

# The experiences of people with dementia and their carers participating in individual cognitive stimulation therapy

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**Background:** The carer-delivered individual cognitive stimulation therapy (iCST) was developed to improve cognition and quality of life of people with dementia. This study aims to explore people with dementia and family carers' concepts of mental stimulation and experiences of participating in the iCST intervention.

**Methods:** A sub-sample of 23 dyads of people with dementia and their family carers who completed the iCST intervention took part in semi-structured in-depth interviews. Data were analysed using framework analysis.

**Results:** Three main themes emerged, 'Concepts of mental stimulation', 'Experiencing changes in everyday life as a result of participating in iCST' and 'Carer adherence to the intervention' along with 10 sub-themes. The overall experience of participating in iCST was described as having opportunities to engage in enjoyable mentally stimulating activities, motivation to stay active and bringing people with dementia and their carers 'together'. Family carers mentioned that finding time to do the sessions and their relatives being reluctant to engage in the activities could hinder their participation in the intervention.

**Conclusions:** People with dementia and their family carers found iCST stimulating and enjoyable, but many had difficulty delivering all the sessions as planned. Family carers suggested that providing extra support by involving other people in delivering the intervention may help to improve adherence to the intervention. iCST may be a useful tool to encourage people with dementia and their carers to communicate. © 2017 The Authors. *International Journal of Geriatric Psychiatry* Published by John Wiley & Sons Ltd.

**Key words:** family carer; mental stimulation; individual cognitive stimulation therapy; interpersonal interactions; dementia; relationship quality

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## Background

Group cognitive stimulation therapy (CST) is an evidence-based intervention that has been shown to be beneficial for cognition and quality of life for people with mild to moderate dementia (Spector *et al.*, 2003). However, many people may be unable to attend CST groups because of certain factors including mobility problems, reluctance to participate in a group setting or lack of available local CST groups. A cognitive stimulation (CS) intervention delivered individually

by family carers at home is likely to be useful in making the intervention more accessible to people with dementia and their family carers. Evidence shows that CS interventions delivered individually by a family carer may improve cognition in people with dementia (Onder *et al.*, 2005).

Cognitive stimulation interventions predominantly focus on improving cognition and quality of life for people with dementia (Woods *et al.*, 2012). A recent review found that carer involvement in psychosocial interventions may enhance mutual understanding,

communication, relationship quality and well-being for both people with dementia and their carers (Moon and Adams, 2013). However, evidence suggests that the inclusion of carers in cognitive training interventions (Zarit *et al.*, 1982) and CS (Milders *et al.*, 2013) can be very challenging as some carers experience increasing depressive symptoms when they participate in these interventions alongside their relatives.

In this study, a theoretical framework of carer involvement in cognition-based interventions (CBIs) for people with dementia (Figure 1) is used to explore the effects of carer involvement in the iCST intervention. This theoretical framework consists of the binding ties theory (Townsend and Franks, 1995), the enrichment process theory (Cartwright *et al.*, 1994) and the scaffolding process theory (Cavanaugh *et al.*, 1989). These theories are proposed as mediators of the relationship between carer involvement in CBIs and carer well-being. In dementia care, interpersonal interactions and mutual understanding help carers to adapt to the changing needs of caring for someone with dementia. As a result, this enhances the caregiving relationship (Townsend and Franks, 1995). Carers who have difficulty adapting to the changes of care demands on the other hand may experience a decline in the caregiving relationship (Yang *et al.*, 2014). Cartwright *et al.* (1994) suggest that the enrichment process provides carers with opportunities to share meaningful and pleasurable activities with people with dementia. However, the enrichment process only occurs within the context of an existing positive relationship or being motivated to improve the relationship quality. During the trajectory of dementia, cognitive

