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How Older Adults Experience Cognitive Stimulation Therapy for Dementia: A Thematic Analysis

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Abstract

Objectives: This research presents the perspectives of people living with dementia. Specifically, there is a lack of research investigating how people with dementia experience Cognitive Stimulation Therapy (CST). This research therefore qualitatively explores the views and experiences of participants following a 14 week CST group.

Method: Five people with dementia (4 males, 1 female) were recruited from one older adult community treatment team. There were no drop outs. Participants completed a group interview directly following the final CST session. This interview was undertaken by the Psychology department. It was recorded and transcribed Verbatim. The data was then analysed utilizing thematic analysis. This revealed the two main themes that CST resulted in 'social interaction and support' and 'benefits of the group'.

Conclusion: The findings underscore the benefit of CST in facilitating a deep social connection among people living with dementia. Reportedly this was a distinctive connection with therapeutic benefit. It is noteworthy that participants felt apprehensive prior to joining the group. The results indicate that people with dementia can experience wellbeing. There is also evidence that CST activates cognition. Specifically, it was therapeutic for people to realise that longer term memory could be accessed. Participants highlighted the emotional impact of the group ending. This raises questions regarding the implementation of follow up CST. This could be explored by future research. It would also be informative to solely investigate how group CST impacts on subjective wellbeing and its links or otherwise with long term memory, socializing, planning and levels of functioning.

Key Words: Dementia, group CST, older adult community treatment team, thematic analysis wellbeing, cognition.

Introduction

Dementia is an umbrella term referring to a number of neurological conditions in which chronic or progressive disease of the brain leads to physical changes (AmericanPsychiatric Association, 2013; World Health Organization [WHO], 2019). Common causesinclude Alzheimer disease, cerebrovascular disease, frontotemporal, Parkinson's disease, and Lewy bodies in addition to numerous rarer illnesses (Lautenschlager & Martins, 2005).Typically caused by age related pathophysiological processes, people experience cognitive impairments in areas including language, judgement, calculation, memory, thinking,orientation, comprehension and learning capacity (WHO, 2019). Clinical presentations can vary depending on the aetiology of the underlying disease in the mild or early stages,however, it is characterised by global cognitive impairment, changes in behaviour or personality and functional independence increasingly becoming compromised (Bahar-Fuchs et al., 2019; Wilson et al., 2012).There can be delays in detecting dementia during the earlier stages due to its misidentification with other issues such as depression or typical age-related brain changes.

Even with a mild cognitive impairment which has been identified through formal examination, individuals are still able to execute most activities of daily living (Albert et al., 2011; Bahar-Fuchs et al., 2019; Petersen, 2004). A shift occurs at the mild to moderate stages where impairments become more profound and functional disability is very evident; oftenleading to a significant increase in caregiver input (Berger et al., 2005; Van Soest-Poortvliet et al., 2015). During the more advanced stages of dementia, people experience extensive impairment within most functional and cognitive abilities; which requires access to older adult services in order to manage symptoms and to enhance quality of life (QoL) (Mitchell et al., 2009; Van Soest-Poortvliet et al., 2015).

Dementia is the leading cause of disability worldwide, and a major increasing global health challenge with 152 million patients predicted to have dementia within the next 50 years (International et al., 2020; Wancata et al., 2003; Wu et al., 2017). It is associated with substantial societal, emotional and economic costs making research in this area imperative (Wittenberg et al., 2019; WHO, 2017). Despite decades of research and clinical trials, there remains no cure or effective preventative treatment for the causes of dementia (Ritchie et al., 2015). Acetylcholinesterase (AChE) inhibitors are the most commonly prescribed pharmacological management method for Alzheimer's disease and other dementias (Marucci et al., 2021; National Institute for Health and Care Excellence [NICE], 2018). Although, its effect on cognitive symptoms is suggested to be mild, unlikely to alter the course of then disease, temporary and not universal (Birks, 2008).

