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Renata Naylor Pavanelli Batista

The resounding sound of silence: giving voice to persons living with dementia who took part in Cognitive Stimulation Therapy and virtual Cognitive Simulation Therapy groups

Dissertação de Mestrado

Dissertation presented to the Programa de Pós-graduação em Psicologia of PUC-Rio in partial fulfillment of the requirements for the degree of Master em Psicologia.

Advisor: Prof. Daniel Correa Mograbi

Rio de Janeiro,
August 16, 2022.

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Abstract

Naylor, Renata; Mograbi, Daniel Correa (Advisor). **The resounding sound of silence:** giving voice to persons living with dementia who took part in Cognitive Stimulation Therapy and virtual Cognitive Stimulation Therapy groups**.** Rio de Janeiro, 2022. 86p. Master's Dissertation – Department of Psychology, Pontifical Catholic University of Rio de Janeiro.

In Brazil, there is a lack of investment in psychosocial treatments for dementia. Cognitive Stimulation Therapy (CST) is an evidence-based psychosocial intervention for people living with dementia (PlwD) that has been adapted and validated to several countries. Developed in the UK, it involves 14 sessions over seven weeks. It aims to improve cognitive function through themed group activities, which implicitly stimulate skills including memory, executive function and language. Sessions follow a set of guiding principles which include 'mental stimulation', 'new ideas, thoughts and associations' and 'opinions rather than facts'. Studies suggest that CST can improve cognition, mood, quality of life and activities of daily living in mild to moderate dementia. In Brazil, a randomized controlled trial (RCT) sought to investigate the feasibility of CST in the country. The results suggest that those who took part in the CST groups had a significant improvement in measures relative to mood and activities of daily living. Due to the COVID-19 pandemic, adaptations were made for virtual delivery, and virtual CST (vCST) groups are being conducted. The first study was conducted alongside the randomized RCT to explore the real-life effectiveness of CST and to access the perspective of group participants. Individual semi-structured interviews were applied to PlwD who took part in the groups and their care partners (n = 23). The transcripts of interviews were analysed using Framework Analysis. From the analysis, two general themes, 'Personal benefits of being part of the group' and 'Changes to daily living' and 7 subthemes, 'Benefits for caregivers', 'Benefits por people with dementia', 'Memory', 'Sociability', 'Language', 'Mood', 'Orientation', 'Everyday activities' and 'Behavioural and psychological symptoms' have emerged. Results indicate that CST brings perceived personal benefits to PlwD and caregivers, and there are many perceived improvements, which are consistent with previous qualitative findings and supported by empirical findings from CST trials. The second study aimed to access the experience and perspectives of Plwd who have participated in vCST groups and their care partners (n = 25), during the COVID-19 pandemic. Qualitative information that has emerged from the analysis will be compared with quantitative data to understand the effectiveness and feasibility of vCST. The transcripts of interviews were analysed using Framework Analysis. From the analysis, two general themes, ‘Personal benefits of being part of the group’ and ‘Design of vCST’ and 12 subthemes, ‘Enjoyment’, ‘Mental stimulation’, ‘Continued stimulation’, ‘Occupation’, ‘Cognition’, ‘Mood’, ‘Sociability’, ‘Online’, ‘Duration’, ‘Structure of sessions’, ‘Person-centred’ and ‘Evidence-based’ have emerged. The findings indicate that vCST led to perceived improvements for PlwD and personal benefits for those who took part in the groups. Similar results are found in CST studies, which suggest that vCST is viable as studies have suggested with the face-to-face intervention.

Keywords

Dementia; Cognitive Stimulation Therapy; virtual Cognitive Stimulation Therapy; qualitative analysis; framework analysis.

Resumo

Naylor, Renata; Mograbi, Daniel Correa. **O retumbante som do silêncio:** dando voz às pessoas vivendo com demência que participaram de grupos da Terapia de Estimulação Cognitiva e Terapia de Estimulação Cognitiva virtual**.** Rio de Janeiro, 2022. 86p. Dissertação de Mestrado – Departamento de Psicologia, Pontifícia Universidade Católica do Rio de Janeiro.

No Brasil, há uma falta de investimento em tratamentos psicossociais para demência. A Terapia de Estimulação Cognitiva (CST) é uma intervenção psicossocial baseada em evidências para pessoas que vivem com demência (PvcD) que foi adaptada e validada para vários países. Desenvolvida no Reino Unido, a CST envolve 14 sessões que acontecem ao longo de sete semanas. Seu objetivo é melhorar a função cognitiva por meio de atividades em grupo temáticas, que estimulam implicitamente as habilidades, incluindo memória, função executiva e linguagem. As sessões seguem um conjunto de princípios básicos que incluem "estimulação mental", "novas ideias, pensamentos e associações" e "opiniões em vez de fatos". Estudos sugerem que a CST pode melhorar a cognição, o humor, a qualidade de vida e as atividades de vida diária em PvcD leve a moderada. No Brasil, um ensaio controlado randomizado (RCT) buscou investigar a viabilidade da CST no país. Os resultados sugerem que aqueles que participaram dos grupos da CST apresentaram melhora significativa nas medidas relativas ao humor e às atividades de vida diária. Devido à pandemia COVID-19, foram feitas adaptações para que a CST pudesse ser oferecida virtualmente (vCST). O primeiro estudo foi realizado juntamente com o RCT para acessar a perspectiva dos participantes do grupo e explorar os efeitos da CST. Foram realizadas entrevistas individuais semiestruturadas com as PvcD que participaram dos grupos e seus cuidadores (n = 23). As transcrições das entrevistas foram analisadas por meio da Framework Analysis. A partir da análise, dois temas gerais, 'Benefícios pessoais de fazer parte do grupo' e 'Mudanças na vida diária' e sete subtemas, 'Benefícios para cuidadores', 'Benefícios para pessoas com demência', 'Memória', 'Sociabilidade', 'Linguagem', 'Humor', 'Orientação', 'Atividades cotidianas' e 'Sintomas comportamentais e psicológicos'. Os resultados indicam que a CST traz benefícios pessoais percebidos às PvcD e aos cuidadores, e há muitas melhorias percebidas, que são consistentes com achados qualitativos anteriores e apoiadas por achados empíricos de ensaios da CST. O segundo estudo teve como objetivo acessar a experiência e as perspectivas das PvcD que participaram de grupos da vCST e seus cuidadores (n =25), durante a pandemia do COVID-19. As informações qualitativas que surgiram da análise serão comparadas com dados quantitativos para entender a eficácia e a viabilidade do vCST. As transcrições das entrevistas foram analisadas por meio daFramework Analysis. A partir da análise, dois temas gerais, 'Benefícios pessoais defazer parte do grupo' e 'Design da vCST' e 12 subtemas, 'Prazer', 'Estimulação mental', 'Estimulação contínua', 'Ocupação', 'Cognição', 'Humor', 'Sociabilidade', 'On-line', 'Duração', 'Estrutura de sessões', 'Centrada na pessoa' e 'Baseada em evidências'. Os achados indicam que a VCST levou a melhorias percebidas para a PvcD e trouxe benefícios pessoais para aqueles que participaram dos grupos. Resultados semelhantes são encontrados em estudos da CST, que sugerem que a vCST é viável, como a intervenção presencial

Palavras-chave

Demência; Terapia de Estimulação Cognitiva; Terapia de Estimulação Cognitiva virtual; análise qualitativa; framework analysis.

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List of Abbreviations

ADI Alzheimer's Disease International

BPSD Behavioural and Psychological Symptoms of Dementia

CDA Center for Alzheimer’s Disease

CST Cognitive Stimulation Therapy

DSM-IV/5 Diagnostic and Statistical Manual of Mental Disorders

FA Framework Analysis

GBD Global Burden of Diseases

MSME Mini Mental State Examination

NICE National Institute for Health and Care Excellence

PlwD Persons Living With Dementia

RCT Randomized Controlled Trial

vCST Virtual Cognitive Stimulation Therapy

Hear my words that I might teach you
Take my arms that I might reach you
But my words like silent raindrops fell
And echoed in the wells of silence**.**

Paul Simon, 196

1
Theoretical Background

1.1
Aging and dementia

Control of infectious diseases, decline in the mortality rate, advances in medicine, increased income and better living conditions of the people are among the possible reasons for populational aging (Areosa et al., 2016). With the increase of life expectancy around the world, a growing number of people are affected by chronic health conditions associated with aging, including dementia (Chariglione & Janczura, 2013), which has been considered a global challenge (Mograbi & Morris, 2018). According to the Alzheimer's Disease International (ADI) report (Fleming et al., 2020), there were over 50 million persons living with dementia (PlwD) worldwide in 2020. This number will almost double every 20 years, reaching 82 million in 2030 and 152 million by 2050. Much of the increase will bein developing countries. Already 60% of PlwD live in low- and middle-income countries, but by 2050 this will rise to 71% (Fleming et al., 2020).

