

Reflections on a personalised cognitive rehabilitation intervention: experiences of people living with dementia and their carers participating in the GREAT trial

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Abstract

Cognitive rehabilitation for people living with early-stage dementia improves functional ability in areas targeted in the therapy, but little is known about how participants experience this intervention. This **qualitative** paper investigates participants' views about a cognitive rehabilitation intervention in a randomised controlled trial (the GREAT trial) and aims to help explain and interpret the findings and to inform further intervention development. Using in-depth thematic analysis, 43 semi-structured interviews (35 individual and 8 dyadic) were conducted with 25 people living with dementia and 26 family carers from three sites. The person-centred, individualised approach was valued. **Some participants' views about dementia were questioned as a consequence of taking part in the therapy; they considered the effectiveness of the intervention in the context of the progressive nature of the condition.**

Certain participants continued to be doubtful, focussing on the inevitability of decline, rather than the possibility of reablement. Such views may have influenced engagement. The therapeutic relationship played a vital role as it was how personalised care was provided and participants' views had changed positively. Therapists engendered greater confidence and reduced anxiety and social isolation. Positive responses support personalised rehabilitative care to address the specific needs of people living with dementia.

Keywords: reablement; person-centred care; Alzheimer's disease; ageing; rehabilitation

Introduction

There is a need for adequate care and support for people living with dementia following diagnosis and throughout their life to help them manage the effects of the condition, maintain independence and live as well as possible (Low, Swaffer, McGrath, & Brodaty, 2018; Moniz-Cook, Vernooij-Dassen, Woods, Orrell, & Interdem Network, 2011). Early diagnosis creates a group of people living with dementia who know they have the condition, and who are trying to adjust and live with the condition, but for whom often little support and few interventions are available. In the UK, this has been labelled as the 'Psychosocial Intervention Gap' in the Early Stage Dementia Care Pathway (Guss & the Faculty of the Psychology of Older People, 2014, p. 5). It is recommended that this gap be addressed with evidence-based interventions, and services should ensure that people with dementia and their carers receive the necessary support and care.

Given the relationship of dementia to disability and dependency (World Health Organization, 2017), intervention strategies must go beyond supportive care and enable people to function at the best level possible and to manage cognitive impairment. A person-centred rehabilitation model in dementia care involves a personalised approach that takes into account the perspective of the person with dementia and the individual, social and environmental context. Inherent to this approach is selecting a focus that is relevant to everyday life and meaningful for the individual to improve wellbeing and quality of life (Clare, 2008). By defining rehabilitation as a 'process of active change' to achieve optimal physical, psychological and social functioning (Clare & Woods, 2001, p. 193), a rehabilitation programme can be applied to support people with dementia who have unmet needs and difficulties or who just want to manage their daily lives and activities better. Principally, it has the potential to mitigate the impact of dementia on functioning and independence (Poulos et al., 2017).

Originally developed for people with neuropsychological injury, cognitive rehabilitation is a goal-oriented, problem-solving approach for managing or reducing disability and maximising engagement and social participation; it does not aim to train cognition or directly improve performance on cognitive tasks (Clare, 2008, 2017). Instead, this intervention is intended to support everyday activities of daily living by addressing the impact of cognitive impairment on functional ability by using a mixture of evidence-based rehabilitative approaches aimed at restoring function (where feasible), implementing compensatory strategies, or modifying the environment (Clare, 2008; Clare & Woods, 2001; Poulos et al., 2017). Cognitive rehabilitation aims to tackle the difficulties considered most relevant by people living with dementia and their carers (family members and/or supporters) (Clare, 2008, 2017).