Subsequently, caring for people with dementia requires a multidisciplinary approach to deliver individualised non-pharmacological treatments (NPT), in conjunction with input from the primary caregiver (Bahar-Fuchs et al., 2019; Poulos et al., 2017; Zucchella et al., 2018). NPT interventions may promote independence, improve function, cognition and well-being. Despite having no impact on the underlying biological markers, they target other clinically meaningful outcomes. Within NPT interventions, cognitive stimulation therapy (CST) has been utilised for almost 20 years and is a well-established intervention for mild to moderate dementia (Spector et al., 2003; Yates, Yates, Orrwell, et al., 2018).

CST by definition; 1) includes a social element usually occurring within a group or with a family caregiver; 2) targets social and/or cognitive function; and 3) incorporates cognitive activities that do not primarily involve practice on specific cognitive modalities (Aguirre et al., 2013; Clare & Woods, 2004). Typically it is administered as a 7-week, 14-session programme with themed activities such as money, childhood, orientation, current affairs and word associations (Spector et al., n.d.). Although due to limitations in resource and time constraints, many National Health Services deliver the programme once a week for 14-weeks (Cove et al., 2014; Kelly et al., 2016). Numerous randomised controlled trials report CST improves QoL and cognition whether or not a person with dementia is being treated with AChE's (Aguirre et al., 2013). Further, some studies suggest improvements extend beyond medications' effects, and that these benefits can be maintained for more than a year (Woods et al.,

2018). Qualitative studies also indicates that participants experience improvements in their ability to engage in conversation in or outside of sessions, report feeling more positive, relaxed and confident, and are more able to share difficulties (Khan et al., 2014; Spector et al., 2011). Moreover, improvements in QoL were significantly correlated with improved communication and a reduction in depression symptoms (Spector & Orrell, 2006). CST remains the only NPT recommended by the NICE to improve cognition for people with mild/moderate dementia (NICE, 2018). Both the NICE and Social Care Institute for Excellence (SCIE) have published national clinical practice guidelines on supporting people with dementia concluding people with mild to moderate dementia should all be given the opportunity to participate in a CST programme (NICE-SCIE, 2007). As a cost effective

Treatment it has been incredibly successful within the United Kingdom, leading to an increase in CST being culturally adapted for use internationally (Knapp et al., 2006; Lobbia et al., 2019).

The Present Study

When evaluating complex interventions, it is advised to utilise qualitative methods alongside randomised controlled trials to gain a richer understanding of the real-life and long term effectiveness of the intervention (Lewin et al., 2009; O'cathain et al., 2013). It was the first time that this Cumbria Northumberland Tyne and Wear (CNTW) Older Adult Community Treatment Team had utilised CST as an intervention for people with dementia.Thus an evaluation of its effectiveness was considered appropriate in accordance with national guidelines (NICE, n.d.; Sheldon & Harding, 2010). Involving service users in the planning, provision and evaluation of services is an essential NHS requirement, and ensures that the service is inclusive, high quality, accessible and meets the needs of the potential clients. There are numerous qualitative studies investigating the impact, acceptance, feasibility and benefits of CST for people with dementia and their carers (Gibbor et al., 2020; Kvande & Damsgaard, 2022). Further, qualitative studies have been utilised to understand people's experiences of living with dementia (Steeman et al., 2006). There are few studies investigating the overall experience and perspectives of CST for people with dementia. To add to this literature base, this research qualitatively explored the views and experiences of a group of people living with dementia participants following a CST intervention.

Methodology

Design

A qualitative study design was considered appropriate to explore the research question due to its constructivist nature and its ability to obtain the subjective view of participants in depth (Camic et al., 2003). The primary researcher acknowledges that personal beliefs, background and experiences will have inevitably influenced the generation of themes and interpretation of findings. This includes a family history of dementia. An iterative process of self-reflection was therefore undertaken in order to identify any potential bias, and ensure that an openness remained to the diverse perspectives presented within the data. Furthermore, reflective practice and ongoing discussion with Psychologists resulted in maintaining a transparent stance. It is noteworthy that the interviews were conducted by a Psychologist, who recognised the intricacies of communication within this population thus, gentle guidance was occasionally provided to help participants delve deeper into their experience of the CST intervention.