In Brazil, there were more than 29 million people aged over 60 and two million were living with dementia in 2019. By 2050 is predicted that this number will rise to 3,728,000 (Oliveira et al., 2019). These numbers are probably lower than the reality given that many people never get a proper diagnosis or even have access to a specialist and the estimation is that only 20% of PlwD are formally diagnosed, with Alzheimer's disease being responsible for 40 to 60% of cases (Nakamura et al., 2015). Although Brazil has the highest prevalence of Alzheimer'sdisease and other dementias in Latin America there is no dementia awareness campaign, no national control plan, and data about diagnostic rate is not available (Feter & Leite, 2021). Only recently the Brazilian Senate received the first law project to create a national dementia plan but it hasn't moved ahead due to the lack of political support (Feter & Leite, 2021).

According to the DSM IV (American Psychiatric Association, 1994) dementia is a condition characterized by the loss of function in multiple cognitive domains, including memory and at least one of the following: aphasia, apraxia, agnosia and disturbance in executive functioning. These deficits should cause impairments not only in cognitive functions, but in the social, occupational and instrumental domains of daily life and not occur during delirium. More recently, the DSM 5 (American Psychiatric Association, 2013) has excluded the memory impairment criteria. Diagnosis of dementia is made by neuroimaging and laboratory tests, in addition to neuropsychological assessments.

1.2

Dementia symptoms

The cognitive decline in dementia usually is accompanied or preceded by social and behavioural changes which limit the execution of activities of daily living (ADL) and put the PlwD in a position of total dependence on the help of their care partner (Maresova et al., 2020). These activities are defined as common and essential ones, performed during the day, and usually related to self-care (Maresova et al., 2020). They are divided into basic ones, that can include eating and drinking, taking care of personal hygiene and toileting and instrumental ones, including preparation of meals, shopping, leisure activities and management of medications, household and finances. The ability to perform ADL has a direct effect on the quality of life of the PlwD. Quality of life can be defined as a state of well-being that stems from the capacity to exercise daily activities that are important to the psychological, physical and social aspects. Moreover, it relates to the PlwD functionality and the management of their symptoms (Martyr et al., 2018).

Depression is very common in older population (Korczyn & Halperin, 2009). It can be understood as a psychological reaction to the cognitive deterioration, loss of self-sufficiency and deficits in the quality of life (Carthery-Goulart et al., 2007). The exact nature of the relationship between depressive symptoms and dementia is inconclusive, but some studies have suggested it is a risk factor to the development of dementia (Korczyn & Halperin, 2009; Wiels et al., 2020). Depression symptoms may differ according to the type of dementia, but they are usually manifested around: mood – like anxiety, sadness, irritability; a lack of reaction to events; behavioural symptoms – like retardation, agitation; loss of interest in things – including appetite; a general lack of energy; changes in sleep pattern; suicidal ideation; low self-esteem; pessimism and mood congruent delusions (Alexpoulos et al., 1988).

1.3
Care partners

Dementia has a great impact on the life of the person who receives the diagnosis and their family. The PlwD needs assistance to complete tasks that were easily done before and the family structure needs to accommodate the new challenges (Taub et al., 2004). Due to the lack of preparation and experience, the new role of providing care might lead to an emotional burden of the family member. (Taub et al., 2004). The experience of taking care of a family member has been described as frustrating and extremely stressful (Butcher et al., 2001) which could lead to depression. Schulz & Martire (2004) have commented on the reciprocal impact that caregiver and caretaker have over each other leading to a downward spiral that can undermine the quality of life of both individuals and lead to depression of the carer.

In Latin America, adult children are responsible for caring for their parents once they get old. This tradition is consistent across generations and becoming a care partner is seen as an “opportunity to repay a past debt to the care recipient” (Santos et al., 2013). According to the authors, familism – perceiving the family as a system for assistance, support and socialization – is a central cultural value in this region, and, therefore, taking care of your relatives is a natural process, even in families in which the relationship was not positive prior to the condition. Caregiver burden especially affects the spouses and daughters of PlwD, who usually take the role of main carers, since Latin America has deeply rooted sexist values, with the belief that nurturing and caring behaviours pertain solely to women (ADI, 2019).

1.4.

Theoretical models of dementia

The medical model of dementia sees it as a pathology caused by organic issues of the brain, which causes intellectual deterioration and gradual erosion of mental and physical functions, leading to disability and death (National Institute for Health and Caring Excellence [NICE], 2007). It should be treated by medical doctors with medications such as acetylcholinesterase inhibitors (AChEIs; Tariot, 2003). This model facilitates communication between professionals, giving a common understanding of the condition, which helps the development of public policies and studies. However, it excludes the identity of the PlwD and attributes all the symptoms to the pathology (Lyman, 1989).

The dialectical model of dementia presents it as an interrelationship between neurological damage and psychological factors. This model focus on the combination of factors such as personality, biography, health, neurological impairment, and social psychology. It is used to emphasise the unique personal aspects and person-centred care, changing how dementia is viewed by the medical model (Kitwood, 1997). The NICE (2007) states that from a social perspective, dementia is seen as “one of the ways in which an individual’s personal and social capacities may change for a variety of reasons”. These changes will only be perceived as disabilities in the absence of an adequate environmental support. Furthermore, seeing dementia as a disease and disability that will lead to death may also shape our professional and social approach to this population as people who are “irretrievably ill and fundamentally different from able-bodied healthy young people” (NICE, 2007). Issues regarding care and support, faced by the PlwD and their carers, might be explained by this model.

The biopsychosocial model of dementia takes into consideration neurological factors, mental stimulation, social psychology, personality, sensory stimulation, environment, health, life events and mood (Spector & Orrel, 2010).

Neurological factors take into consideration that different types of dementia are defined by different pathologies (i.e., Alzheimer’s involves atrophy of the brain, plaques and tangles and vascular dementia involves restriction or loss of blood supply to the brain which destroys small areas of brain cells; (Spector & Orrel, 2010). Mental stimulation is based on the “use it or lose it” principle (Swaab, 1991) that states that mental activity can lead to new learning and increased cognitive functioning in dementia. Social Psychology identifies 17 common factors that can exacerbate the symptoms of dementia, such as disempowerment, infantilisation and outpacing (Kitwood, 1997). Sensory stimulation which considers the high incidence of impairment in all senses in older people and how for PlwD the effects of this impairment might be exaggerated, due to inattention or difficulty in selecting appropriate information (Sanchez et al., 2013). Personality, which includes coping mechanisms, intelligence and cognitive reserve (Stern, 2002). Environment that evaluates how the presence of memory aids and other environmental supports might influence in the manifestation of dementia symptoms; physical health which considers how medication and pain might affect mood, increase confusion and impact the symptoms of dementia, respectively. Dramatic life events such as loss of important people or moving into care centers can trigger dementia or exacerbate symptoms and mood that considers how there is a significant overlap between depression, anxiety and dementia (Spector & Orrel, 2010).

1.5

Cognitive Stimulation Therapy

Understanding dementia through different perspectives others than the medical one allows us to think about nonpharmacological treatments. Psychosocial interventions have been shown to improve cognition (Mather, 2020; Lobbia et al., 2018), alleviate behavioural symptoms (O’connor et al., 2009a), increase emotional well-being (O’connor et al., 2009b), help with depression (Teri et al., 2005,Marinho et al., 2021) and with the functionality in the activities of daily living (Kurz, 2013, Marinho et al., 2021).

