Online Cognitive Stimulation Therapy for dementia in Brazil and India: Acceptability, Feasibility and Lessons for Implementation

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Abstract

Background: Cognitive Stimulation Therapy (CST) is an evidence-based, group psychosocial intervention for people with dementia, which has a positive impact on cognition and quality of life. CST has been culturally adapted for use globally. It was developed as a face-to-face intervention, but has recently been adapted for online delivery.

Objective: This study explores the feasibility and acceptability of online or virtual CST delivery (vCST) in India and Brazil, emphasizing barriers and facilitators to implementation.

Methods: A single-group, multi-site feasibility study, with nested qualitative interviews. Primary feasibility outcomes were attendance, attrition, acceptability, and outcome measure completion. Exploratory pre- and post-intervention measures, including cognition and quality of life, were administered. Qualitative interviews with people with dementia, family caregivers, and group and organizational leaders followed intervention delivery, analyzed using the Consolidated Framework for Implementation Research (CFIR).

Results: Seventeen vCST groups with 59 participants took place over seven weeks, with 52.5% of participants attending all 14 sessions. Attrition rate was 6.8%, and outcome measure completion rate at follow-up was 67.8%. Interviews took place with 36 stakeholders. vCST was acceptable to participants and group leaders, and enabled vital access to services during pandemic restrictions. Whilst virtual services broadened geographical access, challenges related to computer literacy, technology access, and building interpersonal connections virtually were raised. Exploratory, uncontrolled analyses indicated positive trends in quality of life but negative trends in cognition and activities and activities of daily living.

Conclusions: vCST demonstrated feasibility and acceptability, serving as a crucial resource during the pandemic. However, challenges relate to technology access, computer literacy, and long-term implementation. The study highlights the potential of vCST whilst emphasizing ongoing development and solutions to address implementation challenges.

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ongoing development and solutions to address implementation challenges.

Keywords: Psychosocial; Intervention; Technology; COVID-19

Background

Dementia affects more than 57.4 million people worldwide [1]. People with dementia in low-income and middle-income countries (LMICs) make up 60% of all global cases [2], however around 74% of global spend on dementia is in high-income countries [3]. There are an estimated 1.8 million people over 60 with dementia in Brazil [4] and 8.8 million in India, representing 5.8% and 7.4% of people over 60 respectively [4-6]. Whilst demographic and socio-economic factors differ between Brazil and India, both countries experience low diagnosis rates, limited access to specialist treatment and care, high levels of stigma and a lack of dementia awareness [7-9].

Worldwide, pharmacological treatments for dementia remain limited, so non-pharmacological interventions are needed to address cognitive and behavioural symptoms of dementia and improve quality of life for people with dementia and their families [10]. Many interventions are developed but few are delivered at scale and in routine practice [11].

Cognitive Stimulation Therapy (CST) is a brief, manualised group programme which has been found to improve cognition and quality of life in people with mild to moderate dementia [12]. It is comprised of themed activities, which stimulate and engage participants in a social group environment led by a trained facilitator, through tasks such as physical activity, word association and discussion of current affairs [13]. Despite evidence for its effectiveness [12], cost-effectiveness [14] and its successful cultural adaptation internationally in over 35 countries [15], CST is yet to be implemented in routine practice outside of the UK. [16,17]The 2022 World Alzheimer's Report recommended further research and implementation of CST globally [18].

This study took place within the CST-International research programme, which explored the implementation of CST three LMICs 19: Brazil, an upper middle-income country; India, a lower middle-income country; and Tanzania, a low-income country [20]. In each country, research teams had previously translated and culturally adapted CST and carried out feasibility studies of face-to-face CST [16,17].

CST was developed as a face-to-face intervention. However, during the CST-International study, access to face-to-face healthcare services was rapidly restricted due to the COVID-19 pandemic [21]. CST started to be delivered virtually in international settings including the UK and New Zealand [22,23], but a standardised protocol was not available. An international collaboration resulted in a framework for global delivery, which was field-tested in Brazil and India, alongside the UK, Hong Kong, and Ireland [24]. This study aims to build upon the initial development and field-testing of the virtual CST (vCST) protocol in Brazil and India, with a focus on feasibility, acceptability, and implementation. Therefore the aims of this study are:

1. To explore the acceptability of vCST to people with dementia, family caregivers, CST facilitators and service managers in Brazil and India.
2. To test the feasibility of virtual recruitment, delivery and assessment for CST in Brazil and India.
3. To explore factors affecting the implementation of vCST.