Participants

Five participants were voluntarily recruited from a CNTW Older Adult Community Treatment Team in the NHS Trust. The inclusion criteria required participants to have met DSM-IV criteria for dementia (American Psychiatric Association, 2013) as documented on the file, have attended 14-sessions Cognitive Stimulation Therapy Intervention over 7-weeks as detailed in

NICE Guidelines (NICE, 2019), have the ability to communicate and understand communication further, to be able to see and hear well enough to participate. Exclusion criteria included no major physical illness or disability which could impact on participation and no diagnosis of a learning disability. There were 4 males and 1 female. There were no drop outs. The participants were interviewed as a group on one occasion.

Materials

A semi-structured interview was developed (Appendix A) that was informed by Spector et al., (2011). The interview considered outcomes which CST is designed to impact including memory, language, mood, communication and functioning. Participants were also asked their views on the intervention.

Procedure

Ethical and research governance was received from NTW. Further approval was obtained by Newcastle University. The interview was conducted by a clinical psychologist in one session at the end of the CST intervention and audio recorded onto one tape. The interview time totalled 47-minutes. Participants consented in writing to engage in the intervention and the research process. Participants presented with the capacity to make this decision. Interview transcripts were analysed with thematic analysis (Braun & Clarke, 2006, 2012). Measures were taken to deidentify any named groups and all personal identifiers were removed to preserve anonymity. Each interviewee was given a personal identifier number (e.g. P1, P2).

Data Analysis

The interviews were transcribed verbatim from digital recording and analysed using thematic analysis (Braun & Clarke, 2006). This involved 6 phases which are described within (Table 1).

Table 1. Phases of thematic analysis

Phase	Description of the process
1. Familiarising yourself with your data	Data was transcribed verbatim, and transcripts were checked against the original recordings to ensure accuracy. The transcribed data was then read and re-read while noting initial ideas and reflections and searching for meanings or patterns.
2. Generating initial codes	Interesting features within the data were coded systematically across the entire dataset. Codes identified either semantic (close to the content of the data) or latent (meaning behind the surface of the data) features. Codes were generated in a theory-driven manner in relation to the research question. Once a code was identified, the data was reviewed to determine whether it was relevant to an existing code; if not, a new code was generated. Relevant surrounding data was retained to ensure context was not lost. This phase ended when the entire dataset was fully coded and all data relevant to each code had been collected.
3. Searching for themes	The different codes and relationships between codes were analysed to consider how they could be combined into different levels of themes, including overarching themes and sub-themes. Codes that did not appear to belong within themes were categorised under the theme "miscellaneous." This phase ended when candidate themes and sub-themes had been created and all relevant data extracts had been coded.
4. Reviewing these themes	**Level 1:** Themes were checked against the coded extracts and the entire dataset by reading all collated extracts for each theme and considering whether they formed a coherent pattern. Themes without sufficient supporting data were discarded, unclear themes were combined, and themes containing excessive or incoherent data were separated into new categories. **Level 2:** A thematic map was generated to assess whether individual themes and the overall thematic map accurately reflected the meanings evident within the dataset. The entire dataset was re-read to identify any themes that may have been missed.

5. Defining and naming themes	Clear names and definitions were identified for each theme. Each theme was considered in relation to the overall story and the research question, and sub-themes within each theme were identified.
6. Producing the report	Vivid and compelling data extracts were selected to provide a logical and concise account of the data in relation to the research question and relevant literature.

Results

2 main themes emerged from the analysis. These are depicted in Figure 1. [Figure 1 near here]

Theme 1: Social Interaction and Support

Sub Theme: New friendships and Social Connection

Participants consistently highlighted the sense of community and support fostered by the group. Five participants expressed that the group led to an increase in social connection which they found very positive. One participant described their group experience as 'great' attributing it to the opportunity to 'make new friends' (P1). Additionally, another participant described the value of new friendships in helping them to 'feel better in yourself' and enhancing their emotional wellbeing (P3). Another participant explained how the group helped them to 'open…life up' as diagnosis can lead to a person becoming 'very insular' (P4). One participant felt they had 'a better in affinity, with the whole group of people here' than they had with their family (P3), attesting to the strength of their new connection. The strength of participants' connection was further evidenced as participants organised additional group meetings independently.