Cognitive Stimulation Therapy (CST) is a brief, evidence-based face-to-face intervention developed in the UK for PlwD. The aim is to mentally stimulate the participants of the group through psychological techniques that happen in structured activities (e.g., word association, current themes; Spector et al., 2003). Currently, it is the only nonpharmacological intervention recommended by the NICE (2018) to treat cognition in dementia and is offered routinely in 96% of UK memory services (Memory Services National Accreditation Programme, 2018). CST is globally approved by the Alzheimer's Association International (2011), used in more than 24 countries and translated into at least eight languages (Bertrand et al., 2019). CST can be applied to all types of dementia, mild or moderate (Spector et al., 2003). The programme groups should ideally have five to eight people and be conducted by two facilitators. The protocol is composed by 14 thematic sessions,that should take place in seven weeks, with two sessions per week (Spector et al., 2003). Each session lasts 45 minutes and should happen in an appropriate place, with some suggested material (Orrell et al., 2014).

For the development and application of activities, CST follows 18 key principles: 1) Mental Stimulation, which highlights the importance of keeping the mind of the PlwD active and engaged; 2) New ideas, thoughts and associations, which promotes the encouragement of these, to the detriment of only talking about the past; 3) Using implicit and sensitive guidance, which recognizes the importance of orientation to reality, but determines that they should be asked implicitly and subtly, avoiding direct questions about reality data; 4) Opinions instead of facts, focusing on people's strengths and asking open questions, without right or wrong answers; 5) Using reminiscences: an aid to the here and now, which advocates the use of memories of the past as a way to explore the ability that people with dementia have to recall old memories; 6) Providing triggers and suggestions to help in memories and concentration, which promotes the use of varied sensory stimuli with a mixture of activities involving vision, touch, hearing, taste and smell, or the combination of these; 7) Continuity and consistency between sessions, that comes from the idea that memory and learning are sustained when there is continuity and consistency between sessions; 8) Implicit (rather than explicit learning), which allows people to learn without feeling pressured; 9) Stimulating language, causing people to name objects and people, to make words association, among other activities; 10) Stimulating executive function, exercising mental organization, considering that this function is greatly impaired in dementia; 11) Centered on the person, that establishes the importance of seeing the person before the disease; 12) Respect, which involves making sure that the members of the groups do not feel diminished; 13) Involvement, which deals with the importance of engaging all participants in the activities, so that the group facilitators do not substantiate the interactions; 14) Inclusion, which means paying special attention to those participants who are isolated from the group; 15) Choices, which allows group members to choose from a variety of activities, so that those described in the manual are not mandatory; 16) Fun, which prioritizes that members should enjoy and have fun with activities; 17) Maximizing potentials, which establishes that people with dementia are able to reach their maximum potentials when encouraged to do activities and, finally, 18) Building and strengthening relationships, giving importance to the aspect of the affective bond that is formed among the participants of the group (Spector et al., 2020).

The results of studies that sought to evaluate the effects of this intervention indicate that it has a comparable performance to the drugs used for the treatment of dementia (Spector et al., 2003). Among the reasons that provide a possible explanation for its effectiveness is the fact that it is a group therapy, which means that the group members themselves are able to compensate for each other's disabilities, transforming the environment into a socially positive place, making participants feel more comfortable and stimulating social interaction (Spector et al., 2003).

In Brazil, a study was conducted to adapt this therapy to the national context. Focus groups were held to understand which would be the facilitators and barriers to the implementation of this intervention in Brazil. Among the barriers listed were the extra work for care partners; lack of motivation of PlwD to attend the groups; frequency of the sessions; distance from the PlwD’s home to the sessions and lack of information available to the Brazilian population about this type of intervention. The identified facilitators were: having the support of the care partner; ensuring that the two sessions take place in the same day; providing care partners with an activity while waiting for the sessions to end; and the fact that the activities were in group (Bertrand et al., 2019). 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 our country and suggested that participants had significant improvements in mood and activities of daily living compared to those in the control group (Marinho et al., 2021).

1.6
COVID-19 pandemic

On March 2020 the World Health Organization (WHO, 2020) has declared the novel coronavirus (COVID-19) outbreak a global pandemic. Concerned with the level of spread and the severity of the virus (Cucinotta & Vanelli, 2020), many parts of the world went into lockdown and staying at home and avoiding face to face interactions were recommended by the organization. For older people – who were considered especially vulnerable to the virus (Cucinotta & Vanelli, 2020) – these measures could directly and indirectly affect their health and general well-being (Cheung & Peri, 2020).

The WHO (2020) alerted that, with the pandemic, older adults could become angrier, more anxious, agitated and withdrawn. Indeed, the imposed restrictions had substantial adverse effects on older adults' loneliness (Macdonald & Hülür, 2021; Kasar & Karaman, 2021). Studies have also shown how social distancing has negatively affected the emotional well-being and quality of life of this population (Hwang et al., 2020; Kasar & Karaman, 2021) and editorials have highlighted the importance of social connection during times of uncertainty (Dahlberg, 2021; Rodney et al., 2021).

The current situation reinforced the emergency of treatments that could be accessed from home, in a virtual setting. Even before the pandemic, there was a great deal of interest in neuropsychological rehabilitation that makes use of technology (Charchat-Fichman et al., 2014)

Focus groups were run with service managers, CST facilitators, care partners and PlwD to gather feedback on how to adapt the existing CST manual to a virtual context (Perkins et al., 2022). A vCST protocol was then developed with 14 virtual CST sessions and a guide for facilitating and cofacilitating the sessions. This protocol is being field-tested with groups of PlwD and their care partners in Brazil using a virtual platform.

1.7
Qualitative studies

RCTs are considered the gold standard design in health studies to evaluate causal relationship between a complex intervention and the outcomes because it can control for unknown or unmeasured confounders (Lewin et al., 2009). However, the relevance of qualitative studies when evaluating an intervention should not be disregarded. Adopting multiple, integrated approaches may be useful when evaluating the effects of complex health treatment interventions as they involve social or behavioural processes that are difficult to explore or capture using only quantitative methods (Lewin et al., 2009). Qualitative data can provide insight on the acceptability of the intervention and be used to explore the experience of participants and their care partners (Naylor et al., submitted). Involving the PlwD can give them a sense of worth and personhood through seeking their opinion and perspectives (Jonas-Simpson, 2001; Beuscher, L., & Grando, ano). Additionally, it may also help defining more suitable outcome measures for future research (Gibbor et al., 2020).

2

Objectives

The general aim of the dissertation is to explore the experience of PlwD, as well as their care partners, who took part in CST and vCST.

In order to achieve this goal, the following specific aims were established:

- to investigate qualitatively, through Framework Analysis (FA), self-reported experiences of PlwD receiving CST in-person and virtually;
- to explore qualitatively, also using FA, how care partners react to the experience of their relatives receiving CST;
- to compare the experience and perspective of those who took part in CST and vCST groups.

3

Articles session

Article 1

“Experiences of Cognitive Stimulation Therapy (CST) in Brazil: a Qualitative Study of People with Dementia and their Caregivers” – submitted Aging & Mental Health

Article 2

“Experiences of Virtual Cognitive Stimulation Therapy (vCST) in Brazil: A Qualitative Study of People Living with Dementia and their Care Partners” (in prep.)

Experiences of Cognitive Stimulation Therapy (CST) in Brazil: a Qualitative Study of People with Dementia and their Caregivers

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ABSTRACT

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.Individual interviews were applied to the participants of the group (n=12) and their caregivers (n=11). Framework analysis was used to inspect the data. Two main themes have emerged: 'Personal benefits of being part of the group' and 'Day-to-day changes' and seven subthemes: memory, sociability, language, orientation, mood, behavioural and psychological symptoms, and everyday activities were identified. 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.

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 (Brazil Geriatrics and Gerontology Society, 2019). 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. This leaves people living with dementia (PlwD) who are ineligible for medication without treatment options (Nakamura et al., 2015). Given the number of PlwD who do not have access or are ineligible for pharmacological therapies, interest in psychosocial treatments for dementia has increased substantially in recent years (Piras et al., 2017). There is good evidence that some of these interventions can improve global physical and cognitive functions, activities of daily living skills, social interaction and quality of life (McDermott et al., 2019) with the added benefit of some being cost-effective (Knapp et al., 2022).