Methods

Design

This study was a single-group, multi-site mixed-methods feasibility study, with pre- and post-intervention outcome measures followed by semi-structured interviews with people with dementia, carers and intervention group leaders.

Methodological framework

This study is guided by the Consolidated Framework for Implementation Research (CFIR) [25]. The CFIR is a determinant framework, which incorporates domains that are hypothesized or found to influence implementation outcomes, and has been applied in LMIC settings [26]. The five domains relate to: 1) intervention characteristics (e.g. evidence strength and quality as viewed by stakeholders, and its core and adaptable components); 2) outer setting (e.g. local attitudes to the condition of interest, and external partnerships and financing); 3) inner setting (e.g. available organizational resources and staffing); 4) characteristics of individuals involved in implementation, and their need for the intervention, and their capability, availability and motivation to be involved (based on the COM-B model [27]); and 5) process of implementation (e.g. assessing needs of intervention recipients, planning, and tailoring strategies). Use of the CFIR as a deductive qualitative framework enables comparisons of barriers and facilitators in other settings and for other interventions.

Participants

People with mild-to-moderate dementia, supported by their family caregivers, took part in vCST groups. For the qualitative component people with dementia, caregivers, group leaders and organizational decision-makers were invited to participate in qualitative interviews following completion of the vCST groups.

Setting

In Brazil, the study site was a psychology department at a university in Rio de Janeiro. In India, the study site was a mental health non-governmental organisation (NGO) in

Chennai, offering outpatient, inpatient and day center services for people with dementia. Both sites had previously been involved in cultural and virtual adaptation of CST [16,17,24], and therefore already had access to face-to-face CST manuals, vCST guidance and CST trainers and facilitators.

Recruitment

In Brazil, recruitment took place through partnerships with memory clinics and NGOs, advertising on social media and local media, and snowball sampling. In India, people with dementia were recruited from the patient caseload at the NGO, with additional promotion through caregiver support groups and mobile-messaging groups.

Inclusion criteria for people with dementia at both sites was as follows:

1. Meet the ICD-10 criteria for dementia, as assessed by a trained clinician [28].
2. Be rated as having mild to moderate dementia on the Clinical Dementia Rating Scale [29].
3. Have sufficient hearing and vision to follow conversation and comment on visual material.
4. Have the ability to participate in an online group for one hour.

Informed consent was received from people with dementia and their caregivers upon recruitment.

Intervention procedure

People with dementia were allocated to a vCST group. vCST groups were delivered according to the culturally adapted CST Brazil and India manuals [16,17], which had been further adapted according to the recently developed protocol for virtual delivery of CST [24]. Groups took place twice weekly over seven weeks via video-conferencing software, between February 2021 and September 2022. Each group consisted of three to five participants. In

Brazil, participants needed to use their own devices, whereas in India, devices were loaned from the NGO if needed. In Brazil, the language of instruction was Brazilian Portuguese, and in India, it was Tamil or English. Group facilitators were trained by site leaders and worked in pairs to deliver the intervention. In Brazil, the group leaders were two psychologists, a gerontologist, and eight trainee psychologists. In India, the group leaders were three psychologists and a nursing assistant.

Feasibility outcomes

The following pre-specified main outcomes relating to intervention acceptability were adapted from Proctor et al. (2011):

- **Recruitment rate**. The recruitment target was 50 in Brazil and 15 in Chennai, recruited by September 2022. This target was calculated pragmatically based on available time and resources in each site and was deemed suitable to run enough vCST groups to explore feasibility, acceptability and implementation issues.
- **Attendance**. Overall attendance rate of over 60%, based on the international team's judgement and experience of running CST groups and supporting people with dementia in each setting.
- **Attrition**. Retention rate of at least 75% of participants to follow up, again based on the team's previous experience and judgement.
- **Acceptability of intervention**. This will be assessed through semi-structured interviews (see below).
- **Outcome measure completion.** The inclusion of cognition, quality of life, activities of daily living and caregiver burden measures are in line with those used in previous trials and studies of CST [12]. The main goal of the outcomes was to assess the feasibility and acceptability of collecting these data.