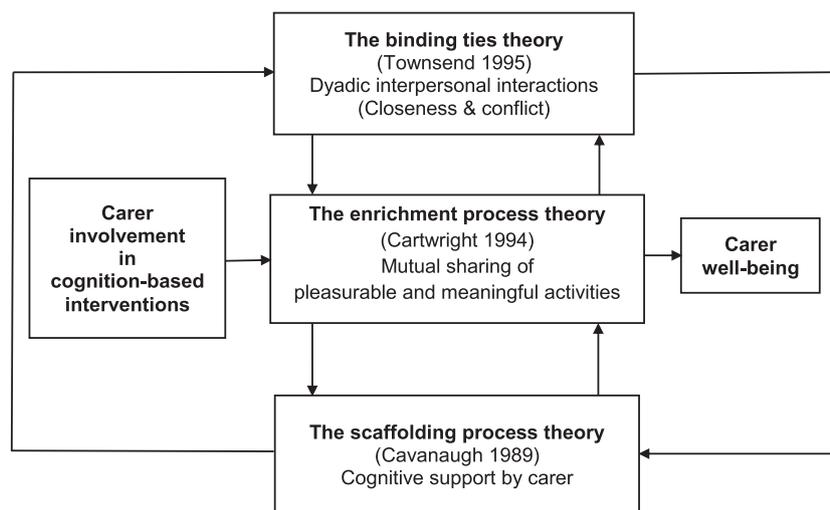
support by the carer can play a vital role in terms of improving cognitive performance and enhance the competence of people with dementia to accomplish their goals. As a result, it enhances the quality of the caregiving relationship (Cavanaugh *et al.*, 1989).

Many randomised controlled trials (RCTs) have evaluated the effects of CBIs for people with dementia (Bahar-Fuchs *et al.*, 2013; Woods *et al.*, 2012). However, little is known about the experiences of people with dementia and their carers participating in these interventions. The use of qualitative methods embedded in RCTs of complex interventions is increasingly recognised as adding value to research studies, providing opportunities to have a better understanding of the effects of interventions and fully utilising participants' experiences (Lewin *et al.*, 2009). These methods help in understanding the experiences, benefits and limitations of interventions (das Nair and Lincoln, 2013; Lewin *et al.*, 2009). The aim of this study was to explore people with dementia and family carers' concepts of mental stimulation and their experiences of participating in the iCST intervention.

## Methods

### Design and study population

This was a qualitative study using semi-structured in-depth interviews. A sub-sample of 23 dyads of people with dementia and their carers was selected from 180 dyads randomised to the intervention group in the iCST study (Orgeta *et al.*, 2015).



**Figure 1** A theoretical framework of carer involvement in cognition-based interventions for people with dementia.

## Ethical consideration

The iCST study was approved by the Multi-centre Research Ethics Committee (ref no.10/H0701/71). People with dementia and family carers gave informed consent to participate in the qualitative study. They were additionally asked for permission to have the interview audio recorded.

## Individual cognitive stimulation therapy study

The iCST study was funded by the National Institute for Health Research (NIHR), Health Technology Assessment (HTA) programme. This study was a multi-centre, single-blind, randomised two-treatment arm (iCST over 25 weeks vs. treatment as usual, or TAU) controlled clinical trial. The iCST study aimed to evaluate the clinical effectiveness of carer-delivered iCST for people with dementia and their family carers (Orgeta *et al.*, 2015). There were 356 community-dwelling participants (mean age 78.2 years) with mild to moderate dementia who had a relative (family carer) or other unpaid (informal) carer who acted as an informant and delivered the intervention. A total of 273 dyads completed the study.

## The individual cognitive stimulation therapy intervention

The iCST intervention consisted of one-to-one structured cognitive stimulation sessions for people with dementia delivered by carers at home. The iCST intervention offered a total of 75 activity sessions based on a variety of themes including current affairs, being creative, word games and quizzes. People with dementia and their carers were asked to complete three 30-minute sessions weekly for 25 weeks. Carers were trained at the first home visit to deliver the intervention. During the iCST sessions, carers were instructed to implement the key principles, which included using a person-centred approach, offering choice, focusing on opinions rather than facts, using reminiscence, always having a tangible focus, maximising potential, enjoyment and fun, stimulating language and strengthening the caregiving relationship.

## Data collection

The first author undertaking the individual interviews for this study was not involved in recruiting or providing the intervention to participants in the

quantitative study. Semi-structured in-depth interviews were fully audio recorded. The iCST manual and activity workbook were used as a visual aid to help the person with dementia and their carer to recall their experiences of engaging in the activities. Interview topics were derived from the literature of CST (Woods *et al.*, 2012) and interpersonal interactions (Townsend and Franks, 1995), mutual sharing of pleasurable and meaningful activities (Cartwright *et al.*, 1994) and cognitive support (Cavanaugh *et al.*, 1989) theories. People with dementia and their carers were asked separately to describe their experiences of participating in the iCST intervention using initially open-ended questions, followed by questions focusing on specific areas such as mentally stimulating activities, memory, everyday life activities and relationship quality (Table 1).