Cognitive rehabilitation is a potential way to address the current gap in dementia care and support for people living with early-stage dementia (Clare, 2017; National Institute for Health and Care Excellence 2018). Person-centred, goal-oriented cognitive rehabilitation has been shown to provide some benefits for people living with dementia and their carers (Clare, Kudlicka, Oyebode, Jones, Bayer, Leroi, Kopelman, James, Culverwell, Pool, Brand, Henderson, Hoare, Knapp, Morgan-Trimmer, et al., 2019), but these outcomes may be influenced by certain factors such as awareness, coping style and social relationships (Clare, 2008). Thus, a greater understanding of the mechanisms and moderators of cognitive rehabilitation is warranted.

The present study

The present qualitative study was part of a larger programme of work undertaken for the aforementioned GREAT trial (Clare, Kudlicka, Oyebode, Jones, Bayer, Leroi, Kopelman, James, Culverwell, Pool, Brand, Henderson, Hoare, Knapp, & Woods, 2019). In the GREAT

trial, an individualised, goal-oriented cognitive rehabilitation intervention designed to improve everyday functioning for people with mild-to-moderate dementia was evaluated using a multicentre single-blind randomised controlled design (Clare, Kudlicka, Oyebode, Jones, Bayer, Leroi, Kopelman, James, Culverwell, Pool, Brand, Henderson, Hoare, Knapp, & Woods, 2019). Participants randomly allocated to the intervention received up to 10 weekly sessions over 3 months and a further 4 maintenance sessions over the following 6 month period. Participants were followed up 3 and 9 months post-randomisation. The primary outcomes were self-reported goal attainment and carer-reported goal attainment. Secondary outcomes included quality of life, mood, self-efficacy, cognition, carer stress, and quality of life. The design and methods of the randomised controlled trial are described in detail in the published protocol (Clare et al., 2013) and the outcomes are reported in full elsewhere (Clare, Kudlicka, Oyebode, Jones, Bayer, Leroi, Kopelman, James, Culverwell, Pool, Brand, Henderson, Hoare, Knapp, Morgan-Trimmer, et al., 2019).

Cognitive rehabilitation was shown to improve participant and carer perceptions of functioning in relation to specific, personally meaningful goals that were targeted in the intervention (Clare, Kudlicka, Oyebode, Jones, Bayer, Leroi, Kopelman, James, Culverwell, Pool, Brand, Henderson, Hoare, Knapp, & Woods, 2019). A statistically significant large positive effect of the intervention was found for both primary outcomes at 3 months and was maintained over time. Participants in the intervention group were also more satisfied with their ability to carry out the everyday activities targeted in the intervention. Despite previous evidence finding some benefits for the secondary outcomes (Clare et al., 2010; Hindle et al., 2018), no effects relating to secondary outcomes were observed in the GREAT trial.

As part of the GREAT trial's process evaluation, interviews with a sub-sample of participants were conducted to understand more about how the intervention was experienced

and perceived. Interviews with people with dementia and their carers were included as part of the GREAT trial as a result of discussion with the patient and public involvement group who advised the trial. It was deemed important to understand participants' perspectives and experiences to attest to whether their specific needs were being addressed in the intervention, to help explain and interpret the GREAT trial findings, and for developing the intervention further either in research or clinical implementation. Accordingly, we examined what participants reported were the crucial aspects of the individualised intervention and whether the participants experienced any changes as a result. To our knowledge, there are no previous accounts describing the experience of an individualised cognitive rehabilitation intervention from the perspective of people with dementia and carers.

Methods

A qualitative interview study of GREAT trial participants who had experienced cognitive rehabilitation was conducted using an in-depth thematic analysis. Participants who had completed the intervention were interviewed at three out of the 8 trial sites. Interviews were conducted in the Bangor (March 2014 - January 2015), Cardiff (July – December 2015) and Manchester (April –May 2015) sites. These sites were selected as there was interest in taking part and there was capacity, i.e. the local Principal Investigator could identify a researcher not otherwise involved in the trial who could conduct detailed interviews. We reported according to Standards for Reporting Qualitative Research or SRQR (See Supplementary Material; O'Brien, Harris, Beckman, Reed, & Cook, 2014).

