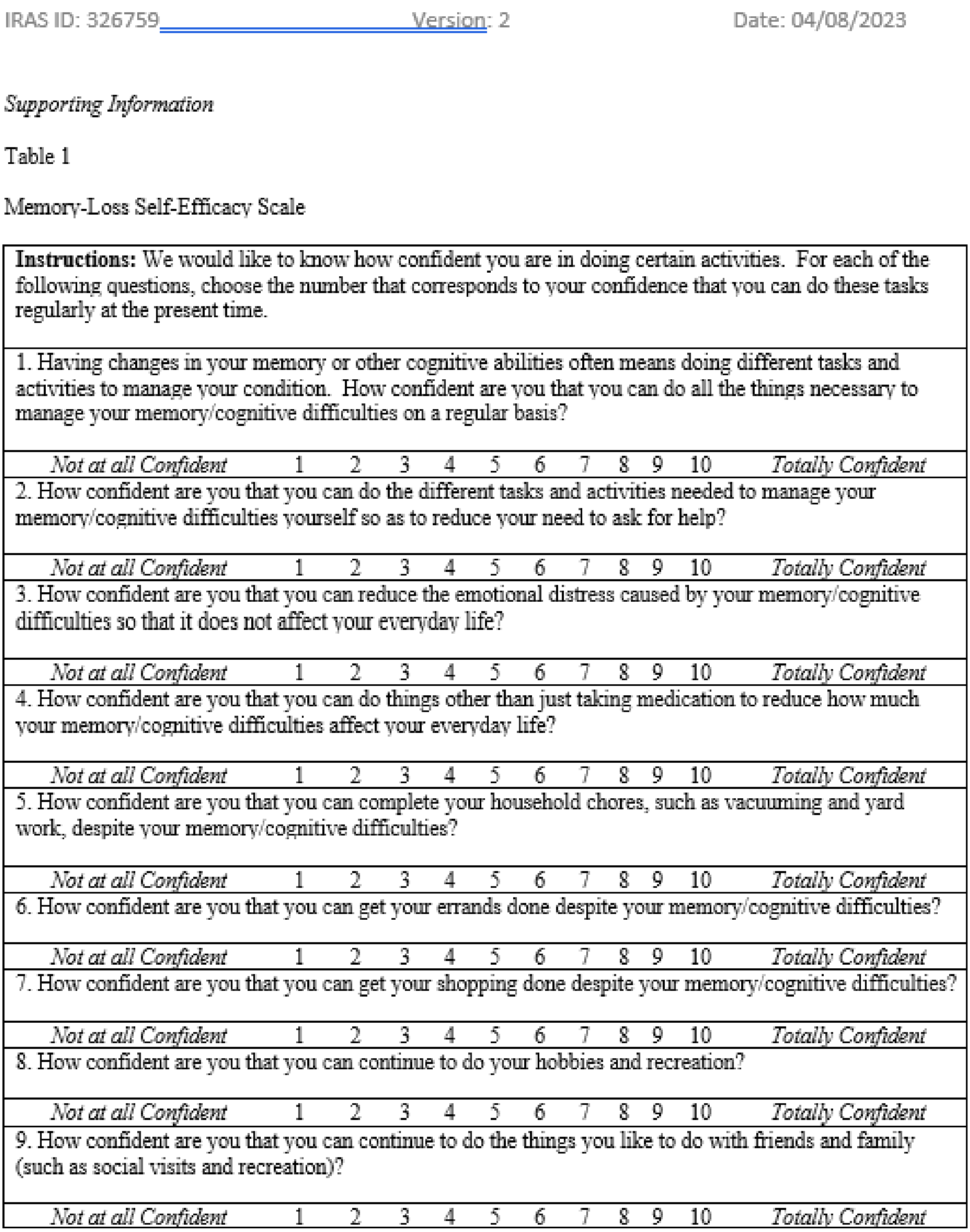
Goal Attainment Form

Please circle the number which corresponds most with the person with dementia's daily level of progress. Thank you.