## Data analysis

Interviews were analysed using framework analysis, which is developed to meet specific information needs and outcomes within a short timescale (Ritchie and Spencer, 1993). It includes five key stages: (i) familiarisation and identifying a thematic framework; (ii) indexing; (iii) charting; (iv) mapping; and (v) interpretation (Ritchie and Spencer, 1993). The interviews were transcribed professionally. Two researchers independently read interview transcripts thoroughly

Table 1 Key topic questions

1. Introduction to the topic of mental stimulation
  - What is mental stimulation?
  - Why mental stimulation is important?
  - What types of activities are mentally stimulating?
2. Experiences of taking part in iCST
  - How would you describe your experiences of taking part in iCST?
  - What did you find helpful in taking part in iCST? What about your relative?
  - Have you experienced any changes in everyday life as a result of taking part in iCST? If yes, what has changed for you and your relative?
  - Have you experienced any changes in your relationship with your relative? If yes, what has changed for you?
3. Barriers of offering iCST
  - What is likely to hinder you in offering iCST to your relative? Any specific factors?
  - What is likely to help you succeed in offering iCST to your relative in the future? Any specific factors?

(Both the person with dementia and their carer were asked to respond to key topics 1 and 2. Only the carer was asked to respond to key topic 3).

iCST; individual cognitive stimulation therapy.

to become familiar with the broad themes. A coding frame was developed using Nvivo 10 software (QSR International, Southport, UK). Researchers discussed, compared and contrasted styles of summarising in the early stages of the analysis process to ensure consistency (Ritchie and Spencer, 1993).

## Results

Thirty-five dyads in the intervention group were approached as they expressed interest in extending their involvement in other aspects of the iCST trial. Twelve dyads were excluded because of ill health, family crisis, reluctant to take part or because they completed far fewer sessions than recommended. Data saturation was reached after analysing 23 dyads (Marshall, 1996). Therefore, 23 dyads were included; 22 people with dementia (one participant refused to participate) and 23 family carers. Ten dyads were recruited from London, four from Manchester, five from Norfolk and Suffolk and four from Dorset. The mean age of people with dementia participating in this qualitative study was 74.7 years, and the average age of carers was 65.9 years. People with dementia taking part in the qualitative study had a mean baseline Mini-Mental State Examination (Folstein *et al.*, 1975) score of 22.5, which is indicative of mild dementia. There were 17 spousal carers, five adult-child carers and one sibling carer. The average number of iCST sessions delivered (two per week) was 49. The minimum number of sessions completed was 18, and the

maximum was 75, with 61% ( $n=14$ ) of the sample completing more than 38 sessions (Table 2). The analyses identified three main themes which included 'concepts of mental stimulation' and 'experiencing changes in everyday life as a result of participating in the iCST intervention' and 'carer adherence to the intervention' alongside 10 sub-themes (Table 3).

### Theme 1: Concepts of mental stimulation

*Effects of mentally stimulating activities.* Most people with dementia perceived mental stimulation as an activity that provided opportunities to keep 'the brain going', reflect, concentrate and stay alert. They also emphasised the importance of being mentally active as 'if you do not use it you lose it'.

It gives an opportunity to think, reflect, review words and understand them, to reflect on what you want to say and what you're hearing somebody else saying and about the whole situation. (Person with dementia)

Some carers suggested that mental stimulation provided opportunities to be in the present, link with the past and take in new information.

*Types of mentally stimulating activities.* People with dementia and their carers identified a broad range of mentally stimulating activities (Table 4). Engaging in conversation and games/puzzles were amongst the most popular suggested activities. Both people with dementia and carers suggested practical tasks and

Table 2 Demographic characteristics of people with dementia and family carers

	People with dementia $n = 22$	Carers $n = 23$
	Mean (SD) or %	Mean (SD) or %
Age	74.7 (6.00)	65.9 (13.68)
Age range	From 65 to 84	From 32 to 86
Gender		
Male	16 (73)	4 (17)
Female	6 (27)	19 (83)
Ethnicity		
White British	15 (68)	20 (87)
Other White European	4 (18)	2 (8)
Caribbean	3 (14)	1 (4)
Education		
School leaver (14–17)	12 (54)	10 (43)
School leaver (18 years of age)	4 (18)	2 (9)
Higher education	4 (18)	6 (26)
Further education	2 (9)	5 (22)
Mean MMSE at baseline	22.5 (3.38)	
Mean number of iCST sessions completed	49 (18.38)	
iCST session range	From 18 to 75	

iCST; individual cognitive stimulation therapy; MMSE, Mini-Mental State Examination.