Cognitive Stimulation Therapy (CST) is a brief, evidence-based group programme developed in the United Kingdom 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. Clinical trial results suggest a significant improve in cognition and quality of life (Lobbia et al., 2018). 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 PlwD 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 (ADI, 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 notbe overlooked when evaluating an intervention, as it provides insight on theacceptability 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 PlwD 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 in-depth 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 and colleagues (2021). All members of the two groups and their caregivers were invited to and agreed to take part in the interviews. 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

PlwD 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 the main outcomes assessed in the RCT. 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 PlwD who participated in CST groups, and each of their caregivers (two participants were married to each other and had the same caregiver). 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 PlwD.

Qualitative themes

Two central themes and seven subthemes were identified from the interviews (Table 1). There was a total of 300 minutes of recorded interviews. Excerpts from the interviews are provided to illustrate each subtheme. Caregivers and participantsare numbered to provide identification, from one to 11 (caregivers/‘C’) and one to 12 (participants/‘P’).

PLEASE INSERT TABLE 1 HERE

Theme 1: Personal Benefits of Being Part of the Group

Subtheme: Benefits for Caregivers

Several caregivers reported personal benefits for themselves and for the PlwD 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 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, take care of my spinal pain.* (C1)

Subtheme: Benefits for People Living with Dementia

Personal benefits for the PlwD were identified by the caregivers and group members themselves. 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 you 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)

PlwD 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 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 interviewees about the benefits of sociability experienced during the groups. 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 in 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 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 to it.* (C3)

Subtheme: Mood

Caregivers and PlwD 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 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 you would say something, and he would get agitated, complain a lot, and nowadays, with this therapy he hasnot been complaining that much, he's been less agitated.* (C11)

Subtheme: Orientation

Some of the caregivers highlighted how taking part in CST groups have 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 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

To the authors' knowledge, this is one of the few studies exploring the experiences of CST participants and their caregivers. 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 in-depth qualitative data adds to the findings from the RCT of CST in Brazil (Marinho et al., 2021). In the 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 finding by the theme 'Changes in daily life', with subthemes 'Mood' and 'Everyday activities'.

The RCT 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 PlwD and caregivers did perceive improvements in these areas. For example, the subthemes 'Memory', 'Language' and 'Orientation' describe participant 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 PlwD 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 of some participants but not others, such is the nature of qualitative data. The sample size for the RCT may not have had the power to detect significant effects. Finally, 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. This could be explored in future research through measurement and analysis of domain-level outcomes.

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 enoughto detect effects resulting from CST, which can instead be explored throughqualitative outcomes (Toh, Ghazali & Subramaniam, 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; however, the topic guide for our study included questions with these topics, which are likely to haveprompted these responses. Further qualitative research could explore the perceived 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., 2018.

Limitations

Recruitment was from two CST groups run in an outpatient setting in Rio de Janeiro, Brazil – a vast country with large economic and cultural differences. This may have led to sampling bias, with findings not being representative of PlwD/caregiver from other settings across Brazil. Further studies in other settings should explore the experiences of PlwD 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. 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 theanalysis to avoid bias. Finally, the qualitative data is mostly from caregivers, as many of the participants with mild to moderate dementia were limited in their abilityto provide detailed responses to questions. Therefore, the impact on the person withdementia is more likely to be from the perspective of the caregiver, rather than self-perceived. Given the importance of gathering the opinions of PlwD(Cridland et al., 2016; Øksnebjerg et al., 2018), future studies should investigate this issue further, exploring ways to foster engagement of PlwD in the qualitative interviews.

Conclusion

CST brings perceived personal benefits to PlwD 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 PlwD, mirroring findings from other countries.

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Conflict of interest

We have no conflict of interest to declare

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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*

Experiences of Virtual Cognitive Stimulation Therapy (vCST) in Brazil: A Qualitative Study of People Living with Dementia and their Care Partners

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ABSTRACT

There is a lack of investment in psychosocial treatments for people living with dementia (PlwD) 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. Due to the COVID-19 pandemic, adaptations were made for virtual delivery, and virtual CST (vCST) groups are being conducted. This study aims to explore the experiences and perceived changes of PlwD who participated in vCST groups. Individual interviews were applied to the participants of the group (n=13) and their caregivers (n=12). Framework analysis was used to inspect the data. Two main themes have emerged: ‘Personal benefits ofbeing part of the group’ and ‘Design of vCST’’ and 12 subthemes: ‘Enjoyment’, ‘Mental stimulation’, ‘Continued stimulation’, ‘Occupation’, ‘Cognition’, ‘Mood’, ‘Sociability’, ‘Online’, ‘Duration’, ‘Structure of sessions’, ‘Person-centred’ and ‘Evidence-based’ were identified. The findings indicate that vCST led to perceived improvements for PlwD and personal benefits for those who took part in the groups. Similar results are found in CST studies, which suggest that vCST is viable as studies have suggested with the face-to-face intervention.

Keywords

Dementia; Virtual Cognitive Stimulation Therapy; qualitative analysis; framework analysis

Introduction

Populational aging and growth will significantly increase the number of people living with dementia (PlwD) worldwide. This growth will create high economical and societal needs drawing attention to the importance of investing in treatments for this population (Nichols et al., 2022).). In 2019, it was estimated that 57.4 million people were living with dementia globally and that this number would increase to 152.8 million cases by 2050 (GBD 2019 Dementia Forecasting Collaborators, 2022). In Latin America, it is estimated that the prevalence of dementia will increase four-fold between 2015 and 2050 (Prince et al., 2015), meaning that in Brazil this number will go from approximately 927,000 in 2010 to 3,728,000 in 2050 (Oliveira et al., 2019).

Despite those numbers, there is a significant lack of investment in dementia-specific programs or research in Brazil, with most funding coming from private or international institutions (Feter & Leite, 2021). Additionally, Brazil has no national dementia control plan, dementia awareness campaigns, or reliable data on diagnostic rates (Feter & Leite, 2021). A national plan for dementia should go beyond informing and providing support for family members and care partners of PlwD, presenting the basis for appropriate diagnosis procedures, training health professionals to detect and treat dementia, coordinating actions between private and public health services, and adapting existing health systems to specific needs (Manes et al., 2016).

The main Brazilian government policy focuses on subsidizing high-cost medication (da Costa et al., 2015). The use of acetylcholinesterase inhibitors (AChEI) is the standard treatment for Alzheimer's Disease (AD) (Picon et al., 2013), following the medical model of dementia. While the use of AcheI can help mitigating some of the cognitive symptoms of dementia, the medication is not accessible for all PlwD (Moraes et al,, 2018) and benefits are limited (do Vale et al., 2011). Furthermore, medicalizing the condition may lead to symptoms being attributed only to dementia, without consideration of wider issues. There is a lack of community-based care and support which can lead to unmet needs (Cieto et al., 2014). Therefore, it is recommended that PlwD also receive also non-pharmacological treatments (Spector et al., 2003).

Several studies have shown the benefits of psychosocial interventions: for relieving behavioural symptoms (O'connor et al., 2009a), increasing emotional well-being (O'connor et al., 2009b), helping with symptoms of depression (Teri et al., 2005, Marinho et al., 2021), maximizing functionality in activities of daily living (Kurz, 2013, Marinho et al., 2021). A recent synthesis of 22 systematic reviews, covering 197 studies across various psychosocial interventions, also highlighted that group cognitive stimulation improved cognitive functioning, social interaction, and quality of life for people with dementia (McDermott et al., 2018).

Cognitive Stimulation Therapy (CST) is an evidence-based psychosocial intervention for people with mild to moderate dementia that has been adapted and validated to several countries (Lobbia et al., 2018). Developed in the UK, it involves 14 sessions over seven weeks. It aims to improve cognitive function through themed group activities, which implicitly stimulate skills including memory, executive function and language through tasks such as categorisation, word association and discussion of current affairs. Sessions follow a set of guiding principles which include ‘mental stimulation’, ‘new ideas, thoughts and associations’ and ‘opinions rather than facts’. A Cochrane systematic review of 15 RCTs found consistent evidence that Cognitive Stimulation benefits cognition in mild to moderate dementia, over and above any medication effects (Woods et al., 2012). Another review concluded that Cognitive Stimulation demonstrates the best evidence for improving cognitive functioning amongst all psychosocial interventions (Olazarán et al., 2010).