Level of expected outcome	Rating	Behavioural Statement of expected outcome
More than expected change	+3	
Goal achieved	+2	
Partially achieved – some progress from baseline but goal not achieved	+1	
At baseline level/no change	0	
Deterioration from baseline	-1	

Appendix Q

Memory-Loss Self-Efficacy Scale



IRAS ID: 326759 Version: 2 Date: 04/08/2023

Supporting Information

Table 1

Memory-Loss Self-Efficacy Scale

Instructions: We would like to know how confident you are in doing certain activities. For each of the following questions, choose the number that corresponds to your confidence that you can do these tasks regularly at the present time.											
1. Having changes in your memory or other cognitive abilities often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your memory/cognitive difficulties on a regular basis?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
2. How confident are you that you can do the different tasks and activities needed to manage your memory/cognitive difficulties yourself so as to reduce your need to ask for help?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
3. How confident are you that you can reduce the emotional distress caused by your memory/cognitive difficulties so that it does not affect your everyday life?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
4. How confident are you that you can do things other than just taking medication to reduce how much your memory/cognitive difficulties affect your everyday life?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
5. How confident are you that you can complete your household chores, such as vacuuming and yard work, despite your memory/cognitive difficulties?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
6. How confident are you that you can get your errands done despite your memory/cognitive difficulties?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
7. How confident are you that you can get your shopping done despite your memory/cognitive difficulties?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
8. How confident are you that you can continue to do your hobbies and recreation?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*
9. How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?											
Not at all Confident	1	2	3	4	5	6	7	8	9	10	*Totally Confident*

Appendix R

Fidelity Checklist

Cognitive Rehabilitation (CR) in Dementia Fidelity Checklist

Name:
Colleagues Name (completed by):
Date:

Assessment Phase			
Process: Did the person leading the CR assessment:	**YES**	**NO**	**N/A**
Consider suitability for CR			
Gather information from a variety of sources (including case file review, interview with person w/ dementia, interview with family/carers, etc.)			
Develop an understanding of the person, including the person's cognitive ability (formulation)			
Define SMART goals that are meaningful to the person			
Monitor goal achievement and intervention over the duration of the intervention			
Clarify information with family and/or carers			

Clarify information with staff			
Validation of family and /or carer's experiences			
Intervention Phase			
Process: Did the person leading the CR intervention:	**YES**	**NO**	**N/A**
Assist the person with dementia and their carer to choose intervention options and carry out the intervention			
Use appropriate guidelines when using specific interventions			
Develop a person-centred intervention			
Train carer in supporting intervention where appropriate			
Provide clear explanations about the various intervention approaches			

Clinician Signature:

Colleagues Signature:

Appendix S

GAS Scales for three participants

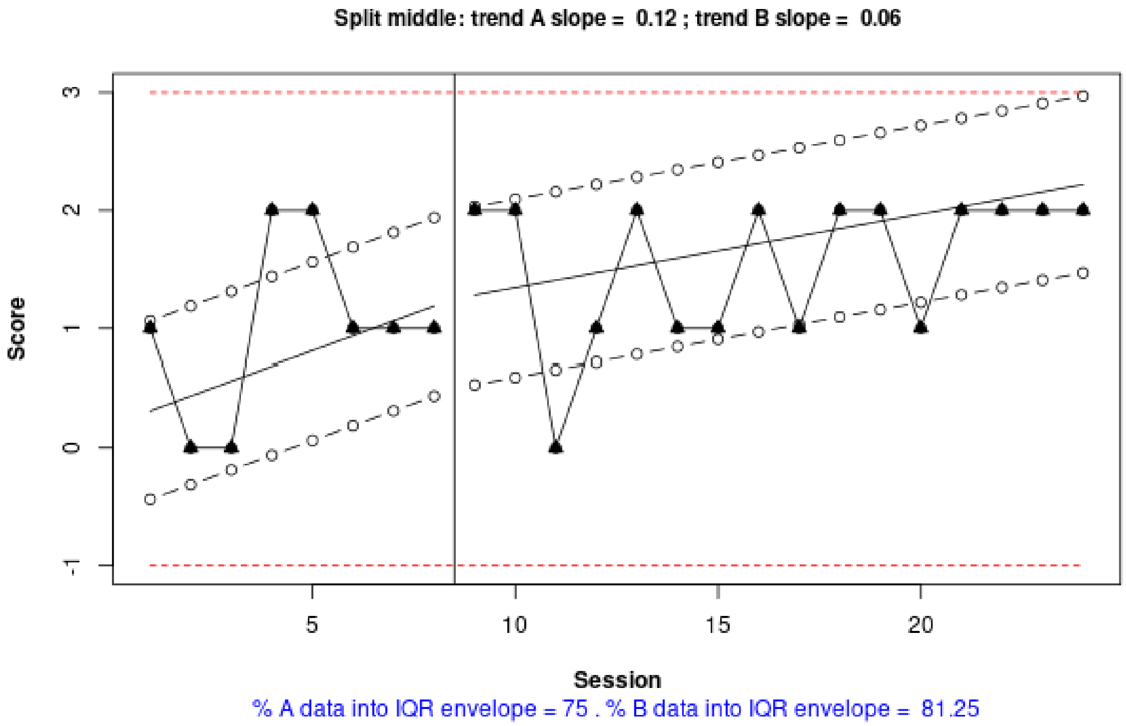
	Participant 1	Participant 2	Participant 3*
-1	Partner takes over entire laundry task	Struggle to generally use phone/unlock it	No interest/not in mood to learn any components of the language programme
0	Required caregiver to take over aspects of laundry	Can generally use phone but cannot send a text even when asked	Not spending 30 minutes attempting to learn any aspects of the language programme
1	Laundry completed with lots of prompting	Initiates some steps of the sequence to send a text but requires assistance	Attempting to learn an aspect of the language programme but not having success
2	Laundry completed with minor prompting	Initiates steps of the sequence to send a text message	Learning a one aspect of the language programme and remembering it
3	Laundry completed independently	Sends text message independently without assistance	Learning and remembering more than one aspect of the language programme

*For confidentiality reasons minor changes to the goal attainment scale have been made.