Table 3 Main themes and sub-themes emerging from the interviews

Main themes	Sub-themes
Concept of mental stimulation	<ul style="list-style-type: none"> <li>• Effects of mentally stimulating activities</li> <li>• Types of mentally stimulating activities</li> <li>• Opportunities for mental stimulation</li> <li>• Opportunities to communicate</li> <li>• Enjoyment and pleasant activities</li> <li>• Being active in everyday life</li> <li>• Brought the carer and the person with dementia 'together'</li> <li>• Carer awareness of the 'needs' of the person with dementia</li> <li>• Barriers to implementing the intervention</li> <li>• Factors increasing intervention adherence</li> </ul>
Experiencing changes in everyday life as a result of participating in the individual cognitive stimulation therapy intervention	
Carer adherence to the intervention	

outdoor activities helped them to stay mentally active and enhance their well-being.

I like making things with my hands, just to keep my mind stimulated. (Person with dementia)

They also described the importance of maintaining a sense of connection to family, friends and community such as having grandchildren around or being involved in voluntary work.

Theme 2: Experiencing changes in everyday life as a result of participating in the iCST intervention

*Opportunities for mental stimulation.* Seventy per cent of people with dementia ( $n=16$ ) and 65% of carers ( $n=16$ ) reported that iCST provided opportunities for general mental stimulation and non-specific memory improvement. People with dementia described their experience of mental stimulation as feeling alert, raising general 'awareness of what is happening' and helping them to 'think better'.

Table 4 Types of mentally stimulating activities

• Art and Craft	Painting, drawing, making masks or making cards
• Conversation and communication	Talking to others, discussing politics or current affairs
• Cultural interests	Going to the theatre or a concert
• Music	Playing piano, accordion, singing or listening to music
• Outdoor activities	Social outings, walking, walking a dog, driving or cycling
• Physical activities	Exercise, bowling, leisure games
• Practical tasks	Shopping, cooking, gardening
• Problem solving	Managing and organising
• Quizzes/games	Word games, board games, crossword, word search or dominoes
• Reading	Reading books, poems or newspaper
• Religion	Going to church or praying
• Reminiscing	Sharing meaningful past events
• Social contact	Family, friends and community (i.e. attending meetings or being involved in voluntary work)

Taking part in the iCST intervention also motivated people with dementia to keep their mind active and look for more information about mental stimulation. Some participants talked about iCST helping them to realise that their memory was not completely lost and motivated them to stay mentally active.

"The course has re-stimulated me to think" and "It does sharpen up what you are doing." (Person with dementia)

Some carers noticed that their relative was more alert and confident.

I noticed that if something has come off, it gives him more confidence, he has a little bit more about him, you know, he is not just shrivelling away, he comes out of himself. (Carer)

However, nearly 20% of the people with dementia ( $n=4$ ) did not find iCST stimulating enough and said the activities were too easy.

Silly things (the activities) they're asking you, they didn't help me think better. (Person with dementia)

I didn't gain much from it, because a lot of it wasn't appropriate for my particular stage of difficulty. (Person with dementia)

*Opportunities to communicate.* Most people with dementia said that the iCST intervention provided them with opportunities to engage in conversations and discussions, which they would not normally have. Carers also stated that the design and structure of iCST helped them to frame conversations.

... Just opening topics of conversation, maybe listening to her, encouraging her to express herself and talk about things. (Carer)

*Enjoyment and pleasant activities.* Eighty-two per cent of people with dementia ( $n=19$ ) found iCST

enjoyable. They described the activities as pleasurable, entertaining and interesting. For some people with dementia, the feelings of enjoyment and achievement were more salient than their memory of specific activities.

I have felt I have done something when it is time to pack up and put the things away ... I enjoy doing them ... feel you've accomplished something. (Person with dementia)

Yeah even though like things might not stay with me ..., but it's brilliant. (Person with dementia)

The intervention provided carers with opportunities to interact with the person with dementia and felt their involvement was not a burden.

*Being active in everyday life.* People with dementia reported that being involved in the iCST intervention added value to their daily life such as taking up new activities, feeling motivated and aware of 'things around' them. For some people with dementia, taking part in iCST was an 'obligation', which helped them not only to 'think better' but also to engage in other activities such as revisit activities/hobbies they enjoyed in the past or look for new events and interests.

