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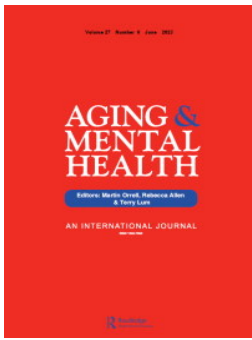
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Experiences of cognitive stimulation therapy (CST) in Brazil: a qualitative study of people with dementia and their caregivers

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ABSTRACT

Objectives: There is a lack of investment in psychosocial treatments for people with dementia in Brazil. Cognitive Stimulation Therapy (CST) is a group-based intervention that has shown to have benefits on activities of daily living and mood for people with dementia in Brazil. This study aims to explore the experiences and perceived changes following CST groups.

Methods: Individual interviews were conducted with the participants of the group ($n = 12$) and their caregivers ($n = 11$). Framework analysis was used to inspect the data.

Results: Two main themes have emerged: 'Personal benefits of being part of the group', containing two subthemes: 'Benefits for caregivers' and 'Benefits for person with dementia' and 'Day-to-day changes', containing seven subthemes: 'Memory', 'Sociability', 'Language', 'Mood', 'Orientation', 'Everyday activities' and 'Behavioural and psychological symptoms'.

Conclusion: Results suggest that CST groups led to perceived personal benefits for the people with dementia and caregivers and that there are perceived changes for the participants of the groups.

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KEYWORDS

Dementia; cognitive stimulation therapy; qualitative analysis; framework analysis

Introduction

Dementia is a global challenge, with increasing life expectancy leading to a growing number of people suffering from chronic health conditions associated with ageing (Mograbi & Morris, 2018). In Brazil in 2019, there were more than twenty-nine million people aged over sixty, and two million Brazilians were living with dementia. It is predicted that this number will rise to more than six million by 2050, with huge social and economic impact (Nichols et al., 2022). Dementia needs to be addressed as a public health priority, and there is an urgent need for further investment in interventions for this condition.

Current government policy in Brazil focuses on pharmacological treatments for dementia, and investment in psychosocial interventions is lacking. However, in the ageing population, particularly in people with dementia (PwD), polypharmacy associated with increased health care needs is common and can lead to a greater risk of development of drug related problems and adverse drug-drug interactions. This can result in an increased risk of mortality, morbidity, hospital admission and health care burdens (Ruangritchankul et al., 2020). Furthermore, considering that pharmacological treatments for dementia might not be effective to or tolerated by all, besides having possible side effects (Vasse et al., 2012), this leaves PwD who are ineligible for medication without treatment options (Nakamura et al., 2015). Yet, there is good evidence that some non-pharmacological treatments can improve global physical and cognitive functions, activities of daily living skills, social interaction and quality of life of PwD (McDermott et al., 2019) with the added benefit of some

being cost-effective (Knapp et al., 2022). Considering that and the ethical prerogative to employ least restrictive clinical alternatives, non-pharmacological treatments may have an important role in the management of dementia.

Cognitive Stimulation Therapy (CST) is a brief, evidence-based group programme developed in the UK for people with mild to moderate dementia. It is composed of fourteen themed sessions that aim to improve cognitive functioning using techniques that stimulate different cognitive skills while also emphasizing the benefits of the social aspect of the intervention. Clinical trial results suggest a significant improvement in cognition and quality of life (Lobbia et al., 2019). A recent review including ten qualitative studies indicated perceived benefits in cognition, mood, confidence, activity and stimulation outside the intervention, enjoyment of the groups, the relationships of both carers and PwD and other non-specific ones (Gibbor et al., 2021). It is the only non-pharmacological intervention recommended by the UK National Institute for Health and Clinical Excellence guidelines to improve cognition, independence and wellbeing (NICE, 2018) and it is endorsed by Alzheimer's Disease International (2011).

A randomised controlled trial (RCT) of CST was performed in Brazil to validate the treatment, which had previously been adapted for Brazilian populations (Bertrand et al., 2019). This RCT provided important evidence on the efficacy of CST in Brazil and suggested that participants had significant improvements in mood and in activities of daily living compared to those in the control group (Marinho et al., 2021). However, the

importance of qualitative research should not be overlooked when evaluating an intervention, as it provides insight on the acceptability of the intervention and can be used to explore the experience of participants.

This qualitative study, therefore, was conducted alongside the RCT to explore the real-life effectiveness of CST and to access the perspective of group participants. The aim of this study is to investigate the experiences of PwD and their caregivers in CST groups, and explore possible changes observed, which are not picked up by the quantitative outcome measures.