Outcome measures were translated, back-translated and finalized by bilingual committee review. The following measures were completed by people with dementia pre- and post-intervention:

- The Alzheimer's Disease Assessment Scale–Cognitive Subscale (ADAS-Cog), an internationally used 21-item measure of cognitive function [31].
- The World Health Organization Quality of Life Brief Version (WHOQOL-BREF), a 26-item quality of life measure addressing four domains: physical health, psychological health, social relationships and environment which was developed for use in LMICs [32].
- Alzheimer's Disease Cooperative Study–Activities of Daily Living Scale (ADCS-ADL), a 23-item scale which addresses basic and instrumental activities of daily living and has been culturally adapted for use in Brazil [33,34]. This scale was used in Brazil only.
- Scale for the Instrumental Activities of Daily Living in the Elderly (IADL-EDR), an 11-item scale developed in South India which addresses cognitive and physical disability [35]. This scale was used in India only.

Family caregivers also completed:

- The Zarit Burden Interview (ZBI), a widely used 22-item self-report measure of strain and stress [36].
- Dementia Caregiver Experience Scale (DemCarES), a 17-item measure to assess stress and strain (personal communication by Vaitheswaran, 2023)., and included due to previous issues with the cross-cultural validity of the ZBI, which has been found to underestimate burden in LMIC settings [37].

Semi-structured interviews

To gather in-depth information about intervention acceptability, feasibility and experiences of implementation, semi-structured interviews took place with stakeholders. People with dementia and carers from the first two vCST groups in Brazil (12 dyads) and all vCST groups in India (15 dyads) were invited to take part in dyadic interviews. A convenience sample of group leaders from Brazil and India (n=7) and organizational decision-makers (n=2, India only) was invited to take part in one-to-one interviews.

Interviews with people with dementia and caregivers took place in the language of vCST group instruction (either English, Tamil or Brazilian Portuguese) and were led by a researcher from the respective institution who had not facilitated the group, to reduce response bias. Interviews with group leaders and organizational decision-makers took place in English. To reduce response bias, these were led by UK-based researchers who were not members of the immediate project team. All interview took place over video-conferencing software.

The interview guide was developed by researchers and clinical psychologists, with questions relating to the participants' experience of taking part in the vCST group, experience of using an online platform, and barriers and facilitators to involvement, based on constructs from the CFIR.

Analysis

Quantitative

Primary analysis was descriptive and assessed recruitment, retention, and outcome measure completion. The pre- and post-intervention outcome measure means and mean differences (calculated through paired t-tests) are reported descriptively. Effect sizes were

calculated using Cohen's *d*. Analysis took place using IBM Statistical Package for the Social Sciences® (SPSS) version number 29. All data were pseudo-anonymized with a unique participant identification number.

Qualitative

Interviews were recorded with consent and transcribed. All transcripts were pseudo-anonymized with a unique participant identification number and any identifying information was removed during transcription. Transcripts in Brazilian Portuguese or Tamil were translated before analysis. First, the researchers read the transcripts for data familiarization. We used a framework analysis approach; transcripts were coded using inductive thematic analysis [38], then we mapped inductive themes onto the CFIR. This enabled us to capture themes which were not covered by the CFIR. Transcripts were coded independently by two researchers using NVivo software, who met regularly to ensure they were approaching the data in a similar way and then agreed on a final coding framework. Any discrepancies were examined and resolved through discussion. The exception is the interview transcripts of caregivers in India, which was coded by an individual reviewer using Atlas software and discussed with a second researcher.

Ethics

Ethical approval was granted by the relevant body in each country. In Brazil, an ethics amendment was granted by the [BLINDED FOR PEER REVIEW] research ethics committee (BLINDED FOR PEER REVIEW) In India, approval was granted by Institutional Ethics Committees at [BLINDED FOR PEER REVIEW] (BLINDED FOR PEER REVIEW). Informed written consent was received from participants. All data have been deidentified, and

participants did not receive compensation.