In Brazil, a randomized controlled trial (RCT) sought to investigate the feasibility of CST in the country. The study involved 47 PlwD (23 CST and 24 TAU) who were users of the services offered by a local day centre. The results suggest that those who took part in the CST groups had a significant improvement in measures relative to mood and activities of daily living (Marinho et al., 2021). Moreover, a qualitative analysis of individual interviews with the members of the group and their family care partners (n=23) suggested that CST led to personal benefits for the members of the group and their caregivers and perceived changes in mood, sociability, memory, language, behavioural and psychological symptoms, orientation and everyday activities (Naylor et al., submitted).

On 12 March 2020, the World Health Organization (WHO, 2020) declared a pandemic as result of the global spread of SARS-CoV-2 and the thousands of deaths caused by coronavirus disease (COVID-19). The pandemic and its social isolation protocol especially affected PlwD given that their health conditions (such as diabetes and hypertension) made them very vulnerable to worse prognosis, with the cognitive and neuropsychiatric symptoms of dementia reducing the ability to follow safeguarding procedures (Mock et al., 2020). For those living in care homes, complete social isolation was not possible and living arrangements facilitated viral spread (Numbers & Brodaty, 2021). There was also increased risk of worsening psychiatric symptoms and severe behavioural disturbances due to the interruptions of visitations and other COVID-19 protocols (Numbers & Brodaty, 2021).

A recent qualitative analysis (Bacsu et al., 2021) tried to understand the impact of COVID-19 on PlwD and their care partners. Five themes have surfaced from the analyses: i) lockdown and confinement challenges; ii) separation and loss; iii) unpaid sacrifices of formal carers; iv) COVID-19 confusion, despair, and declining psychological health; and v) informal carer fatigue and burnout. The first one exposed the challenges that the lockdown have presented like access to health services, delay of dementia diagnosis and changes to the daily routine. Additionally, PlwD struggled with their mental health and feelings of loneliness associated with social isolation. The COVID protocol restricted the access of family members of PlwD to nursing homes. This theme also appeared with separation due to death or the dying process and a psychological disconnection accompanied by feelings of loss. Formal carers have expressed making personal sacrifices while providing care for PlwD, like leaving aside personal commitments or exposing themselves to COVID due to the lack of proper protective equipment. Another theme that has emerged was how PlwD were confused about COVID-19 and how they could not understand the changes imposed by the pandemic response, which led to depression, anxiety, agitation, difficulties sleeping and an overall decline in psychological health, requiring constant reassurance and information. Finally, burnout and carer fatigue were reported, and informer carers had to deal with financial difficulties, increased workload, mental health issues, social isolation, fear of COVID-19 exposure and limited access to support and to usual healthcare services (including the termination of some of them).

The current situation reinforced the urgent need for treatments that could be accessed from home, in a virtual setting. Even before the pandemic, there has been an increasing interest in using technological innovations as tools for neuropsychological rehabilitation (Charchat-Fichman et al., 2014). Focus groups were run with service managers, CST group facilitators, caregivers and PlwD to gather feedback on how to adapt the existing CST manual to a virtual context (Perkins et al., 2022). A Virtual Cognitive Stimulation Therapy (vCST) protocol was then developed with 14 sessions and a guide for facilitating and cofacilitating the groups. This protocol is being field-tested with groups of PlwD and their caregivers in Brazil using a virtual platform.

The current study aims to access the experience and perspectives of Plwd who have participated in vCST groups and their care partners, during the COVID-19 pandemic. Additionally, qualitative information analysed here can be compared with quantitative data that might be crucial in understanding the effectiveness and feasibility of vCST.

Methods

Individual semi-structured interviews were used to explore the experience of the participants of the groups and their care partners and to access possible perceived changes.

Recruitment

Participants were recruited from seven vCST groups that were run virtually using the Zoom platform with PlwD from all over Brazil as part of a feasibility study presently being conducted. A purposeful sample of two members from each group and their caregivers was selected and the most and least engaged participants of each group were invited. Engagement levels were discussed amongst the two facilitators of each group acknowledging factors such as frequency, participation and fun. Participants were recruited for the groups through social media posts and virtual advertisements.

Inclusion criteria

Group members were eligible for inclusion in the groups 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) had mild to moderate dementia (confirmed by the person with dementia and their caregiver, in addition to cognitive screening); (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. Additionally, participants needed access to technology, and the ability to use video conferencing software, or a caregiver who could support them (Perkins et al., 2022).

Interview process

Qualitative interviews were conducted by one member of the research team with participants of the group and their care partners. The topic guide was developed by the research team of psychologists and an epidemiologist – including one of the developers of CST – to access the experience of the interviewees and information on the feasibility of the vCST. Questions were related to the experience of attending the groups, design of the intervention and possible changes. Interviews took place within one week of completion of the 14 vCST sessions. The participants were informed about the study and signed the statement of agreement when they were recruited for the vCST groups. Before each interview, they were also informed that the interview was recorded and gave oral informed consent. Each interview lasted approximately 10 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), as with previous study (Naylor et al., submitted). 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 (RC). 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

28 participants of the groups were invited to take part in the qualitative interviews. A total of 25 participants took part in the qualitative interviews including 13 PlwD who participated in vCST groups, and each of their caregivers. One participant and two caregivers did not show up to the interview. Eleven participants with dementia were female and two were male. All the carers were females and family members of the PlwD.

Qualitative themes

Two central themes and 12 subthemes were identified from the interviews (Table 1). There were around 250 minutes of recorded interviews in total. Excerpts from the interviews are provided to illustrate each sub-theme. Care partners and participants are numbered to provide identification, from 1 to 13 (care partner/‘vC’) and 1 to 13 (participants/‘vP’). vC6 was not available for the interview but the label was maintained to facilitate association with the PlwD.

PLEASE INSERT TABLE 1 HERE

Theme 1: Personal Benefits of Being Part of the Group

Several care partners and PlwD reported personal benefits for the PlwD who participated in the group. These benefits were categorized as follows.

Subtheme: Enjoyment

Participants of the study reported how they have enjoyed being part of the vCST groups.

> *I enjoyed everything (...) it was a good experience.* (vP1)

Some care partners also affirmed that their relative were excited about the vCST sessions.

> *She would get very excited in the beginning of the sessions; she was enjoying it a lot.* (vC12)

Care partners commented on how the PlwD enjoyment of vCST was related to their level of dementia severity.

> *In the beginning [of the programme] she was very excited; she enjoyed the interactions. After a while, she got a bit tired and meanwhile, even though it was in a short amount of time, it seems like she had a considerable decline. So, I think it [vCST] is more beneficial if the person is in earlier stages of dementia. vC12*

Subtheme: Mental Stimulation

Some PlwD talked about how vCST sessions stimulated their minds.

> *It was good for the memory, to activate memories.* (vP8)

Care partners also pointed out how vCST activities were a good source for mental stimulation and creativity.

> *I thought that it was very good [for him] because he has always been planning and plotting things and a very creative*

> *person. Creative in all aspects of things he wanted to do. And after he had the cerebrovascular accident he stopped with his activities, organizing his things, so when we had that opportunity [to join CST groups] I thought that it was excellent for him because it exercises [the mind] again, pulling things [from his mind], forcing him to think.* (vC8)

Subtheme: Continued Stimulation

Care partners felt that participating in vCST groups led to increased activity and stimulation outside of the intervention for their family members.

> *She would get interested in searching for songs, I think it [CST] stimulated her to search for other things besides the [CST] sessions.* (vC2)

They also commented on how being part of the groups led the PlwD to engage in more acts of personal care.

> *I would leave the house and when I got back, she would have taken a shower, was wearing perfume and lipstick [for the session].* (vC1)

Subtheme: Occupation

Some care partners highlighted how having to attend vCST groups gave the PlwD something to do on idled days.

> *Considering her routine, I thought it was very good (...) having an activity, something nice to do.* (vC12)

PlwD also commented on how having an activity to do was beneficial, especially considering the COVID-19 restrictions.