Methods

Individual semi-structured interviews were used to facilitate exploration of possible changes and the overall experience of the participants of the group and to allow participants to freely express their opinions and observations.

Recruitment

Participants were recruited from two CST groups run in the Alzheimer's Disease Centre (CDA) in Rio de Janeiro as part of the RCT by Marinho et al. (2021). All members of the two groups and their caregivers were invited to and agreed to take part in the interviews. After gathering information from two groups, the research team concurred that the data was sufficiently similar (i.e. sufficiently saturated) and thus recruitment was discontinued (Guest et al., 2020). Recruitment details for the RCT have been outlined elsewhere (Marinho et al., 2021).

Inclusion criteria

Group members were eligible for inclusion in the RCT if they met the criteria established in previous CST trials (Spector et al., 2003). These stipulated that they: (a) met the DSM-IV criteria for dementia (American Psychiatric Association, 1994); (b) scored between 10 and 24 on the Mini Mental State Examination (MMSE); (c) had some ability to communicate and understand communication; (d) were able to see and hear well enough to participate in the group; (e) did not have a major physical illness or disability which compromised participation; and (f) did not have a diagnosis of a learning disability. Caregivers were eligible for inclusion in the study if they had face-to-face contact at least once a week with the person with dementia they provided care for.

Interview process

PwD and their caregivers participated in qualitative interviews, which were conducted individually by three members of the research team. The topic guide was developed by the research team of psychologists and psychiatrists—including one of the developers of CST—taking into consideration domains impacted by non-pharmacological interventions in general. Questions were related to changes in cognition, mood, orientation, behavioural and psychological symptoms (BPSD), sociability, memory, language, everyday activities and general aspects of their experience of attending CST groups. Interviews took place within two weeks of completion of the fourteen CST sessions. Six interviews were carried out by a psychology trainee (RN) who was also the facilitator for the two CST groups. A

further seventeen interviews were carried out by IB and BC (a neuroscientist and a psychology trainee, respectively). The participants were informed about the study and signed the statement of agreement when they were recruited for the RCT. Before each interview, they were also informed that the interview was recorded and gave oral informed consent. Each interview lasted approximately thirteen minutes. Participants were free to add any further details that were not covered in the interview. Interviews were audio-recorded then transcribed verbatim.

Qualitative analysis

The transcripts of interviews were analysed using Framework Analysis (Ritchie & Spencer, 1994). Five key stages were followed: (i) Familiarisation; (ii) Thematic framework identification; (iii) Coding; (iv) Charting; and (v) Mapping and interpretation. Data analysis was carried out by (RN) and another researcher (FF) who was not involved in the CST group or interviews. First, both researchers read all transcripts to become familiar with the broad themes expressed. Then each researcher separately compiled and refined the identified themes into a coding key. After that, both researchers categorised and charted the transcripts accordingly. Finally, mapping and interpretation was applied to map the experience and perceived changes in those who have participated in the CST groups and their caregivers. Throughout the analysis process, thematic saturation was reached (Guest et al., 2006). No specialist software was used to perform the data analyses.

Ethics

The research project was approved by the research ethics committee of the (Institute of Psychiatry of the Federal University of Rio de Janeiro (IPUB-UFRJ; CAAE: 57019616.5.0000.5263).

Results

Sample

A total of twenty-three participants took part in the qualitative interviews. This included twelve PwD who participated in CST groups, and each of their caregivers (two participants were married to each other and had the same caregiver). The number of participants from each group (PwD and caregivers) were estimated following studies suggesting that twelve interviews should be enough to achieve thematic saturation (Guest et al., 2006, 2020). Eight participants with dementia were female and four were male. Six participants had mild dementia and six participants had moderate dementia, as assessed by the Clinical Dementia Rating (CDR). Eight carers were female and three carers were male. All the caregivers were family members of the PwD.

Qualitative themes

Two central themes and seven subthemes were identified from the interviews (Table 1). There was a total of 300 min of recorded interviews. Feedback was mostly from caregivers, but PwD were able to generally speak on their experience and some provided more detailed responses. None of the questions produced null

Table 1. Themes and subthemes identified in individual interviews.

Themes	Subthemes
Personal benefits of being part of the group	Benefits for caregiver Benefits for person with dementia
Changes in daily life	Memory Sociability Language Mood Orientation Everyday activities Behavioural and psychological symptoms

findings. Excerpts from the interviews are provided to illustrate each sub-theme. Caregivers and participants are numbered to provide identification, from one to 11 (caregivers/'C') and one to 12 (participants/'P').