Results

Feasibility outcomes

Recruitment rate

A total of 59 participants were recruited to vCST groups, which was 91% of the target figure of 65. Participant demographics are outlined in Table 1. In Brazil, 12 groups took place with a total of 44 participants between April 2021 and November 2022.In India, five groups took place with 15 participants between February 2021 and February 2022. This represents an average of 3.6 participants per group across both sites.

INSERT TABLE 1 HERE

Attendance

In Brazil, 52.3% of participants attended all 14 sessions (23/44), and in India 53.3% of participants had full attendance (8/15).

Attrition

In Brazil, the attrition rate was 9.1%. Four out of 44 participants did not complete the vCST programme due to caregiver unavailability to support the participant (n=2), hospitalization due to COVID-19 (n=1) and going on vacation (n=1). There were no dropouts from vCST groups in India.

Outcome measure completion

Researchers completed pre-intervention outcomes with all people with dementia, however some caregivers were unavailable to take part in pre-assessments (n=3). Retention of people with dementia to follow-up was 88.6% in Brazil (39/44), and 93.3% in India (14/15). In India, 86.7% of caregivers completed all follow-up assessments (13/15), but this figure was lower in Brazil (70.5%; 31/44). This was attributed to caregivers being occupied

with family and work commitments, particularly at a time of increased pressure during the pandemic. Additionally, some people with dementia did not have one named caregiver and were supported by a range of family members or paid caregivers who did not always feel they could provide accurate information. Overall, 67.8% of participant dyads across both sites completed all post-intervention outcome measures (40/59). No measures caused distress, and no measures had individual items missing.

Table 1: Participant demographics

Results are n (%) unless specified otherwise			
	Brazil (n=44)	India (n=15)	Total (n=59)
Person with dementia			
Region			
Southeast Brazil	41 (93.2%)	-	41 (69.5%)
South Brazil	2 (4.5%)	-	2 (3.4%)
Northeast Brazil	1 (2.3%)	-	1 (1.7%)
Chennai (India)	-	15 (100%)	15 (25.4%)
Age – mean (range)	77.1 (61-93)	77.3 (65-93)	77.2 (61-93)
Sex			
Male	10 (22.7%)	10 (66.7%)	20 (33.9%)
Female	34 (77.3%)	5 (33.3%)	39 (66.1%)
Ethnicity			
South Asian	-	15 (100%)	15 (25.4%)
Black	3 (6.8%)	-	3 (5.1%)
Mixed	6 (13.6%)	-	6 (10.2 %)
White	35 (79.5%)	-	35 (59.3%)
Years in education – mean (range)	11.5 (4-20)	13.0 (10-17)	11.9 (4-20)
Type of dementia			
Alzheimer's disease (AD)	22 (50%)	11 (73.3%)	33 (55.9%)
Vascular dementia	4 (9.1%)	3 (20.0%)	7 (11.8%)
Mixed dementia (AD and vascular)	1 (2.3%)	1 (6.7%)	2 (3.4%)
Parkinson's related dementia	0 (0%)	0 (0%)	0 (0.0%)
Dementia with Lewy bodies	1 (2.3%)	0 (0%)	1 (1.7%)
Variant unknown	16 (36.4%)	0 (0%)	16 (27.1%)
Caregiver (n=59)			
Sex			
Male	7 (15.9%)	3 (20.0%)	10 (16.9%)
Female	37 (84.1%)	12 (80.0%)	49 (83.1%)
Age – mean (range)*	52.5 (32-71)	53.2 (29-72)	52.7 (29-72)
Relationship to PwD*			
Spouse	8 (18.2%)	4 (26.7%)	12 (20.3%)
Daughter/Son	32 (72.7%)	11 (73.3%)	43 (72.9%)
Daughter-in-law/ Son-in-law	1 (2.3%)	0 (0%)	1 (1.7%)
Other relative	2 (4.5%)	0 (0%)	2 (3.4%)
Living with PwD*			
No	11 (25.0%)	2 (13.3%)	13 (22.0%)
Yes	26 (59.1%)	13 (86.7%)	39 (66.1%)
PwD = Person with dementia. *Missing data for Brazil: Caregiver age (n=7); Relationship to PwD (n=3); Living with PwD (n=7).			