Ethical considerations

The GREAT trial was reviewed by Wales Research Ethics Committee 5, which issued a favourable opinion on 25 June 2012 (reference number 12/WA/0185), and was also approved by the Bangor University School of Psychology Research Ethics Committee.

Qualitative interviews were added to the protocol and approved by the Wales Research Ethics Committee 5 on 16 September 2014.

Participants

Trial participants from the intervention (not the control) arm were eligible for taking part in interviews when they had completed the trial, defined as receiving the intervention (up to 10 sessions over 3 months), completing the post-intervention assessment (up to 4 follow up sessions over the following 6 months), and completing the follow-up assessment which took place 9 months after randomisation. **As the aim of the study was to understand how the intervention was experienced and perceived, we excluded participants who had withdrawn from the study.** At each selected site, a consecutive series of those people living with dementia and carers who completed the trial was approached following the final assessment and invited to participate in the interview to discuss their experiences of the intervention.

Data collection

The person living with dementia and the carer gave written informed consent for participation in the GREAT trial and, for this qualitative study, informed consent was sought for the interview and the audio-recording. Participants and carers were interviewed separately wherever possible, starting with the person with dementia to encourage the person to speak for themselves. Interviewers took a photograph of the therapist with them on the visit to prompt participants' memory of the intervention sessions. If a participant was struggling to recall the intervention sessions completely, the interview was completed jointly with the carer. Individual interviews were conducted with 35 participants (17 people with dementia and 18 carers) and eight couples were interviewed jointly.

The interviews followed a semi-structured schedule, and interviewers encouraged the people living with dementia and carers to talk freely about their experience of the

intervention. The interviews covered the following topics: (1) how people living with dementia and carers experienced the intervention; (2) their overall perceptions about what was useful and the effort required; (3) what impact, if any, the people living with dementia and carers felt the intervention had on their everyday life. The interviewers had an overall understanding of what the intervention involved, but no specific knowledge of the individual participants' therapy goals or the therapy process, to avoid bias. All interviews were audio-recorded, transcribed verbatim and anonymised.

Data Analysis

The thematic analysis started from a critical realist position and was based on an inductive approach to identifying and exploring patterns of meaning concerning the research questions (Braun & Clarke, 2006; Maxwell, 2012). Four researchers who were not involved in providing the therapy analysed the interview data: KW, SMT, and GT were independent of the trial and the fourth was the Trial Manager (AK). Initially, two researchers (GT and AK) read and re-read the first five transcripts to familiarise themselves with the data and then coded each transcript. Each transcript was labelled with who had been present in the interview, and each code indicated who had been the respondent (carer or person living with dementia). Codes were listed separately, reviewed, and organised into meaningful groups representing initial themes for each interview. The resulting lists of themes were compared and discussed by the other two researchers (KW, SMT) until consensus was reached about content and organisation, after which KW and SMT re-coded the 5 transcripts. Related themes were clustered together and the clusters ordered into group-level themes and sub-themes, and the two researchers worked together to integrate these into an overall thematic map (KW, SMT). The remaining transcripts were then coded by a single researcher (KW) using the identified list of themes.

Results

In total, 36 couples (person living with dementia and carer) were approached and 26 agreed to be interviewed, although in the case of one couple only the carer participated in the interview. We interviewed 12 carers and 11 people living with dementia at Bangor (100% of those approached), 10 carers and 10 people living with dementia at Cardiff (50% of those approached), and four carers and four people living with dementia at Manchester (100% of those approached). Only 2 people living with dementia who were interviewed did not complete all the intervention and follow-up sessions; they both only missed one session. Following the eligibility criteria for the trial, all of the people living with dementia who were interviewed had an ICD-10 diagnosis of dementia, with the majority diagnosed with Alzheimer's disease, and mild-to-moderate cognitive impairment; the average MMSE score was 23.4 (Folstein, Folstein, & McHugh, 1975). Demographic and clinical characteristics are shown in *Tables 1 and 2*.