> *Yes, because of the current situation [COVID-19] there is not much we can do. So, it was something that we could do…an activity to move our minds.* (vP11)

Subtheme: Cognition

Some care partners noted that they had observed an improvement in the cognition of the participants of the group. One care reported that their relative had an improvement in memory.

> *I've noticed a big difference [on her memory], whenever we go on a trip there is a key that is cursed, a torment in our lives, she would just keep asking about the key: 'did you get the key?' and we would say 'yes, we got the key', two minutes will pass and she would ask about the key again. And we have noticed that recently we went on a trip and she did not ask about the key.* (vC1)

One of the care partners also commented on how the orientation of their relative has improved with vCST groups.

> *She started knowing which day of the week it was*. (vC3)

Subtheme: Mood

Care partners reported how participating in vCST sessions had a positive effect on their mood.

> *I have noticed that she does not have as many mood fluctuations as she had before, she's been calmer (...) activities make her calmer*. (vC9)

Care partners also commented on how the PlwD mood would influence their participation in the activities.

> *On the days that she was feeling more excited she would participate a lot in the sessions (...).* (vC5)

Subtheme: Sociability

There was a consensus among the care partners regarding how the social aspects of vCST was beneficial for their relatives.

> *It helped her a lot because when the person has Alzheimer's Disease, they end up socially isolating because the other people do not have much patience. So, I think that the social aspect of the group was wonderful*. (vC10)

Some PlwD highlighted how they enjoyed being able to discuss topics with other participants:

> *I enjoyed it, I enjoyed it a lot. They [other participants of the group] were wonderful, they had a lot of conversational topics and we would talk about several things. It was very good, it was great*. (vP7)

Theme 2: Design of vCST

Subtheme: Online

Participants and their care partners provided feedback on the intervention being online. They commented on how it allowed people from all over Brazil to reunite during a pandemic.

> *I am a big fan of the use of technology, I think it is essential, because you are at Rio and Mrs Z. was in Itapetininga and this other lady is from somewhere else. And look how you are able to do this [vCST sessions], especially with the pandemic and the need to be extra careful, so you are able to do something avoiding physical touch. I think it was great.*(vC8)

Participants also commented on how it was nice to stay at home.

> *I thought that it was nice, it [staying at home] was even better for us. (*vP9)

Care partners informed that having the session done online made the Plwd more comfortable because they were at a place they already knew:

> *I think that if [the sessions] were face-to-face it would not be as good because of the comfort, the familiarity of the place,*

> *the person already knows the whole place so it’s a more relaxing thing. So, if it was face-to-face people would be more self-conscious, less participative.* (vC4)

By contrast, carers commented on how having family members close to the participants of the group during the sessions might have curbed their participation:

> *I thought that having other people, family members around them, made the participant of the group feel a bit uncomfortable, their performance was much worse because of that. vC4*

Some PlwD expressed that they would have liked it better if the sessions were face-to-face:

> *Ah having vCST sessions in a [physical] room is better, right? You laugh, you see [the people], you talk, it is different. (vP11)*

Some care partners and PlwD reported having technological issues and needing full time assistance to access the sessions.

> *She did not know how to access the sessions, [to use] the technology. She always needed assistance. She missed the sessions when there was no one home to assist her with technology.* vC2

<u>Subtheme: Duration</u>

Care partners reported that their relative would keep attending vCST sessions if there were more.

> *She would keep going [if there were more sessions], she misses the group.* (vC2)

They also suggested that the sessions ended right when the participants got into the rhythm of them:

> *I think the number of sessions should be greater, and that is not related only to my mother. When they finally got into a*

> *rhythm, the programme was over. And we have noticed that with the other ladies too [who have participated in the vCST groups] (...). When they were more integrated, getting looser, talking more and their mind was bubbling following the [sessions] rhythm, it was over and I thought it ended too soon*. (vC7)

Subtheme: Structure of sessions

The interviewees commented on the structure of the vCST sessions, stating how they enjoyed singing the group's song:

> *Ah, I enjoyed when we had to sing the song, the song that I like*. (vP2)

Some care partners also talked about how they enjoyed the fact that the sessions would always begin and end with a song.

> *I found very interesting how the sessions would always begin with a song, the group's song.* (vC5)

PlwD also commented how they enjoyed other musical elements of the sessions.

> *I thought that it was nice, it was good. I was able to really enjoy the old songs, it brough good memories*. (vP8)

Subtheme: Person-centred

Care partners reported how much they have appreciated some person-centred aspects of the intervention.

> *The facilitators were extremely careful to make everything work, so that everyone could participate. So that - within the person's limitation - they felt like they could get better, they could be happy (...).* (vC7)

> *I thought that it was an interesting approach, the way that the participants of the group were treated, always being called by their names, trying to capture their attention.* (vC5)

Subtheme: Evidence-based

The participants of the study also reported how knowing that CST is an evidence-based treatment and vCST was part of a study made them feel less suspicious about the efficacy.

> *We see advertisements of things we do not trust in, that promise miracles, but I believe that you do something more serious, with the studies and the activities*. (vC13)

Adding to that, some of the participants expressed a desire to follow the results of the study:

> *When it [the study] is over, will you give us feedback on how this [vCST] may help us*? {vP13)

Discussion

To the best of authors' knowledge, this is one of the first studies to explore the experiences of PlwD that have participated in vCST groups and their care partners. Two general themes have emerged from the analysis: 'Personal benefits of being part of the group' containing seven subthemes: 'Enjoyment', 'Mental stimulation', 'Continued stimulation', 'Occupation', 'Cognition', 'Mood' and 'Sociability'. The second theme, 'Design of vCST' contained five subthemes: 'Online', 'Duration', 'Structure of sessions', 'Person-centred', 'Evidence-based'.

The qualitative data is accordant with the results of previous quantitative and qualitative studies regarding the efficacy of CST and the experience of the people who received the intervention. In the Brazil CST feasibility RCT (Marinho et al., 2021), those who took part in CST groups presented statistically significant enhancements in mood and activities of daily living, compared to those who received treatment as usual. Likewise, a qualitative in-depth exploration of those who received the psychosocial treatment in the RCT (Naylor et. al, submitted) suggested that there were personal benefits for the PlwD and their care partners and changes related to cognition, mood and sociability. These are demonstrated in the qualitative finding by the subthemes 'Enjoyment', 'Mood', 'Sociability' and

'Cognition'. PlwD who were members of the vCST group talked about how much they enjoyed the sessions, and care partners reported the same about their family members. Moreover, PlwD and care partners informed a direct relation of the sessions with the PlwD mood: how being part of the group improved their mood and being in a better mood influenced their participation in the sessions. In addition to that, regarding 'Cognition', participants of CST and vCST reported positive changes in 'Memory' and 'Orientation' with accounts of how vCST led PlwD to remember important facts and to better awareness to time clues. Participants of the virtual and in-person groups also informed an enhancement in sociability for the PlwD, highlighting how the social aspect of the group was beneficial, an opportunity for PlwD to socialize in group and to feel embraced by others who have a similar experience. This is also consistent with a recent systematic review of qualitative studies (Gibbor et al., 2021) that analysed data from 10 relevant studied using qualitative methodology. One of the subthemes that emerged from theanalysis was 'Being with others' and is related to how PlwD could feel safe in the group and experiences with others. Another common theme with the systematic review (Gibbor et al., 2021) was 'Continued stimulation'. Participation in the therapy groups led PlwD to seek stimulation outside the sessions, pertaining to otherleisure activities and actions of self-care.

Our findings are also consistent with a vCST pilot study (Lepore et al., 2021) that explored the experiences of 5 PlwD who took part in the groups. They reported that being part of the group brought them positive emotional experiences regarding exercising the mind, enjoyment and being in a social environment. These were identified in our study as 'Mental stimulation', 'Enjoyment' and 'Sociability'. The theme 'Activities and interactions are inclusive, enjoyable and stimulating' (Lepore et al.., 2021) highlighted other aspects of the intervention like being person-centred. Our results showed that PlwD and their care partners enjoyed person-centred features like calling the participants by the name and going the distance to to include all in the activities. Finally, we found that vCST had an impact on the person's self-care which can be understood as a self-esteem enhancement, similar to the self-esteem finding of the pilot study.