Pre-and post-intervention means and mean differences are outlined in table 2. Analyses were exploratory and not powered to detect specific changes. The results suggest a small decrease in cognitive ability from baseline to follow up. Small improvements across quality of life domains were observed in people with dementia. We observed moderate reductions in activity of daily living ability across all domains in both sites. Conflicting outcomes were observed in carer burden outcomes, with a small reduction in burden scores on the ZBI, but an increase in burden scores according to the DemCarES measure.

Supplementary file 1 presents results by country. The direction and magnitude of change was similar across both sites, apart from cognition where the decrease was smaller in India, quality of life score (social relationships) where the increase was smaller in India, and quality of life score (psychological and environment domains) where a reduction was observed in India compared to an improvement in Brazil.

INSERT TABLE 2 HERE

Table 2: Outcome measures, pre- and post-intervention

Outcome (range)	Pre-intervention		Post-intervention		Mean improvement (pre-post)			
	n	Mean (SD)	n	Mean (SD)	n	Mean difference (95% CI)	p-value	Effect size (95% CI)
ADAS-Cog (0-70)	59	27.11 (12.92)	52	27.36 (14.53)	52	-1.20 (-3.25, 0.85)	0.24	-0.16 (-0.44, 0.11)
WHOQOL-BREF: Physical health (4-20)	59	14.48 (2.82)	51	14.80 (2.56)	51	+0.38 (-0.25, 1.01)	0.23	+0.17 (-0.11, 0.45)
WHOQOL-BREF: Psychological (4-20)	59	14.17 (2.13)	51	14.75 (2.02)	51	+0.58 (0.04, 1.11)	0.04	+0.30 (0.21, 0.58)
WHOQOL-BREF: Social relationships (4-	59	15.12 (1.71)	51	15.48 (1.96)	51	+0.52 (-0.05, 1.10)	0.07	+0.26 (-0.03, 0.53)

20)								
WHOQOL-BREF Environment (4-20)	59	15.03 (1.96)	51	15.25 (1.82)	51	+0.36 (-0.12, 0.85)	0.14	+0.21 (-0.07, 0.49)
ADCS-ADL (0-78)	44	44.34 (16.55)	40	42.00 (16.44)	40	-3.18 (-5.35, -1.01)	0.005	-0.47 (-0.79, -0.14)
IADL-EDR – Cognitive domain (0-100)	15	37.65 (19.77)	14	43.97 (20.72)	14	-8.64 (-17.91, 0.64)	0.07	-0.54 (-1.09, 0.03)
IADL-EDR – Physical domain (0-100)	15	4.20 (7.95)	14	10.57 (15.71)	14	-7.50 (-16.61, 1.61)	0.10	-0.48 (-1.02, 0.09)
ZBI (0-88)	56	35.02 (18.04)	47	32.91 (17.69)	46	+1.33 (-0.96, 3.61)	0.25	+0.17 (-0.12, 0.46)
DemCarES (17-51)	53	28.94 (6.91)	46	29.35 (7.28)	43	-0.67 (-1.90, 0.55)	0.27	-0.17 (-0.47, 0.13)

Abbreviations: ADAS-Cog: Alzheimer's Disease Assessment Scale–Cognitive Subscale; WHOQOL-BREF: World Health Organization Quality of Life Brief Version; ADCS-ADL: Alzheimer's Disease Cooperative Study–Activities of Daily Living Scale; IADL-EDR: Scale for the Instrumental Activities of Daily Living in the Elderly; ZBI: Zarit Burden Interview; DemCarES : Dementia Caregiver Experience Scale.

ADCS-ADL administered in Brazil only, and IADL-EDR in India.

The positive maximum scale score is underlined.

Effect size calculated using Cohen's d (complete case analysis). No adjustments were made for multiple testing because analyses are exploratory.