Sub Theme: Sense of Belonging

It was evident that a shared sense of belonging formed the foundation for the relationship participants were able to build with each other. Moreover, they appreciated the opportunity to share experiences, challenges, and strategies with people who understood their situation. Multiple participants realised they were 'in the same boat' (P5) and that 'they were not the only one' (P2) in their journey with dementia which seemed to have a reassuring effect. One participant highlighted how 'all suffering the same thing' made it 'a lot easier in their mind' (P5). During discussions, one participant emphasised how there was value in 'being able to talk to each other without feeling as though' they were going to be asked 'why is that?' (P4), highlighting how shared experiences facilitated relationship building. Another participant added how having shared experience meant they 'wouldn't have to go on about' things 'for a long time' (P5) when discussing their feelings with group members. There was something meaningful about coming together as a group, and through the shared experience of dementia they found strength. One participant described that dementia was 'not like a broken arm, it's not totally obvious to people you meet..' but since meeting each other they now knew what it was like and what it was about (P4).

Sub Theme: Desire for Continued Support

All participants concurred that the support offered by this group should continue, further, that the session time and the intervention length should be extended. In relevance to the length of the CST sessions, one participant advocated for an extension of 'at least an extra half hour' (P3), a sentiment shared by two other participants. Similarly, another

participant stated due to the time it took to travel to the venue combined with the fact that sessions began with singing meant 'you're only just getting into' the group before it ended (P4). They expressed a preference for an extra hour which received support from three other group members. The value of extended time was discussed amongst group members with one stating that adding an extra half an hour would make travel 'well worth the trouble' (P2), further, that extended time meant any topics that

seemed to be 'really condensed' could be Extended (P4). Another group member added that extended time was important due to the 'comfort' that being in a space with other people that have dementia provided (P5). Although, beyond just extending session, there was a longing among group members for ongoing support and engagement. One participant explained that 'it's not gonna' be the same without coming here' (P3). Another participant suggested that sessions should go on 'for a few weeks more' (P5) with three other participants agreeing. Two group members agreed that the group had become an integral part of their routine, and there was uncertainty about what will happen after the group ended. The emotional impact of the group ending was palpable with different participants stating they could not 'believe this session was the last one' (P2), how it would 'make a big difference…not having the group' (P5), and that they would have 'nought to look forward to after this' (P3). One participant stated that there had 'to be some follow-up after this' as thoughts about 'not going to meet with friends' anymore would arise as they headed home (P4). Additionally, another emphasised how practical it would be to be informed of other available 'associations that deal with Alzheimer's and dementia that have groups' (P1). This all highlighted the significance of ongoing support, and how the group addressed some of the social aspects of living with dementia.

Sub Theme: Reassurance and Encouragement to Attend Similar Groups

Participants emphasised how important it was for others with dementia to attend similar groups and highlighted the benefits in alleviating feelings of isolation, facilitating open discussion about their experiences, and fostering a sense of community. Three participants agreed that CST should be recommended to other people with dementia, in group members. The value of extended time was discussed amongst group members with one stating that adding an extra half an hour would make travel 'well worth the trouble' (P2), further, that extended time meant any topics that seemed to be 'really condensed' could be extended (P4). Another group member added that extended time was important due to the 'comfort' that being in a space with other people that have dementia provided (P5). Although, beyond just extending session, there was a longing among group members for ongoing support and engagement. One participant explained that 'it's not gonna' be the same without coming here' (P3). Another participant suggested that sessions should go on 'for a few weeks more' (P5) with three other participants agreeing. Two group members agreed that the group had become an integral part of their routine, and there was uncertainty about what will happen after the group ended. The emotional impact of the group ending was palpable with different participants stating they could not 'believe this session was the last one' (P2), how it would 'make a big difference…not having the group' (P5), and that they would have 'nought to look forward to after this' (P3). One participant stated that there had 'to be some follow-up after this' as thoughts about 'not going to meet with friends' anymore would arise as they headed home (P4). Additionally, another emphasised how practical it would be to be informed of other available 'associations that deal with Alzheimer's and dementia that have groups' (P1). This all highlighted the significance of ongoing support, and how the group addressed some of the social aspects of living with dementia.