Our study also gathered feedback on other features of vCST, like being online and evidence-based and the duration of the programme. PlwD and their care partners highlighted how being online had advantages like being able to gather people from all over the country in a group and participating from a place they were familiar and comfortable with, following COVID-19 restrictions. These was also reported in a recent study that aimed to raise questions regarded to developing and field-testing vCST (Perkins et al., 2022). PlwD and care partners also commented on how they wish the duration of vCST was longer than 7 weeks and how they appreciated being part of a study on the effects of the treatment.

Limitations

Some of the interviewers also applied the pre and post assessments and were in touch with the care partners. This could have led to demand characteristics and social desirability effects, nudging participants to provide positive answers. Nevertheless, participants were encouraged to provide honest answers. Additionally, data analysis was conducted by the facilitators of two groups and the researchers were part of what was researched and may have led to some bias and overestimation of positive effects. However, as it is often the case with qualitative research, being immersed in the intervention is relevant to the analysis. Finally, qualitative data should not be solely considered to verify the effectiveness of an intervention as it does not intend to provide reliability, so the findings of this study should be regarded with caution.

Conclusion

vCST led to perceived improvements for PlwD and personal benefits for those who took part in the groups. Similar results are found in CST studies, which suggest that vCST is viable as studies have suggested with the face-to-face intervention. In addition, feedback on the design of the intervention should be considered for future studies and possible modifications on the structure of the treatment.

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Conflict of interest

DM, EB, JL and RN have participated in the adaptation and validation of CST to Brazil. AS, DM, RC and RN provide training for CST and receive payment for that. The remaining authors have no conflicts of interest to declare.

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Table 1

Themes and subthemes identified in individual interviews	
Theme	Subtheme
Personal benefits of being part of the group	Enjoyment
	Mental Stimulation
	Continued Stimulation
	Occupation
	Cognition
	Mood
	Sociability
Design of vCST	Online
	Duration
	Structure of sessions
	Person-centred
	Evidence-based

4

General Discussion

This work has presented two qualitative papers showing the experiences of persons living with dementia (PlwD) who took part in virtual and in person Cognitive Stimulation Therapy (vCST and CST, respectively) groups and their care partners. Individual semi-structured interviews were used to allow in-depth exploration of the experiences of the participants of the group. Framework analysis (Ritchie & Spencer, 1994) was applied to inspect the data.

In the first study, data was collected to complement the quantitative findings from a randomized controlled rial (RCT; Marinho et al., 2021). PlwD who received the intervention (CST) and their care partners were interviewed. Since it was part of a validation study, questions focused on the possible changes perceived by the members of the group and their care partners to assess the effects of the intervention as well as aspects related to their general experience. We found 2 general themes, ‘Personal benefits of being part of the group’ and ‘Changes to daily living’ and 7 subthemes, ‘Benefits for caregivers’, ‘Benefits por people with dementia’, ‘Memory’, ‘Sociability’, ‘Language’, ‘Mood’, ‘Orientation’, ‘Everyday activities’ and ‘Behavioural and psychological symptoms’. In the RCT, those who took part in the groups exhibited statistically significant improvements in mood and activities of daily living, compared to the control group. Changes concerning everyday activities and mood were also perceived in the qualitative findings. In regard to the others perceived outcomes of the intervention that were present in the qualitative study and not found in the RCT, there are some possible explanations: the sample size of the RCT may not have had the power to detect significant effects and reported perceived benefits may be true to some participants but not others. Finally, 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.

In the second study, data was collected to explore the experience of PlwD and assess the feasibility of the programme. PlwD who were members of the vCST group and their care partners were interviewed. In this context, there was a focus on questions regarding the design of the intervention, e.g. the fact that vCST was delivered through a virtual platform. From the analysis, 2 general themes, ‘Personal benefits of being part of the group’ and ‘Design of vCST’ and 12 subthemes, ‘Enjoyment’, ‘Mental stimulation’, ‘Continued stimulation’, ‘Occupation’, ‘Cognition’, ‘Mood’, ‘Sociability’, ‘Online’, ‘Duration’, ‘Structure of sessions’, ‘Person-centred’ and ‘Evidence-based’ have emerged.

Participants of both studies have reported perceived benefits. ‘Personal benefits of being part of the group’ was a common general theme as were ‘Sociability’ and ‘Mood’. Care partners of PlwD who received CST also talked about improvements in ‘Memory’ and ‘Orientation’, which were observed in the participants of vCST and were compiled under the ‘Cognition’ theme. From the second study, ‘Enjoyment’, ‘Mental stimulation’ and ‘Occupation’ themes were identified and similar benefits were found in the first study, under ‘Benefits for people with dementia’. These findings are consistent with previous qualitative research that examined the experiences of CST participants and their care partners. A previous review underlined key outcomes similar to our findings, including improvements in sociability, cognition, continued stimulation, enjoyment and mental stimulation (Gibbor et al., 2021). Confidence was also a subtheme present in the review, and even though it was not a subtheme in our studies, an enhancement in confidence is noticeable in many of the reports in the first study and it was classified as ‘continued stimulation’ in the second study.

In the second study, answers regarding the design of the intervention were provided. Aspects such as the use of technology and the fact that the sessions were online were observed only by the interviewees of the vCST study, since those are singular aspects of the virtual delivery. Participants of vCST groups also have highlighted how they appreciated the fact that vCST is a person-centred intervention and although this was not a subtheme in the first study, a similar response was given under ‘Benefits of being part of the group’. Additionally, people’s comments on how they enjoyed the structure of the sessions and the fact that it is an evidence-based intervention, among other general benefits, suggest that the adaptation for a virtual context was successful and, as the face-to-face sessions, vCST has elicited cognitive and emotional responses that might indicate that the intervention is acceptable.However, some care partners reported that Plwd had difficulties with the technology that undermined their engagement, which might indicate that vCST may not be suited for all and these issues should be regarded. Finally, additional themes related to improvements in BPSD, language and everyday activities that were not found in the second study might be explained by the topics of the interview which included questions regarding those domains.

Randomized controlled trials are the gold standards for assessing the efficacy of a treatment. Even though the exclusive use of qualitative data cannot objectively or reliably answer questions of effectiveness, qualitative method can offer meaning, insight and validity that quantitative methods may not capture (Dugmore et al., 2015). Several studies have highlighted the importance of qualitative data to access the nuances of the individual experience of the person receiving the treatment (Dugmore et al., 2015; Górska et al., 2018; Young et al., 2021). Spranger et al. (2021) have reported how mechanisms of changes are influenced by a range of individual factors that consider social and contextual aspects. According to Gibson et al. (2004), qualitative approaches view the world in a more subjective way, focusing on meanings and understanding of experience, instead of what can be reduced to quantitative measures. They can develop new ideas through induction from data, rather than confirming or refuting hypotheses. More recently, the Medical Research Council has recommended that qualitative methods should be used to support RCT evaluation of complex interventions (Medical Research Council, 2000). Qualitative studies are also important considering the scarcity of studies using this methodology in the area (Dugmore et al., 2015). The authors emphasize how ‘qualitative research can offer important insights into what makes psychosocial interventions “work”’ (Dugmore et al., 2015) and contribute to the process of building theories on which clinical interventions will be based. Qualitative findings can help identifying barriers and facilitators of the delivery of the intervention, which will designate the way an intervention is implemented and enhance the possibility of being effective. Moreover, identifying and applying what works maximize the likelihood of resources for PlwD being used more efficiently.

Additionally, CST is a person-centred intervention that prioritizes seeing the person and their singularity (Spector et al., 2020). Amongst its 18 principles are ones related to individual aspects of the PlwD and how to foster their engagement in the sessions. Principles like ‘Respect’ that asserts that participants of the groups come from different backgrounds and it is essential to know what is important to each individual, valuing the diversity of views, opinions and beliefs; ‘Involvement and inclusion’ that underline how PlwD should be involved in the planning of activities and their contribution is cherished and respected and ‘Person-centred’ that states the importance of seeing the person first and foremost, rather than focusing on the dementia and the associated impairments, considering how each person is unique. In view of these, it is indispensable to gather PlwD’s feedback on the intervention, to ensure that the treatment reflects its participants. Furthermore, recently, activists and advocates have voiced the negative impact of assuming that Plwd are unreliable narrators (Young et al., 2021) and that their first-hand experiences should be left out of the scientific literature due to them being perceived as too vulnerable or to the complexity and ethics of involving them in research (Carmody et al., 2015). Following the mantra ‘Nothing about us, without us’ it is important that social and health care provided to PlwD be ‘shaped by the accounts of person with dementia themselves’ (Young et al., 2021).