Theme 1: personal benefits of being part of the group

Subtheme: benefits for caregivers. Several caregivers ($n=7$) reported personal benefits for themselves and for the PwD who participated in the group. Caregivers mentioned the satisfaction of seeing their family member enjoying the groups.

We noticed how it [CST] was very interesting, very good for her, how she was talking to everyone, how much she enjoyed it. So, to us, seeing her happy e how everything happened made us pleased, we also found that it was interesting (...). (C9)

Caregivers also praised the way that the therapy was conducted by the CST team.

Until today we had only dealt with doctors, with prescription drugs, who look and say 'look, you have a memory problem, you are disoriented, so I'll give you a medicine for Alzheimer's and one for depression' and we followed this thoroughly, without seeing any improvement, quite the contrary. And since the first time we came here we felt something different. First because we felt very welcomed, you were all very nice, with a contagious joy (...) And the work you did, the groups, it was very good, very good for her, very positive, and I would recommend it to other people, so that they also feel that other people care about them, it's not just the caregivers (who care about them). (C6)

They also commented on how they were able to relax while their relatives took part in the group and how that reflected on their own wellbeing.

It gave me a good feeling that I could do something for myself, I started to exercise [and] take care of my spinal pain. (C1)

Subtheme: benefits for people with dementia. Personal benefits for the PwD were identified by all the caregivers ($n=11$) and group members themselves ($n=11$). These related to fun and enjoyment in the groups.

It was great. I enjoyed it a lot and now I miss it. I enjoyed everything: singing, the games, the ball we would play, because those are things I don't do at home, and I have to do it somewhere. (P9)

In the beginning, she would create some resistance, but after she would leave the session, she would be happy, she would talk all the time about how it was so good, she would thank me so much for having brought her to the session, [she would say] 'thank you very much'. She says that everyone got along super well, [she would say] 'I loved it, where did you find this [CST groups]?'. (C1)

Her experience was good, she would be very lively at the end of the sessions (...) the housekeeper mentioned how much she enjoyed the activities (...). The overall impact on her was positive. (C8)

PwD and their caregivers also commented on the benefits of being in a group environment.

I loved being part of the group, people there were so connected to each other. (P1)

Her experience [with the group] was excellent, she enjoyed it a lot, she would dress up [for the sessions], would get all excited, she wanted to be here [at the sessions], she made friends [in the groups]. She went from being closed off to being socially open, doing the activities and meeting people. It was very good. (C9)

Caregivers also highlighted that CST helped to keep their relatives occupied.

With or without any perceived changes, it was very good for her to be with people ... because we [the family] don't have that free time to be with her, so she usually has five idle days of the week. (C10)

Theme 2: changes in daily life

Subtheme: memory. Some of the caregivers ($n=5$) reported that they had observed an improvement in the memory of the participants of the group, including in relation to the contents addressed during the groups.

The other day she asked a friend of mine: 'how is Ricardo?' and my friend said: 'she is doing great, she remembered the name of my friend's husband', which is very good, my friend asked if I am positive she has Alzheimer's. And I said: 'I am sure, it's the treatment she's been receiving [CST]'. (C1)

His memory has improved, including for playing cards. My niece said that he has been playing better, creating better games, he started to win more matches, and has been thinking faster. (C2)

There was a slight improvement, in the sense that he became aware of our commitments, for example, today he woke up knowing that I had a commitment. (C8)

Subtheme: sociability. There was a consensus among the caregivers ($n=11$) about the benefits of sociability experienced during the groups. PwD ($n=9$) also reported those benefits. In addition, these benefits were reported to have extended outside the therapeutic environment.

I've noticed that she has become more receptive to conversations. Before [CST], the neighbour would visit and she wouldn't say anything, and now she gets up, goes [after the person] and initiates the conversation, which she wouldn't do before. (C5)

It was very good because we were learning from each other. It was worth the time we were spending there [at the sessions]. Being able to talk, to communicate in groups is very good for us that are older people, because usually we don't do much. (P12)

It was good, it was very good and let me explain it to you: she's usually a very secluded person, poor thing, she practically doesn't have friends and I think that seeing other people on a regular basis is very important too, so I thought that it was very good for her. It's a shame it's over. (C7)

Subtheme: language. Some of the caregivers ($n=3$) pointed out that an improvement in language was observed in relation to the words used to describe things and their speech.

She has been more alert, she's had fewer episodes of 'what was I going to say again?', the word comes faster, sometimes forgetting

[the word] would make her nervous, angry, and she's been feeling calmer about it. (C1)

He's been thinking about the words more carefully before saying something. He didn't used to do that, he'd say 'I don't know, I don't know [the word]', but now he concentrates more before saying something, he puts a little more effort into it. (C3)

Subtheme: mood. Caregivers ($n=8$) and PwD ($n=2$) reported improvement in their moods, which came from being part of the group and knowing its benefits, but also from simply being there, sharing that moment with other people.