Sub Theme: Reassurance and Encouragement to Attend Similar Groups

Participants emphasised how important it was for others with dementia to attend similar groups and highlighted the benefits in alleviating feelings of isolation, facilitating open discussion about their experiences, and fostering a sense of community. Three participants agreed that CST should be recommended to other people with dementia, in particular one expressed that 'it's the best thing they could do… providing they've got somewhere to go' (P5). Moreover, another participant emphasised the importance of not being 'alone' in their dementia journey (P2), which three other participants agreed with. One participant described how groups like this 'open up your life' (P4) and provided opportunities for reconnection. Participants also acknowledged initial scepticism or anxiety was common among those considering attending similar groups in the future. Although, they agreed that the benefits outweighed any initial apprehension. For example, one participant recalled their initial hesitation stating, 'they didn't want to come' when they were invited, but they were 'so glad that they did' (P5). Another explained that they were unsure if they should attend but 'enjoyed it' in the end (P2). One participant attributed their initial fear was due to not 'knowing

what to expect' and having false beliefs about what they would be asked to do as part of the group (P3). Despite this anxiety, three participants agreed that it was 'very good to go' (P4) (P5), emphasising the importance of 'getting that initial 'frightness' out of the way' (P4).

Theme 2: Benefits of the Group

Sub Theme: Enhanced Memory

Participants spoke about personal benefits from the group including enhanced long term memory. Three participants agreed that there had been improvements in their long term memory. When asked what they had noticed, one participant explained that they were able to 'go right down to a long term memory…in a lot more detail than before…and remember the acting on the telly' which they previously struggled with (P1). Another group member referred to learned group skills including writing things down so they do not forget things which they had 'never done before in their life' (P2). One participant explained that 'all the different sections…like the money and things about what you did as a child' (P4) helped long term memory to be activated. There was also discussion about how the group's structure helped to retrieve memories with P3 explaining, 'things like this that bring them back up, bring them back to the front but…because we…from being here get into that structure it has been useful'. In complement, another participant referenced how the group's routine or singing a few times a week helped to activate long term memory.

Sub Theme: Enhanced Mood

Participants mentioned benefits from attending the group including improved well-being, increased happiness and feeling better about themselves. All of the group members reported that they looked forward to coming to the group. There was agreement from four participants that the group had led to them being more open to laughter with one participant stating that 'when we're all together, there's always a smile on someone's face' (P5). Moreover, another explained that the group enabled them to 'have a bit of a laugh' (P3). There was agreement between two participants that they should find ways to 'smile a bit more at home' (P5) (P2). Participants made a number of references to lower well-being prior to attending the group again suggesting that participation led to a positive change in affect. For example, participants stated that they no longer 'felt sorry for themselves' (P5), 'now felt a lot brighter' (P5) and no longer felt as scared (P2).

Sub Theme: Sense of Change and Growth

Participants acknowledged that there was personal growth and changes in their attitudes since joining the group. Four group members agreed that they had changed because of the group and one participant commented that they had all 'grown up together' (P3) which another agreed with. One participant commented on another's personal growth with P1 telling P5 that she 'was a different lady, to what she was when we all started' due to coming out of herself suggesting an increase in confidence. One participant spoke about how a reduction in fear meant they were able to visit the places they used to go with their late wife with P3 explaining 'when me wife died when I went down because we…I went down 'cus we use to do all our courting down there…and uh, I couldn't go any further than the railway line 'cus I was frightened of going down to the beach where we used to walk and along the cliffs. But I've been down since'. During discussion, one participant acknowledged that people in the group had changed due to their ability to laugh about things they struggled to before. One participant stated that prior to the group they 'couldn't remember that life still goes on' (P5) which another group member agreed with suggesting that this group created space for learning to live with a dementia diagnosis. One participant commented that it was 'better to get dementia out' (P3) which another agreed with suggesting an increased openness to talking about the impact of illness.