The present study is also important considering how in Brazil the main government policy focuses on investing in high-cost medication at the expense of psychosocial treatments (Picon et al., 2013). The standard treatment forAlzheimer’s Disease (AD is using acetylcholinesterase inhibitors (AChEI) and eventhough it can help with some symptoms, not everyone can access the medication (Moraes et al., 2018), leaving a large portion of the population without treatment options. The available services and support for PlwD are insufficient which can result in excessive unmet needs (Cieto et al., 2014). On the other side, several studies have highlighted the benefits of psychosocial interventions for PlwD to relieve behavioural symptoms (O'connor et al., 2009a), increase emotional well- being (O'connor et al., 2009b), help with symptoms of depression (Teri et al., 2005, Marinho et al., 2021), increase functionality in activities of daily living (Kurz, 2013, Marinho et al., 2021) and improve cognitive functioning, social interaction, and quality of life (McDermott et al., 2018), indicating that PlwD would benefit from receiving non-pharmacological treatments (Spector et al., 2003). CST has a large body of evidence and has been adapted and validated in several countries (Lobbia et al.,2018). Adding to that, an analysis conducted in conjunction with London School of Economics has indicated that CST has effectiveness advantages over, and may be more cost-effective than, treatment as usual (Knapp et al., 2006).

The relevance of this study is notable especially considering the current situation. The COVID-19 pandemic has raised concerns regarding the management of PlwD and their care partners and highlighted the need for interventions that could be remotely accessed (Dourado et al., 2020). A group of facilitators have adapted the CST programme for a virtual context, as an urgent response to the need of providing social connectedness and care for PlwD (Cheung & Peri, 2020). The second study is one of the few collecting feedback from PlwD and their care partners on the virtual version of CST and it should add to the quantitative data. TheCOVID-19 pandemic has accelerated the process of adopting technology in dementia care, which will probably stay beyond COVID-19 and our findings shouldhelp with the continuous adaptation process.

Some limitations in this study should be considered. Both studies mostly reported positive feedbacks. Some of the interviews were conducted by the groups facilitator in the first study and the researchers who were responsible for the assessments in the second study which may have nudged participants to give positive responses, creating a demand characteristics variable. However, participants of the groups were encouraged to provide honest answers. Additionally, data analysis was conducted by the facilitator of all groups in the firstpaper and of two groups in the second paper and that may have led to some overemphasizing of positive effects. While qualitative data can contribute to the evaluation of interventions, adding insights that cannot be presented by qnantitativeresearch, it should not be exclusevily considered when assessing the efficacy of anintervention, so the results of this study should be taken with attention.

Our findings indicate that CST and vCST bring perceived personal benefits to PlwD and care partners, and there are many perceived improvements. Moreover, that CST can be successfully adapted to a virtual setting. This result should be explored by the development of a RCT to fully assess the efficacy of vCST. Adding to that, considering the growing number of populational aging, CST and vCST protocols should be expanded to address different populations such as people with mild cognitive impairment and healthy older adults. Finally, there is an urgency to develop policies focusing on non-pharmacological treatments for dementia in Brazil, so future studies should formulate an ongoing and sustainable CST implementation programme, contemplating different settings such as primary care and care partners association.

5
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Appendix

Interview 1 – Person living with dementia – CST groups

1) How was the experience of being part of a CST group?

2) What was the impact of the intervention?

3) Have you noticed any change in your memory ever since you took part in the group?

4) Have you noticed any change in your language ever since you took part in the group?

5) Have you noticed any change in your orientation regarding time and space ever since you took part in the group?

6) Have you noticed any change in your mood ever since you took part in the group?

7) Have you noticed any change in your behaviour (e.g., more or less agitated etc.) ever since you took part in the group?

8) Have you noticed any change in your social relationships ever since you took part in the group?

9) Have you noticed any change in your activities of daily living (e.g., eating, getting dressed) ever since you took part in the group?

10) Would you refer other people to CST groups?

11) Is there anything you would like to add?

Interview 2 – Caretaker – CST groups

1) How was the experience of being part of a CST group?

2) What was the impact of the intervention?

3) Have you noticed any change in your relative's memory ever since you took part in the group?

4) Have you noticed any change in your relative's language ever since you took part in the group?

5) Have you noticed any change in your relative's orientation regarding time and space ever since you took part in the group?

6) Have you noticed any change in your relative's mood ever since you took part in the group?

7) Have you noticed any change in your relative's behaviour (e.g., more or less agitated etc.) ever since you took part in the group?

8) Have you noticed any change in your relative's social relationships ever since you took part in the group?

9) Have you noticed any change in your relative's activities of daily living (e.g., eating, getting dressed) ever since you took part in the group?

10) Would you refer other people to CST groups?

11) Is there anything you would like to add?

Interview 2 – Persons living with dementia and caretakers – vCST groups

Interview schedule:

"Hello, my name is [name of interviewer]. Thank you for meeting with me to talk about your experience of the online Cognitive Stimulation Therapy groups. Your thoughts will help us understand the problems and successes of using online CST so that we can improve in future. We are interested in learning more about your own experience and there are no right or wrong answers. This interview will be recorded and we will later write down what has been said. What you say will be anonymised and the recording and your transcript will be kept completely confidential. The only exception to this is if you tell me information that I must report, such as harm to yourself or others. If you tell me something that I have a duty to report, I will discuss this with you first. Once your interview has been written down, the recording will be destroyed. If you feel the questions are too sensitive or you would prefer not to answer a question, you do not have to answer. Please let me know if you would like a break or if you want to stop the interview at any point. Do you have any questions before we begin?””

Interview questions

1) General experience of the group

Questions for person with dementia

a) Tell me about your experience of attending the CST groups online.

Prompts:

What did you like?

What did you dislike?

What do you think about the other participants in the session? Did you interact? Make friends?

Tell me about the activities you did in the group. How did you find them?

Did you notice any benefit from taking part? (e.g. did it help with your memory skills, or general wellbeing)?

Did you have any problems from taking part?

b) Would you recommend CST to other people in this region/country? Why/ why not?

Questions for carer

c) Tell me about your relative’s experience of attending the CST groups online

Prompts:

Did your relative have any positive changes from taking part? e.g. did it help with your memory, skills, or general wellbeing?

Did your relative have any negative changes from taking part?

Did your relative's behaviour changes affect their ability to participate & engage with the group?

2) Online CST

Questions for person with dementia

d) What did you think about using video-calls/a computer/a tablet to attend the group?

Prompts:

Was there anything helpful about doing it online?

Was there anything unhelpful about doing it online?

Would you prefer video-calls or in-person meetings for future such programmes? Why?

Would you choose to do something similar online again?

Questions for carer

e) What did you think about your relative using video-calls/a computer/a tablet to attend the group?

Prompts:

Was there anything helpful about doing it online?

Was there anything unhelpful about doing it online?

Did you have any concerns about virtual CST sessions? (Security, privacy, confidentiality)

Are there any other online, telephone or face-to-face services available for your relative?

3) Barriers and facilitators

Questions for person with dementia

f) Did you have any problems attending the groups online? Was there anything that helped you to attend?

Prompts

Were you able to attend every session?

Did you need help to set up the technology?

Did you experience any technical issues? (For example, slow internet, unable to connect to the video call, quality of the video/sound during the sessions, etc.)

Was the screen large enough? Could you see all the participants on the screen at the same time?

Questions for carer

g) Did your relative have any problems attending the groups online? Was there anything that helped them to attend?

Prompts:

Did you or anyone else need to support your relative with the technology?

Do you think your relative would have been able to attend without help with the technology?

Did you have problems accessing a computer/tablet? Did you have to share or borrow one?

Did you have problems accessing reliable Wi-Fi or data?

Would you say it was easier/harder to attend online than in real life?

4) Open questions

Question for both

h) Is there anything else that we haven’t covered that you wanted to add about your experience of online CST?