Qualitative results

A total of 36 qualitative interviews took place. In Brazil, 12 people with dementia and their caregivers took part. In India, interviews took place with 15 people with dementia and caregivers. This comprises all participants from the first two vCST groups in Brazil, and all participants from the five groups in India. Additionally, four group leaders from Brazil took part in interviews, and from India, three group leaders and two organizational decision-makers from the NGO in India. All participants who were invited to the interviews agreed to take part.

Two main areas were explored in the analysis: 1) Acceptability of vCST and 2) Barriers and facilitators to implementation, guided by the CFIR.

Acceptability of vCST

All interview participants were asked directly about their experiences of taking part in CST virtually, and were asked to reflect on how it compares to previous face-to-face activities. Overall, participant and caregiver evaluation of vCST was positive, with key benefits relating to providing occupation, enjoyment and social interaction at time of isolation:

> *"I liked her activeness and purposefulness… that itself is important. Earlier she used to simply sit but now she has something to do, so that kind of purposefulness is really appreciable"*. Caregiver 4 – India
>
> *"We talk and such in the house, but we are only a few here. Now my family is almost just me and him.... [the] television doesn't interact*". Caregiver 8 - Brazil
>
> *"At first I didn't want to attend the sessions (laughs), I fought, I wanted to hit everyone, but I liked it."* Person with dementia 1 - Brazil

The remote delivery and national recruitment in Brazil also enabled attendance of some participants from outside the urban centers of Rio de Janeiro and Sao Paulo, where the

majority of services are provided:

"You're interacting there from Rio, [name of another participant] there from Itapetininga, the other lady also from another place… with this pandemic business… we don't need to have physical contact. I think it's great" Caregiver 8 - Brazil

However, many felt that the social connection and stimulation would have been stronger if the intervention could take place face-to-face, in particular the facilitators who had experience of delivering both virtual and face-to-face CST:

"There are many more activities that can be done in person, rather than virtually… like for example, throwing ball to each other, doing physical activities together. Even sensory stimulation like… hearing sounds or seeing things…. And I feel just physically being present and seeing other people is definitely… much more helpful." Group leader 3 - India

"I think it would have been better if it could have happened in person. But during the COVID situation… this was more helpful and comfortable as anybody can attend from any place. Maybe still, I feel it would have been more beneficial for the dementia group if it were a direct session." Caregiver 6 - India

Additional issues with intervention acceptability relate to participants' access to suitable technology and computer literacy, which was compounded by cognitive impairment:

"The main issue was internet. I would say… so we had only three participants in a group… along with a facilitator and a co-facilitator… which means that, like five different internet connections. So, the problem was if even one participant had a disruption in their internet, it tends to affect the whole group." Group leader 1 - India

"At first it was more difficult, because the computer she could use at this time, I was using for work... so she had to do it on her phone... The images were too small for her to see, so that got in the way." Caregiver 7 - Brazil

Group leaders also reflected that it was more difficult to gauge engagement and facilitate a group virtually, as opposed to face-to-face:

> *"Just knowing the body language, if the person is feeling sleepy, or the person's not enjoying it and stuff like that. You're not able to notice it as much because it is a virtual set up"* Group leader 1 - India

> *"Sometimes… the participants would talk over other people. We will ask someone a question, and that person… would answer, but then another person would answer also, and the two answers were colliding there, and it was hard to manage that, because it was virtual sessions."* Group leader 2 – Brazil

Facilitators and barriers to implementation

Facilitators and barriers are included in tables 3 and 4, categorised by CFIR domain with illustrative quotes. Key facilitators included:

- **Innovation.** Facilitators included the evidence base of CST and its advantage over other psychosocial interventions as a manualised intervention, which was also flexible to the needs of the participants. Some group leaders reflected that they were aware of few other interventions for people with dementia taking place virtually at the time.
- **Outer setting.** An international collaborative effort enabled funding, sharing of protocols and training materials. Many caregivers reflected that they were appreciative that the person with dementia could attend vCST at a time of social isolation due to COVID-19 restrictions.
- **Inner setting.** Staff in both sites were motivated to offer a service for people with dementia, and many participants reflected on the need for more support for people with dementia. Another facilitator to implementation was the training and supervision of staff at the NGO and trainee psychologists at the university. The NGO in India were able to appoint permanent staff members to take on vCST responsibilities as part

of their role and integrate vCST into the existing services and caseload.