Discussion

This study aimed to investigate the overall experience and perspectives of people who completed CST within an Older Adult Community Treatment Team. This initiative aligns with NHS professional practice guidelines, which stresses the importance of evidence-based interventions to improve the care and support provided to individuals with dementia. The findings suggested that participants benefited from the CST in multiple ways. All members reported increased social connectedness and a sense of community forged by the group, further, there was a feeling of belonging underpinned by the new relationships. All participants expressed that group support should continue, sessions should be extended, moreover, that other people with dementia would benefit highly from attending the group despite any initial apprehension. Participants also reported improved wellbeing and happiness as they looked forward to sessions and were more open to laughter due to the group. In addition, participants spoke about cognitive benefits of the group such as enhanced long term memory. Participants also noted personal growth and changes in their attitudes since joining the group. For example, with some participants overcoming fears, and becoming more open to discussing their illness or its implications. A systematic review of 37 randomised controlled trials evaluating the effectiveness of CST for people with dementia compared to usual care/unstructured social activity found similar results regarding improved wellbeing, day-to day ability, mood and cognition (Woods et al., 2023). Furthermore, the benefits equated to approximately a 6-month delay in cognitive decline. The study suggested that benefits were greater when sessions occurred bi-weekly, further, when participants were of mild severity at onset. Earlier qualitative studies of the impact of CST for dementia also reported similar themes including feelings of not being alone due to common difficulties, easier communication in or outside of the group, improvements in memory, concentration and alertness (Mason et al., 2005; Spector et al., 2011). Further, participants also reported improved confidence and mood. This study is also in line with literature focused on 'the experience of interactions' in group CST which found themes such as shared identity and sense of togetherness among group members (Orfanos et al., 2021). Thus, the results of this study are consistent with both qualitative and quantitative previous CST research. When considering the mechanisms in which CST leads to benefits, researchers already discuss the view that a lack of cognitive stimulating activity can lead to decline even for normal ageing (La Rue, 2010; Woods et al., 2023; Yates, Yates, Orrell, et al., 2018). CST provides opportunities to cognitively engage within a socially stimulating interpersonal environment which may slow cognitive decline. Another possible mechanism for

Improvement is related to 'excess disability' whereby, a person with dementia may not be functioning at their optimal level due to becoming socially withdrawn, unmotivated, and anxious or lacking confidence (Sabat, 1994). CST in turn addresses some of these barriers by creating a relaxing, non-judgemental environment where participants are given a greater sense of purpose and engage with others who share their identity (Gibbor et al., 2021; Yates, Yates, Orrell, et al., 2018). Therefore, removing any fear of failure inhibiting their responses during conversation and providing more opportunity to practice.

Future research and limitations

Overall the intervention was well received and considered a positive experience by participants. Future research could explore the psychological impact of the ending of the group as well as the issue regarding follow up CST. It would also be informative to explore the impact of CST on longer term memory in tandem with participant's experiences. Future research could also investigate the specific processes underpinning changes in subjective wellbeing. The links or otherwise between subjective wellbeing and longer term memory recall, socializing, planning and levels of functioning could be investigated. Whilst participants did engage in recall, interviews could have been facilitated at the beginning, middle and the end of the intervention. This would have resulted in monitoring the process of change. It was clear that interviewing at the end of the intervention influenced responses. Another limitation is that carers observations regarding changes or otherwise within participants mental health and functioning was not recorded. Indicators of caregivers caring capacity was also not monitored. Additionally, it was beyond the scope of this research to report on each client's unique context. There may be differences regarding how people experience CST based on factors such as co-morbid physical health issues, ease of access to services as well as by family presence. This could be explored by future research.

Conclusion

This study explored the experiences of individuals with dementia following CST. The findings highlighted its significant advantages, including increased social connection and a sense of belonging among participants. Participants supported the continuation and extension of group sessions, citing positive impacts on well-being, happiness, and cognitive abilities.

The study adds to the literature base supporting the use of routine CST groups for people with mild to moderate dementia.

Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

Appendix A

Semi structured Interview informed by Spector et al., (2011) General Impact of the group

Impact on:

- Memory
- Language
- Mood
- Communication
- Functional abilities
- Relationships

What worked well in the group?

What would you change about the group?

What would you say to other people with dementia about the group?

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