Overall, cognitive rehabilitation was received positively by both carers and people living with dementia. Three key themes were developed reflecting factors that influenced the experience of the intervention and whether it was considered beneficial (Table 3). These related themes were: the person-centred and individualised approach of the intervention; negotiating with the nature of the condition, and the role of a supportive therapeutic relationship.

Person-centred and individualised approach

People living with dementia and carers both appreciated the personalised approach of the intervention. The individual tailoring and flexibility that this approach provided were crucial for developing and implementing strategies in addition to gaining confidence with problem-solving and finding solutions. As one carer describes below, there was flexibility to ensure that what was covered was relevant to the person and paced appropriately:

They were always relevant to... obviously, relevant to the issues that [therapist] wanted to raise... And also relevant to, the issues that were important for [person living with dementia]... she worked at a pace that was good for him as well. (Carer 5)

For people living with dementia, this meant that time was given for understanding their difficulties and preferences as well as tailoring the intervention components to suit their interests, abilities and needs. For example, as one person living dementia describes:

I felt I was getting better with [therapist], you know... Cos I felt as if she was, she understood me, that's what I felt. (Person living with dementia 6)

The specific goal or task preferences of the people living with dementia were considered and acknowledged. As one carer described:

It was very, you know, let's listen to what [person living with dementia] wants, let's listen to what he thinks might be useful for him...I think the work that was done was absolutely relevant to that agenda. And also ... suited [person living with dementia]'s expectations, needs, abilities. (Carer 16)

The personalisation made the experience positive, and the intervention was considered helpful. People living with dementia gained enjoyment, empowerment and a sense of achievement from completing their goals. This potentially resulted in more positive outcomes for both the person living with dementia and carer over and above the functional gains. One person living with dementia discussed the confidence and improved outlook that he gained as a result of the intervention and achieving the goal of participating in social activity:

I don't feel ... as if there isn't a future....I'm not frightened of going out on me own. If you understand what I mean. I feel that much [more] confident... (Person living with dementia 6)

The flexibility of this approach also allowed for the adaption and modification of tasks or goals over time, which was deemed important by people living with dementia and their carers. These modifications made the tasks ‘*fit in*’ to their lives, and alterations could be made to manage changes in cognitive or physical health. One person with dementia described the efforts taken by the therapist to make adaptations:

But she done it a stage at a time...She explained. And when I wasn't sure, she'd write it down. And ...simple ways to- in order- so I could be able to remember it. (Person living with dementia 6)

This flexibility was closely related to the therapist's responsiveness and the ability of the therapist to match the intervention strategies to the needs of the person living with dementia to accomplish the chosen goals.

Negotiating with the nature of the condition

Perceptions of success of the intervention could be dependent on people's views about the nature of their changes in dementia symptoms over time and level of cognitive impairment. Respondents expressed uncertainty about the impact of intervention due to the progressive nature and inevitable decline associated with the condition. This was illustrated by the response of one carer when asked about the impact of the intervention:

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)

A few carers and people living with dementia were not sure whether the intervention had been truly beneficial as they believed dementia would only get worse and nothing could

ultimately be done to help. They noted that the intervention did not improve memory as such (although cognitive rehabilitation was not being designed or intended to improve cognition, which was explained to all potential trial participants). A few carers questioned the extent to which the intervention was worthwhile or successful given that normal functioning could not be restored and decline was considered inevitable.

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. (Carer 19)

Furthermore, there was a concern about the lasting benefit of cognitive rehabilitation. As one carer recalled, the performance of the person living with dementia on the selected goal had declined since the end of the intervention (note: 'the number that it was originally' in the quote below refers to the goal attainment rating provided at the post-intervention assessment).

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)

A few carers and people living with dementia believed that future deterioration would possibly undo any improvements generated by the intervention. They thought the intervention had been and could be useful but also acknowledged the eventual decline that occurs in dementia.