It's made me start thinking about doing what I used to do which was painting... I think I could do more painting, and that might make me better, you know, and I can get up and do things more easily. (Person with dementia)

Carers also experienced changes in their everyday life such as having 'more of a focus' or looking for further information related to mentally stimulating activities with their relative. Carer involvement in the intervention gave them a break from routine care tasks and opportunities to engage in mutual sharing of pleasurable and mentally stimulating activities with their relative.

*Brought the carer and the person with dementia 'together'.* Most people with dementia reported that iCST activities brought them closer with their carers. Taking part in iCST activities enabled them to 'do things together' to see 'another side of their carer' such as 'being very patient'. Carers also found doing iCST together with their relative provided them with opportunities to engage in enjoyable mentally stimulating activities and enhanced the relationship quality.

It's keeping the relationship going and although I can see that there can be changes in the relationship, doing this kind of activities together cements it and makes you stay involved in each other's lives. (Carer)

*Carer awareness of the 'needs' of the person with dementia.* Engaging in iCST provided carers with opportunities to interact with the person with dementia and gain a better understanding of their cognitive needs. Interactive cognitive support enabled carers to be aware of situations that people with dementia might encounter in everyday life.

... but the main changes were in how I was probably relating to her and thinking about how she would understand things, and how that could be in everyday situations ... The change is probably more about me that I noticed about her. (Carer)

### Theme 3: Carer adherence to the intervention

*Barriers to implementing the intervention.* Carers reported that it was difficult to fit in the activities because of time constraints such as having a full-time/part-time paid job, role strain or other family commitments.

We might have had a problem with identifying the time to sit down and organise ourselves. (Carer)

Some carers found it difficult to be positive as they perceived dementia as a progressive condition.

It is so easy to be negative and very difficult to be positive because you know when you are working with somebody, he isn't going to get better. (Carer)

Physical health problems or decreased emotional well-being also affected engagement for people with dementia.

Only the period when he was reluctant and I suppose that was also tied to him having an emotional response to his condition. (Carer)

A few carers found their approach and communication skills in delivering the sessions could hinder their engagement with the person with dementia.

I was teaching him like a little boy in school. (Carer)

*Factors increasing intervention adherence.* Carers suggested having more help to deliver the intervention by involving other people would improve adherence.

Involvement with other people would be a great aid (Carer)

Peer support was also seen as an extra source of support.

Another way of looking at it I suppose is if there is anyone else in the district that is doing the same thing. (Carers)

Some carers emphasised the importance of mentally stimulating activities for people with dementia commenting it was essential to prioritise their daily tasks to fit in the iCST intervention.

Having to fit it in and knowing that we were going to do it that day...that is a key thing that the carer needs to be aware of their input to stimulate the person that is really crucial. (Carer)

## Discussion

To our knowledge, this study is the first qualitative study embedded in an RCT to explore concepts of mental stimulation and experiences of people with dementia and family carers in taking part in the iCST intervention. The findings suggested that people with dementia and their carers were able to relate to the concept of mental stimulation and identified a variety of mentally stimulating activities. Their appraisal of the meaning of mental stimulation helped them to stay mentally active (Yates *et al.*, 2015a). The iCST intervention provided people with dementia with opportunities to engage in general and intellectual stimulating activities that might help them to 'think better' and to increase their alertness and awareness (Onder *et al.*, 2005; Spector *et al.*, 2011). However, this finding is not supported by the quantitative results showing no clinically significant improvement in cognition for people with dementia, which may be attributable to the low adherence rates.

People with dementia and family carers valued iCST as a tool, which enabled them to initiate conversations and provided a framework for communication (Onder *et al.*, 2005). It also strengthened interpersonal communication skills, especially when adopting the iCST key principles (Spector *et al.*, 2003). The majority of people with dementia and family carers found that iCST offered opportunities to be involved in enjoyable and pleasant activities, revisiting or focusing on new interests and hobbies. This study provides further evidence of the importance of taking part in enjoyable activities so that people with dementia remain engaged (Cartwright *et al.*, 1994; Hellström

*et al.*, 2007). The results are consistent with the enrichment process theory that people with dementia might not remember details of the activities, but they were able to reflect on 'feelings of enjoyment' and 'feeling good' (Cartwright *et al.*, 1994; Nygard, 2006). People with dementia felt motivated by taking part in the iCST intervention as they realised that their memory was not completely lost (Moebs *et al.*, 2015; Thomas and Velthouse, 1990). Therefore, they wanted to 'fight back' as much as they could by remaining mentally active (Clare, 2002; Genoe and Dupuis, 2014). Additionally, engaging in the iCST intervention helped carers to have a break from routine care tasks and build a rapport with their relative (Roland and Chappell, 2015).