My mood improved, because while I was waiting for her, me and the other caregivers kept talking and exchanging experiences, it was very good. (C1)

I thought her mood improved a little, I thought because she would wake up singing [after the groups have started]. (C7)

I feel that her mood has been more stabilised, from the tone of voice, from the way she speaks [...]. She would be in a better mood at the end of the group meetings, she would express herself in a positive way. I would ask her if she enjoyed it and she would say she enjoyed it, 'we sang together', she would talk about the group meetings. (C4)

I was feeling more joyful, [because] I was doing something, an activity, you are rejoicing [when you are there]. It is cheerful, right? (P3)

Subtheme: behavioural and psychological symptoms. Caregivers ($n=5$) reported changes related to behavioural and psychological symptoms stating that their relatives have become less agitated and less aggressive, with fewer episodes of false beliefs and delusions.

He's not as aggressive as he used to be. He was threatening me a lot, swearing and offending me. Now he has been more affectionate. Before [CST], he always used to accuse me of having stolen something from him, but this month he did not say anything, he was more attentive to our expenses and bills and did not accuse me [of stealing]. (C3)

She has been less agitated and less irritated. Before [CST], if she could not find the scissors, she would say I was the one who took it, but she has been less aggressive, talking in a calmer way. She still says something sometimes, but in a less irritated way, not as angry. (C4)

Before [CST], sometimes I would say something, and he would get agitated, complain a lot, and nowadays, with this therapy he has not been complaining that much, he's been less agitated. (C11)

Subtheme: orientation. Some of the caregivers ($n=3$) highlighted how taking part in CST groups has helped their relatives to become more aware of their time and space clues.

After the treatment has started, her notion of the days of the week got really better. She is able to relate the day of the week with the TV programs, like: 'Today is Faustão day' [a programme broadcast on Sundays]. (C1)

Now that the sessions are over, she still wants to come [to the CST sessions], and today she got ready to come at eleven a.m. [the day and time she would normally leave to attend CST] and asked me if the people from the group would be there. (C9)

Subtheme: everyday activities. Caregivers ($n=2$) noted how CST has helped their relatives to feel more independent

and to be able to perform everyday tasks without needing full support from them.

Recently, she has used the phone, she called me the other day to ask what time I was coming back home, she used the phone for that, and she was not [using it before]. She became more independent and created more resistance to me helping her: 'you do not have to give me a bath, I am not a child, I know how to manage myself'. It [CST] has improved her self-confidence. (C1)

He has been more independent. He says: 'let me do it!'. Before [CST] he asked me to do it for him, he was more accommodated, now he has been more stimulated to do things on his own. (C2)

Discussion

This study has been conducted in order to gain insight into the experiences of the participants of CST and their carers. Two overarching themes were identified: 'Personal benefits of being part of the group' containing two subthemes: 'Benefits for caregivers' and 'Benefits for person with dementia'. The second theme, 'Changes in daily life' contained seven subthemes: 'Memory', 'Sociability', 'Language', 'Mood', 'Orientation', 'Everyday activities' and 'Behavioural and psychological symptoms'.

The qualitative data add to the findings from the RCT of CST in Brazil (Marinho et al., 2021). In this RCT, participants receiving CST exhibited statistically significant improvements in mood and activities of daily living, compared to those who received treatment as usual. This is demonstrated in the qualitative findings by the theme 'Changes in daily life', with subthemes 'Mood' and 'Everyday activities'.

The RCT (Marinho et al., 2021) did not find statistically significant effects on the cognition and quality of life of the person with dementia or caregiver burden. The qualitative findings show that some PwD and caregivers did perceive improvements in these areas. For example, the subthemes 'Memory', 'Language' and 'Orientation' describe participants' improvement in remembering names, passwords, song lyrics and instructions to games, improved word finding abilities and better awareness to time and space clues. In terms of caregiver burden, subtheme 'Benefits for caregivers' describes the satisfaction that caregivers felt at doing something to help the person they care for, and their ability to relax whilst their relatives took part in the group. These outcomes are perceived by PwD and caregivers in the qualitative results but not observed in the quantitative results. There are a number of possible reasons for this: the reported perceived benefits may be true for some participants but not others, such is the nature of qualitative data. The sample size for the RCT (Marinho et al., 2021) may not have had the power to detect significant effects. Also, there may have been domain specific improvements in some outcomes, which were not captured by the total score of the outcome measure in the RCT (Marinho et al., 2021). Finally, gold standard measures and questionnaires that are typically used to assess the efficacy of CST might not fully capture the benefits provided by the treatment or any potential role of individual differences. Indeed, studies have suggested that individual characteristics, such as education and age, might influence the effect of CST (Carbone et al., 2021, 2022). These could be explored in future research through measurements and analysis of domain-level outcomes and examining whether individual variables affect individual responses to CST.