Well, they helped a great deal really and with the knowledge... it's got to be a good thing to talk across a table, how you feel, ... and then you're thinking, what's going to go on in the future, what's going to happen in the future. I'm prepared that my memory is going to... go downhill... because that's part of the problem. (Person living with dementia 22)

Despite these concerns about longer-term benefits, several participants discussed how self-perceptions and their outlook on the future had changed. One person living with dementia explained how the therapist improved her self-view and made her feel better about herself: *'I'm not as soft as I think I am.'* She went on to describe how the therapist had empowered her to make more decisions for herself. Carers often discussed how they had developed a more problem-solving approach and specific strategies which would help with future problems and decline:

No, I think it was enlightening... because as I say, you're in a little box aren't you with your own little world and it just opens it out, there are people worse off...It's changed my perception of what's needed...Uh, she made you think about things that you thought you perhaps knew, but think about them in a different way ... And approach them in a different way. So I felt she really crystallized a lot of what we'd been talking about...That made it in a very practical way (Carer 3)

Some participants' views had changed positively and they felt they were managing well for now, but they still acknowledged that the future outlook was not optimistic due to their condition:

I know what's coming...I've seen it. But, uh... what they've told me is enough... for me to work along now...You know. The future will have to sort itself out. I can't... do so...There's no point in me messing about now...Uh, wait for things to change, you know ...In the fullness of time ...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. (Person living with dementia 10)

They accepted that dementia is a process of progressive decline for which there is no cure, but they wanted to try to learn strategies and make small changes to manage things better in

the here-and-now and improve the current situation, even though it would not change the prognosis. Two carers described the desire to take part and benefit from the therapy:

I think we wanted specific practical goals. [The therapist] had shown us some examples of things that other parties had gone through and suggested. (Carer 23)

We felt that it was worth trying to participate and get the best out of the therapy that we'd been offered. So if things were suggested, we made an effort to try and do that (Carer 26)

The role of the therapeutic relationship

The therapeutic relationship was the vehicle by which the person-centred approach of the intervention was implemented and beliefs that nothing could be done to help were countered. The relationship with the therapist played an important role in participants' perceptions of the intervention, especially as some of the people living with dementia were unable to recall the specific goals that they had been working towards in the intervention. The therapeutic relationship was a significant aspect that both people living with dementia and carers enjoyed about their experience of the intervention, and supported the 'living well' orientation of the intervention. They looked forward to the therapist visits, and they said that they missed the visits after the intervention had ended.

Building a positive relationship with the therapist was believed to be crucial for cognitive rehabilitation by both people living with dementia and carers. People living with dementia described feeling comfortable, relaxed and at ease when talking to their therapists. Moreover, they also said that they did not feel distressed or disturbed during these interactions. Carers and people living with dementia believed that the therapeutic relationship was the foundation for several aspects of the intervention: education for people

living with dementia and carers about the dementia experience (often confronting negative views about whether anything could be done to help); distribution of information or resources that could help with daily functioning; and providing social support.

The information and explanations that therapists gave about dementia were considered to be very beneficial for both carers and people living with dementia. The relationship with the therapist made asking questions and communication comfortable and easy. Also, this information-sharing allowed for a relationship to be developed between the person living with dementia and the therapist:

Oh fine, yeah fine, got on well ... Easy, yeah she explained everything and, you know, it was no hardship (laughs)... That's right, yeah, well sometimes when people come to see you, ... you're afraid to talk, you know, afraid to say anything when it's a little bit dumb. But she made me feel so, er, comfortable and within a couple of minutes, we were just like as though we'd been friends for a long time. (Person living with dementia 1)

As described above, not only was the conversation relaxed and friendly, but this interaction was positive when compared to interactions with other people so that people with dementia did not feel anxious or fearful. This comparison highlighted how people living with dementia may feel inadequate or stigmatised by others; however, that was not how they experienced the interaction with the therapist.