Individual cognitive stimulation therapy provided opportunities for people with dementia and their carers to 'come closer' and further strengthen their caregiving relationship. This finding is consistent with the quantitative result that participating in iCST enhances the quality of the caregiving relationship from the person with dementia's perspective. Improvement in the relationship quality may relate to people with dementia engaging in daily activities (Bartlett, 2015). Participating in iCST sessions provided people with dementia with opportunities to mutually share pleasurable and mentally stimulating activities with their carers and experience a sense of self-worth. Carers found that being involved in iCST enabled them to gain a better understanding of the cognitive needs of their relative in everyday life. This result is consistent with the scaffolding theory, which asserts that cognitive support helps carers to be sensitive to the cognitive needs of the person with dementia (Cavanaugh *et al.*, 1989). Furthermore, cognitive support by carers can help people with dementia to stay mentally active and improve the relationship quality (Fauth *et al.*, 2012; Genoe and Dupuis, 2014; Phinney, 2006; Townsend and Franks, 1995) and enhance carer well-being (Moon and Adams, 2013).

Carers identified several barriers to implementing the intervention. They found it hard to fit iCST into a busy schedule (Yates *et al.*, 2015b). This might relate to them having little time or energy for pleasurable activities (Adams, 2008; Campbell *et al.*, 2008). Carers found that engaging people with dementia in iCST could be particularly challenging because of the progressive nature of the illness. Poor physical health or decreased emotional well-being was considered a barrier to activity participation for people with dementia (Choi and Twamley, 2013). Some carers did not feel skilled enough to deliver the intervention, which could impact on intervention adherence (Chee

*et al.*, 2007). Carers suggested that having extra support by involving other people in delivering the intervention and prioritising their daily tasks would help to reduce role strain (Lopez-Hartmann *et al.*, 2012). As a result, it might improve carers' adherence to the intervention.

## Limitations

There are several limitations in this qualitative study. A possible bias is that most participants who were interviewed had done well with the intervention. This bias could have influenced external validity by not approaching dyads, who did not complete any sessions or reported poor compliance (i.e. 10 sessions or less) (Prick *et al.*, 2014). The data may have been affected by social desirability bias such as participants' positive perceptions of the intervention.

The qualitative findings indicated that although most people with dementia and carers enjoyed the sessions, there were also a few comments that the iCST sessions were not challenging enough. Some people with mild dementia thought the intervention was probably not stimulating enough for them. Future research should investigate issues of suitability of cognitive stimulation interventions and the importance of matching activities to personal preferences and level of stimulation.

## Conclusion

People with dementia and their carers found iCST stimulating and enjoyable, but many had difficulty completing all the sessions as planned. The feedback from carers suggested that providing extra support by involving other people in delivering the intervention may help to improve intervention adherence. The findings also support the theoretical framework of carer involvement in CBIs for people with dementia where interpersonal interactions, mutual sharing of pleasurable and mentally stimulating activities and carers' cognitive support mechanisms are conceptualised as mediators of carer well-being.

From a clinical perspective, iCST may be a useful tool to help people with dementia and their carers to communicate and enhance the quality of their relationship. This has important implications for clinical practitioners and policymakers. Although the iCST intervention was primarily designed to deliver benefits for people with dementia, the findings suggest that future research should involve carers in the development of interventions where possible to achieve maximum benefits and improve their evaluation.

## Conflict of interest

L.Y., M.O., P.L. and V.O. have a patent of the Making a Difference 3: individual cognitive stimulation therapy: a manual for carers.

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## Author contributions

P. L. prepared the manuscript based on a chapter of her PhD thesis. P. L. recruited participants, conducted individual interviews and analysed the data gathered. P. L., V. O. and M. O. were involved in the development of the design and methodology of the qualitative study. L. Y. and F. H. contributed to the recruitment and the analysis of the data gathered. All authors reviewed and commented on drafts of the manuscript, revising it critically for important intellectual content and read and approved the final manuscript for publication.

### Key points

- The qualitative data reported that individual cognitive stimulation therapy (iCST) provides opportunities for people with dementia and their carers to engage in pleasurable and mentally stimulating activities.
- iCST may be a useful tool to help people with dementia and their carers to communicate and can enhance the quality of the caregiving relationship.
- Carers delivering iCST reported that the intervention increased their awareness of dementia as a disease and the every-day difficulties their relative may experience.
- Involving others in the delivery of sessions may improve intervention adherence in future evaluations of similar interventions.

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