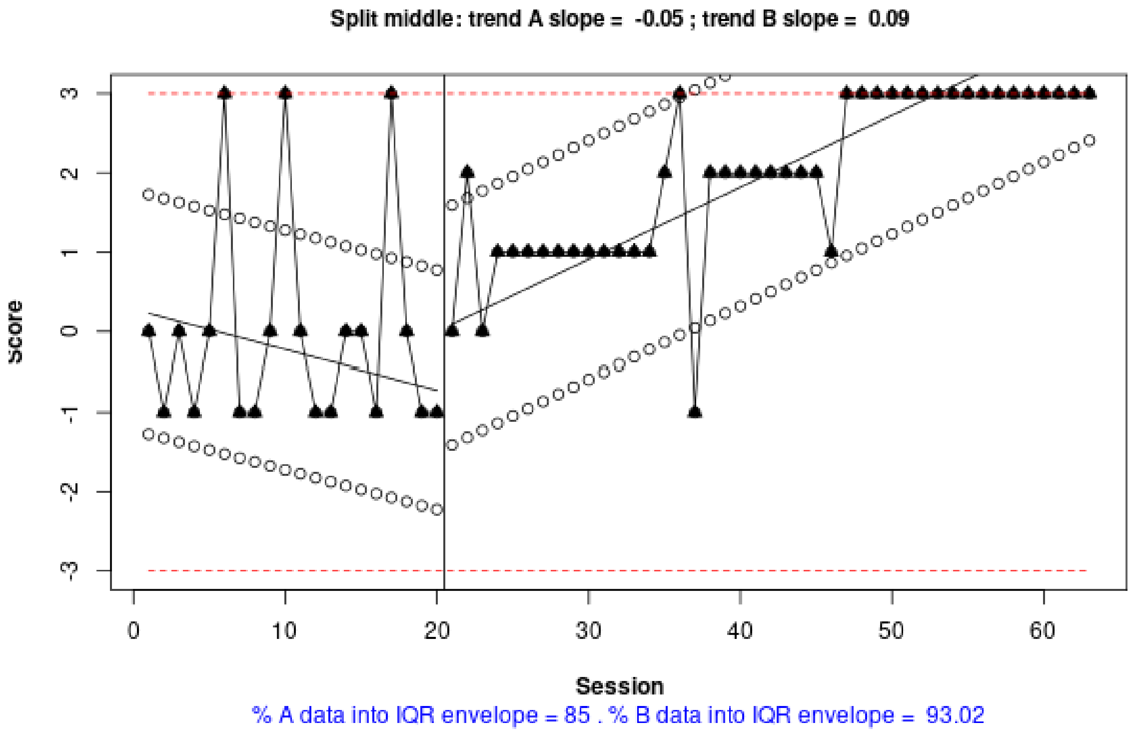
Appendix T

Goal Attainment Split-Middle graphs for three participants

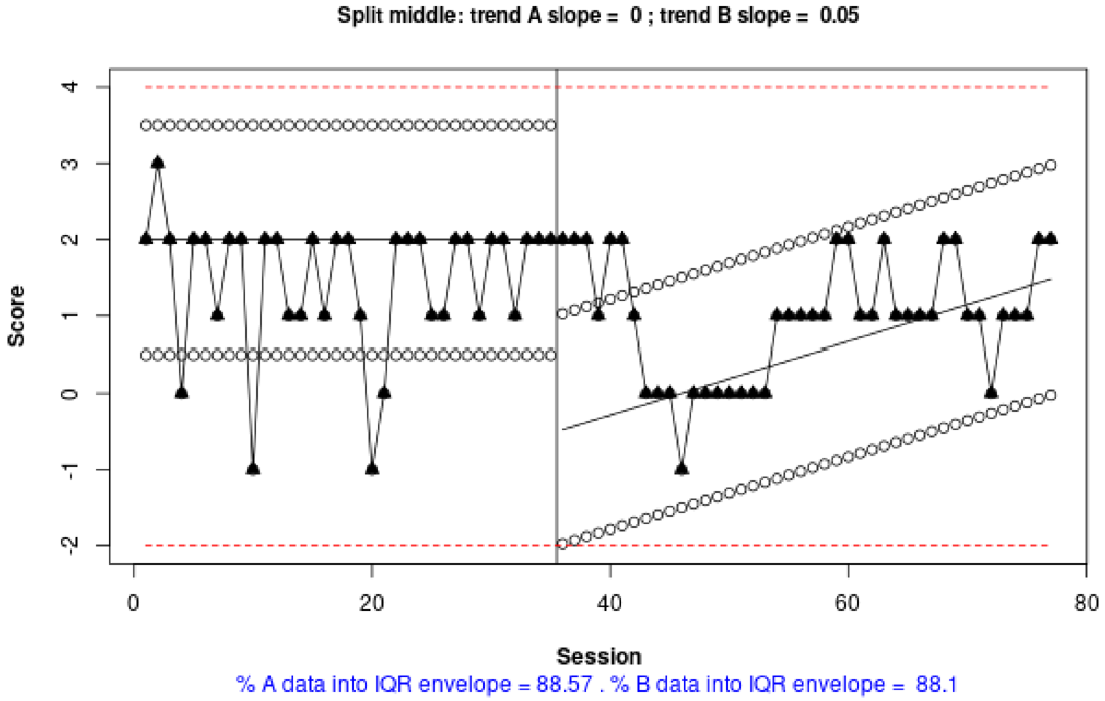
Participant 1



Participant 2

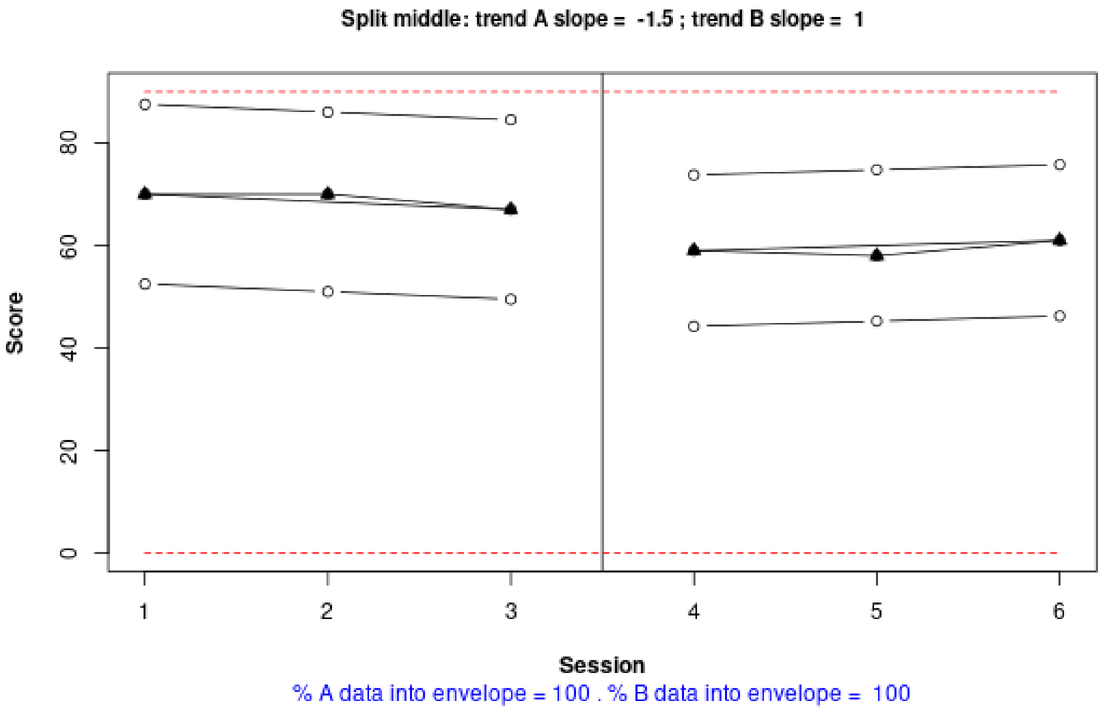


Participant 3

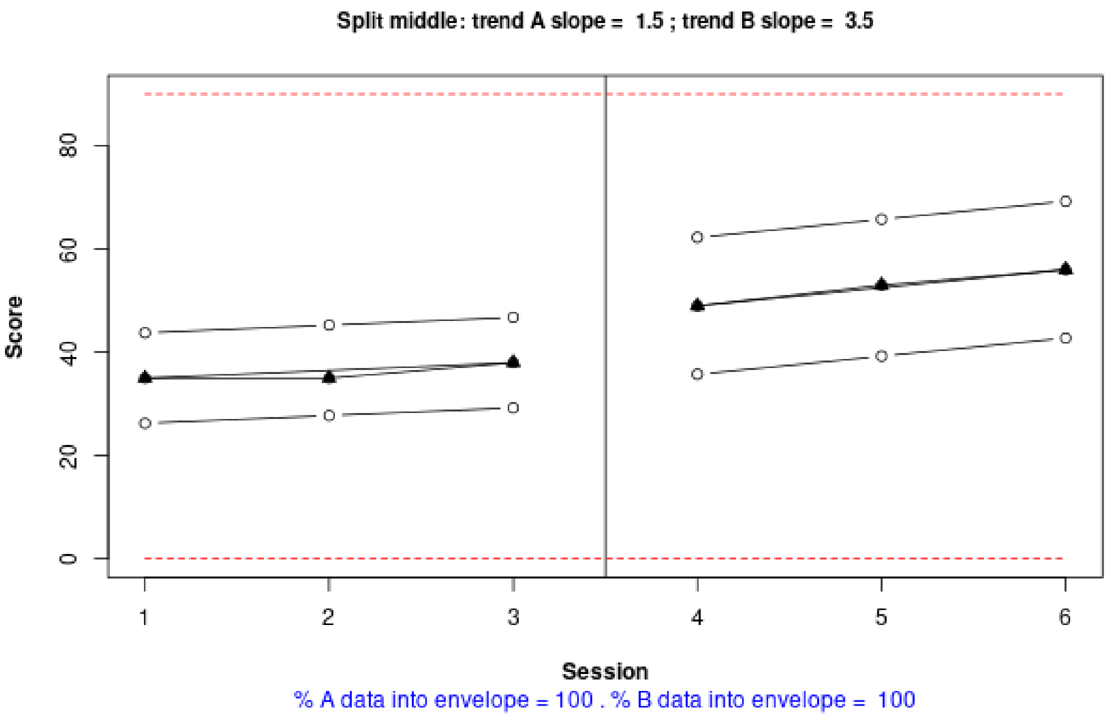


Self-efficacy Split-Middle graphs for three participants

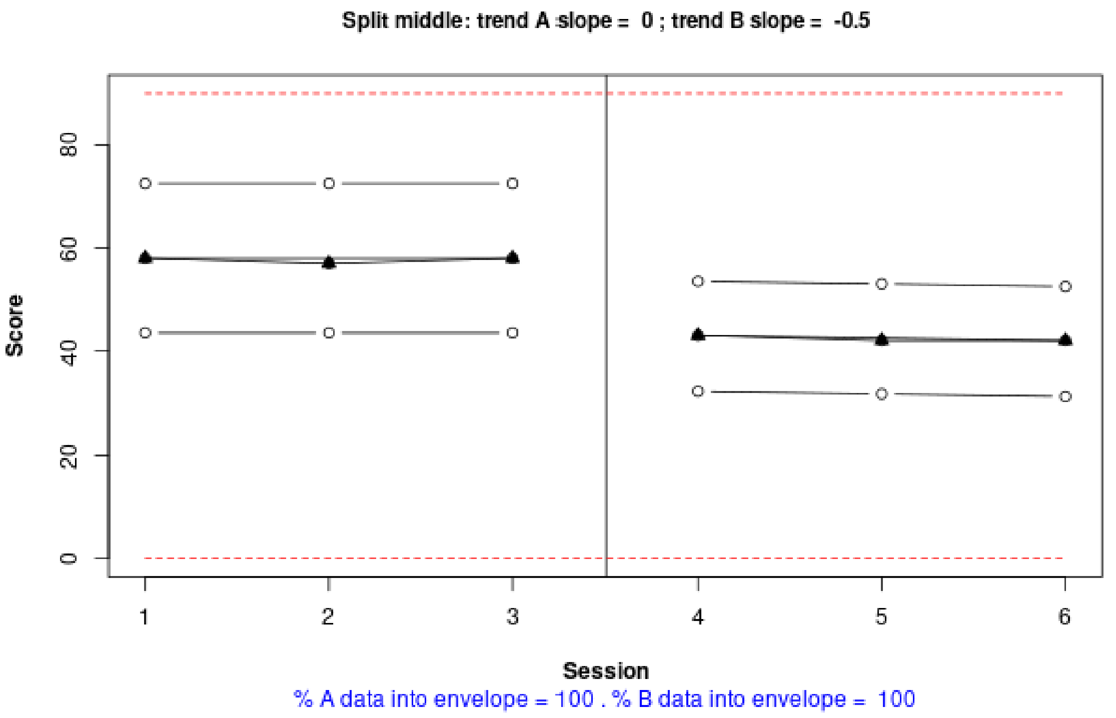
Participant 1