The educational component was related to several perceived positive outcomes for people living with dementia. As one person living with dementia describes:

Yeah, she was very good explaining things and, you know ... I did become very positive ... after she'd been. ... Cos she, she did, she made me feel good. (Person living with dementia 1)

Particularly, it increased their understanding and fostered a more positive view of how to manage the challenges of dementia, to which they attributed their resulting better psychological adjustment and wellbeing. Some participants reported a new and more optimistic perspective on their diagnosis which resulted in less anxiety. One person living with dementia described how the therapist increased awareness and reduced worry:

She explored areas, you know that I hadn't thought about, and...I found a great help... it showed me to be less worried about it. (Person living with dementia 2)

Before the intervention, several people living with dementia described being wary of, or anxious about, performing tasks in some situations. People living with dementia discussed how the therapist empowered them to make their own decisions about what they wanted to do and about working towards their goals.

Social support and contact seemed to be another important element provided by the therapist, even if the intervention was not viewed as successful. As one carer describes:

I don't think it was successful. Other than it gave – [the person living with dementia] company... Which she would not normally have had... I don't think it really achieved what we hoped it would. (Carer 11)

Several carers reflected on how the person living with dementia 'enjoyed the company', suggesting that they do not have visitors who engage with them regularly and that they are socially isolated:

I think my mum just enjoyed it more that somebody was, the social aspects of it, that somebody was coming. (Carer 1)

The visits also became part of the routine for the person living with dementia, which was viewed positively.

Carers described the therapist visits as helpful because they offered opportunities to talk and provided support to them as well, which was something that they described as lacking in their lives. Several carers described how the therapist gave them recognition that their experience was shared, as described below:

And she made you feel that ...this was a problem that other people have and in a way, it sort of normalises what is not a normal problem and she sort of made you feel it's ... something that other people experience, that there are ways through it... (Carer 2)

Other people who were also caring for a person living with dementia were talked about as being ‘*in the same boat*’. This knowledge helped the carers feel they were not alone or ‘*neglected*’ and ‘*ignored*,’ which was what they mostly experienced in relation to others or society as a whole. It seems that the therapist not only provided empowerment and agency for the people living with dementia but also decreased social isolation and stigma for both carers and people living with dementia.

Differences between persons living with dementia and carers

Responses from family carers and people living with dementia were generally similar and aligned. However, there were a few differences in their accounts. The people living with dementia would more often focus on the relational and emotional impact of the therapy and positive interactions with the therapist, as they frequently could not recall their specific therapy goals and strategies. In contrast, the carers tended to focus on the helpful aspects of the strategies that they had learned and how the therapy had benefited their everyday lives. Additionally, carers were more likely to acknowledge the limitations of the therapy and the progressive nature of dementia. Some of the differences may reflect emotional thinking on the part of the people with dementia as they tuned into sociotropic features (that is, the relationship with the therapist). Whereas the carers’ responses may have been an artefact of the questions that they were asked (e.g., what impact did the therapy have on your everyday

life?). The demand characteristics of this sort of question may have resulted in some of the negativity.

Discussion

This study was the first to explore the perspectives of people living with early-stage dementia and carers on the cognitive rehabilitation programme. The main findings can be summarised as follows. Overall, there was a positive experience of the intervention, and the participants found that the intervention helped with the process of adjustment to living with dementia, leading to feelings of greater confidence, less anxiety and better coping strategies. The participants, both people living with dementia and their carers, appreciated the person-centred, individualised approach. The individual tailoring and flexibility were considered crucial to goal attainment. The knowledge that dementia would inevitably progress led, however, to uncertainty about the effectiveness of the intervention and its lasting impact. The relationship with the therapist was deemed extremely important, both as a vehicle for providing information, changing views and giving social support as well as how rehabilitative strategies were developed, accepted and personalised.