Group participants and their caregivers reported benefits and changes resulting from CST which are evident and

meaningful to them. The use of qualitative data may increase the sensitivity to effects of the intervention. This is consistent with previous findings that quantitative outcomes measures may not be sensitive enough to detect effects resulting from CST, which can instead be explored through qualitative outcomes (Toh et al., 2016). Alternatively, demand characteristics and investigator bias may have led to qualitative findings that are not matched by quantitative improvements.

Our findings are consistent with previous qualitative research into the experiences of CST participants and their caregivers. A previous review highlighted key outcomes including improvements in cognition (including language), mood and relationships, enjoyment of groups and continued stimulation outside of the intervention environment (Gibbor et al., 2021). An additional theme in the review was confidence, and although this is not an explicit theme within our study, an improvement in confidence is evident within many of the caregivers' and participants' accounts. Our study also highlights perceived outcomes such as an improvement in BPSD, everyday activities and orientation, which were not highlighted in the most recent review of qualitative data (Gibbor et al., 2021). To some extent, these responses might have been prompted by the questions addressing these domains. Indeed, the topics included in our guide were chosen in order to encompass a variety of domains possibly impacted by non-pharmacological interventions (Olazarán et al., 2010). However, interviews may allow for subtle changes or nuances to be reported that may not be captured by quantitative questionnaires. This is because qualitative methods often allow for open-ended questions and probes that encourage participants to provide detailed and nuanced responses, whereas quantitative questionnaires typically have more structured and standardised questions that may not capture the full range of participants' experiences and perspectives. In addition, a recently published Cochrane review has suggested that different techniques of cognitive stimulation might improve various domains of their participants, such as cognition, communication, social interaction, well-being, quality of life, activities of daily living and challenging behaviour (Woods et al., 2023). Further research on CST could explore the benefits on these outcomes. However, a review of RCTs found that CST has no impact on challenging behaviour or activities of daily living (Aguirre et al., 2013), and there is weak evidence that CST has an impact on orientation (Lobbia et al., 2019).

Limitations

Recruitment was from two CST groups run in an outpatient setting in Brazil—a vast country with large economic and cultural differences. This may have led to sampling bias, with findings not being representative of PwD/caregiver from other settings across Brazil. Further studies in other settings should explore the experiences of PwD and caregivers in relation to CST. As outlined in the methods, one interviewer was also a group facilitator, so some interviewees might have felt compelled to provide positive answers. Also, a positive bias toward staff could have influenced their report. However, the interviewer/facilitator encouraged honest and critical feedback, and led only six out of twenty-three interviews. The facilitator of all the groups also carried out the data analysis, however a second researcher who was not part of the groups reviewed the analysis to avoid bias.

Additionally, even though PwD were adequately involved to represent themselves, some experienced difficulty remembering

the activities and were limited in their ability to provide detailed responses to questions. Thus, some results are more likely to be from the caregivers' perspective. However, consistent with previous qualitative findings (Morrish et al., 2022; Orgeta et al., 2015), most participants were able to reflect on their general experience, the social aspect of CST and moments of enjoyment. Given the importance of gathering the opinions of PwD (Cridland et al., 2016; Øksnebjerg et al., 2018), future studies should investigate this issue further, exploring other ways to continue fostering engagement of PwD in the qualitative interviews (e.g. bringing back some of the materials used in the sessions). Furthermore, as documented in several patient populations, the subjective judgement regarding the efficacy of treatment relies partly on the expectations that patients and their families have about the treatment outcomes (Di Blasi et al., 2001). Therefore, further studies with a larger sample of PwD and their caregivers should be considered to answer questions regarding possible discrepancies between the expectations of participants and their caregivers and their perceived experience with CST. These should help to better understand CST effects and maximise the efficacy of the intervention.

Conclusion

CST brings perceived personal benefits to PwD and caregivers, and there are many perceived improvements, which are consistent with previous qualitative findings and supported by empirical findings from CST trials. Furthermore, the results of this study corroborate with previous qualitative findings indicating that CST is beneficial for PwD, mirroring findings from other countries.

Disclosure statement

We have no conflict of interest to declare.

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