Participant 2



Participant 3



Appendix U

Raw data

Days	Participant 1	Participant 2	Participant 3
1	1	0	2
2		-1	3
3		0	2
4		-1	0
5	0	0	2
6		3	2
7		-1	1
8	1	-1	2
9	2	0	2*
10	2	3	-1
11		0	2
12		-1	2
13		-1	1
14		0	1
15	1	0	2
16	1	-1	1
17	1	3	2
18		0	2
19		-1	1
20		-1	-1
21		0	0
22		2	2
23	2	0	2
24	2	1	2
25		1	1
26		1	1
27		1	2
28		1	2*
29		1	1*
30	0	1	2
31	1	1	2
32	2	1	1
33		1	2
34	1	1	2
35		2	2
36	1	3	2
37	2	-1	2
38	1	2	2
39		2	1
40		2	2
41		2	2
42	2	2	1
43		2	0

44	2	2	0
45		2	0
46		1	-1
47		3	0
48	1	3	0
49		3	0
50		3	0
51	2	3	0
52		3	0
53		3	0
54		3	1
55		3	1
56		3	1
57	2	3	1
58	2	3	1
59		3	2
60		3	2
61	2	3	1
62		3	1
63		3	2
64			1
65			1
66			1
67			1
68			2
69			2
70			1
71			1
72			0
73			1
74			1
75			1
76			2
77			2

*Data that were inputted using the minimum-maximum method for managing missing data.