The GREAT trial found that cognitive rehabilitation improved goal attainment for people with mild-to-moderate dementia but found no effects for quality of life, mood, self-efficacy, cognition, carer stress, and quality of life (Clare et al., 2019). However, the interview findings indicate that trial participants reported improvements in some of these outcomes. The trial findings showed that functioning in targeted areas was improved by the intervention, but, as the underlying condition is progressive and cannot be reversed or cured, the effects of this and other non-pharmacological interventions are necessarily limited in duration. Improvement captured by the specific primary outcome may not be reflected in secondary measures such as quality of life because the participants were aware of this broader context.

In other words, there is an existential issue about the extent to which a short-term improvement would be ‘objectively’ worthwhile when decline remains inevitable, and an individual’s stance on it might be a moderating factor in assessing impact of any psychosocial intervention. Alternatively, the null effects may be due to the quantitative measures lacking sensitivity and not capturing individual changes. For example, in a comprehensive systematic review and meta-analysis of the factors associated with quality of life for people living with dementia, small or negligible associations with quality of life were found in most of the studies, and the authors suggested a need to reconsider approaches to understanding and assessing what it means to ‘live well’ with dementia (Martyr et al., 2018). The findings question the use of quality of life as an outcome measure in psychosocial intervention trials (such as the GREAT trial). Perhaps new and better measures need to be developed and tested to capture the changes reported by the participants in the present study and what is important to people living with dementia.

Cognitive rehabilitation, like any psychosocial approach, is a complex intervention and as such, it includes several components with various interconnecting parts (Campbell et al., 2000). In such interventions, it can be difficult to define the active ingredients, and how these relate to each other. The present study findings suggest three important, interrelated components from the perspective of the people living with dementia and their carers participating in the GREAT trial. Firstly, a personalised approach was considered helpful as it allowed the intervention to target what was important and relevant for the person with dementia (and the carer) and modifiable to suit them and as the person’s needs changed. These findings indicate that personalised care underscores useful therapies and strategies for the person with dementia and carers (Innes & Manthorpe, 2013), and can enable people with dementia to live fuller lives (Vernooij-Dassen & Moniz-Cook, 2016).

Secondly, perceptions and expectations of cognitive rehabilitation may have to be addressed for the intervention to be perceived as helpful and worthwhile. Participants' beliefs about dementia were challenged as they questioned whether cognitive rehabilitation was beneficial and whether anything could be done in the here-and-now to improve their situation and everyday life. Some participants' views were changed by the therapist who imparted a better understanding and a more positive view of the potential for living well with dementia; whereas others still questioned whether an intervention was worthwhile if the benefits did not last. It must be noted that this is participants' lived experience; one which includes both decline and progress and people living with dementia can not always be expected to have a narrative of 'living well or successfully' (McParland, Kelly, & Innes, 2017). The intervention (and therapists) may need to understand and adapt to this realistically nuanced perspective rather than expecting participants to change their views (McParland et al., 2017). Some health professionals also share these negative views about the possibility of living well with dementia and the potential of reablement or rehabilitation (Cations et al., 2019) and it is here that efforts to change attitudes could be best focused. It is the belief that nothing can be done to help manage or live with the condition that needs to be confronted; cognitive rehabilitation showed that some improvements can be made and teaches the problem-solving approach and specific strategies that can enable this process to happen. The GREAT trial found significant improvement in goal attainment despite some participants being uncertain that anything could be done to help. To change these views, there will need to be a reframing of practice to conceptualise dementia as a disability (Cations et al., 2019; Clare, 2017; Swaffer, 2014) and re-conceptualisation of rehabilitation as suggested by the World Health Organization (2017) so that it is adopted in dementia care services (Clare, 2008, 2017; Poulos et al., 2017).

The third important component of cognitive rehabilitation that emerged was the therapeutic relationship. The relationship built with the therapist seemed to be a major mechanism by which the intervention was perceived favourably by the person living with dementia and the carer. During the intervention, the therapist made the person living with dementia feel comfortable and respected, and the carer felt less alone and despondent. Although the main objective of the intervention was to support everyday functioning for the person living with dementia, improved psychosocial outcomes were reported by both the person living with dementia and carers. The therapist not only provided social support and contact but also fostered confidence, reduced worry, and increased engagement. This finding reinforces the importance of relational aspects of psychosocial interventions and the ability of these interventions to combat social isolation among people living with dementia and their carers (Moebs, Gee, Miyahara, Paton, & Croucher, 2017). It also highlights the wider social needs and contexts in which people living with dementia experience stigma and isolation (McParland et al., 2017). As in all therapies, the therapist and the person living with dementia (and carer) must build a therapeutic relationship so that cognitive rehabilitation is a collaborative process (Sohlberg & Mateer, 2017). This relationship, sometimes called the working alliance, has been found to influence rehabilitation compliance and functional outcomes for people with neuropsychological injury (Schönberger, Humle, Zeeman, & Teasdale, 2006; Stagg, Douglas, & Iacono, 2019). Future work is needed to explore how this relationship is developed and its impact in the context of cognitive rehabilitation for people living with dementia and their carers so healthcare providers can maximise this effect when planning dementia care packages.

Limitations of the study

The findings of this study should be interpreted in the context of some limitations. First, as the qualitative work was embedded in the larger trial, the trial design meant that

participants were interviewed 6 months after the completion of the main part of the intervention, although they had less frequent follow-up sessions during this period. The responses may have been different if it had been possible to interview participants during, or on completion of, intervention sessions. This delay in time introduced a risk for cognitive bias because participants (especially those living with dementia) experienced difficulties in recalling the content of the intervention. Several of our participants living with dementia reported not remembering the goals and activities that were targeted. However, the delay in time can also be considered as a strength because it gave participants time to adjust and reflect on their experiences. It also perhaps revealed the aspects of the intervention that had the most lasting impact on the participants.

Second, the sample may not represent all participants experiences in the cognitive rehabilitation intervention as recruitment for interviews was conducted at only three out of the eight research sites in the trial. Although data saturation was achieved, the views expressed may not reflect the experience and perceptions of participants at the other five sites and with different therapists. Inclusion of a wider range of views may identify additional themes. However, one strength was that over 70% of participants approached participated in the interviews, with two sites having 100% agreement to participate.

Steps were taken to reduce positive response bias, as interviewers and data analysts were not involved in delivering the intervention or otherwise involved in the trial – and this was made clear to the participants so they could state what they truly thought about the intervention and the therapist. However, some bias may still have been present because participants were recruited as a result of their participation in the trial and had not withdrawn from the study. For participants allocated to the intervention, the overall attrition was low (10%) and adherence rate was high (90% completed at least 10 sessions). Those who took part in the interviews may be more likely to view the intervention positively than those who did

not want to take part or dropped out might have been. As the study's aim was to explore participants' views of the intervention to help interpret the trial findings and inform further intervention development, participants who had completed the intervention sessions were included instead of those who had withdrawn from the intervention. Nevertheless, the interviews elicited varied and nuanced experiences of the intervention which mitigates against this concern.

Conclusions

The overall aim of the present research was to explore the experiences of people living with early-stage dementia and their carers who participated in an effective goal-oriented cognitive rehabilitation intervention. This study has found that generally cognitive rehabilitation was viewed positively. The findings suggested that the intervention empowered people living with dementia and carers by employing a personalised approach and encouraging the view that something can be done to help people manage the challenges of dementia and live well with the condition. Responses from the GREAT trial participants support recommendations for person-centred care to address the specific needs of people living with dementia. Widespread implementation of personalised cognitive rehabilitation will require training and reframing of practice as well as a shift in views about dementia.

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Disclosure of interest

The authors report no conflict of interest.

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