- **Individuals.** The majority of people with dementia relied on caregivers' support, and would often miss sessions if their caregiver was unavailable. All groups also required two group leaders – one to lead the activities and another to provide technological support and to contact caregivers if a participant was struggling to engage. In India, group leaders reflected that take up was improved if vCST was suggested to participants by a clinician.
- **Processes.** Key implementation strategies included providing mock vCST sessions with caregivers and people with dementia to orient them to the platform, and posting out activity packs to those who did not have resources at home.

INSERT TABLE 3

Table 3: Facilitators to implementation

CFIR domain	**Sub-domains** *(context-specific description)*	**Quotes**
Innovation	Innovation evidence-base	"In terms of evidence based published literature information… the effectiveness of CST and the cost effectiveness in other centers… That helped in choosing the most appropriate intervention". Decision maker 1 - India
	Innovation relative advantage	"There was this one organization… a day center facility were doing... one-on-one video calls to have some sort of a social interaction during the pandemic". Group leader 2 - Brazil
	Adaptability *(of vCST protocol)*	"I think we had flexibility, because as I said one was the education level of patients and then the language that had to be used" Decision maker 2 - India
Outer setting	Local conditions *(Need for socialising during lockdowns)*	"He was... looking forward to the session, especially social interaction because the pandemic had obviously you know sort of cut down a lot of such interactions" Caregiver 1 - India
	Partnerships and connections *(International research partnership)*	"We based it ourselves in this protocol, which was already published with some guidelines for developing the CST virtually". Group leader 1 - Brazil
	Financing *(International research funding)*	"We were able to purchase the items that we need to deliver CST at our center. And for regarding technology… we were able to provide some of the participants with a tablet computer and the data for them". Decision maker 1 - India
Inner setting	Tension for change (*Need for psychosocial treatment)*	"There is no actual evidence based structured manual intervention available in India prior to this, so this provided as an opportunity to make it available for our patients." Decision maker 1 - India
	Culture – Learning centredness *(Supporting trainee psychologists – Brazil)*	"I really like participating on the project from my experience, in gaining experience, on like clinical experience and also a little bit of research too" Group leader 3 - Brazil
	Compatibility *(With service/caseload - India)*	"We have a regular clinic so we identify participants from the clinic" Decision maker 1 - India
	Access to knowledge and information *(Training and supervision)*	"We had training, of course, and we also had regular supervision from our supervisor." Group leader 1 - India
	Work infrastructure – Staff (*at NGO - India)*	"Making sure that the facilitators are in substantive posts and not in fleeting positions so they are available for a longer time." Decision maker 1 - India
Individuals	Opinion leaders *(Recommendation from doctors)*	"If the doctor sometimes says, 'you should do this, this will be beneficial for you', it really helps in the Indian context of the doctor's word for you" Group leader 2 - India
	Other implementation support – availability / capability*(Caregivers)*	"Some of [the caregivers] would stay next to the person living with dementia… especially when the person was a little bit shy, [or] had more difficulty with technology… They were… mediating this communication". Group leader 2 - Brazil
	Other implementation support - availability / capability *(Co-facilitator)*	"One of the psychologists is delivering the session, and we need someone to support us at the technical end, we need someone to support us" Group leader 2 - India

	Intervention recipient - need *(Person with dementia – need to stay home and subsequent isolation)*	"Some of these people would not have come for in-person CST, because they could not afford transportation, did not have proper transportation, were frail, or had some kind of physical comorbidity or pain" Group leader 2 - India
Implementation process	Tailoring strategies (*Mock vCST sessions and activity packs)*	"We do have one trial session, where I sit with them individually. And then we have one group trial session, to see if they're comfortable in a group". Group leader 2 – India "We posted the materials… for number games, we had paper sheets. And colouring papers and some origami papers… We took printouts and posted it to their house." Group leader 1 - India

Table 4: Barriers to implementation

CFIR domain	**Sub-domains** *(context-specific description)*	**Quotes**
Innovation	Adaptability *(Virtual delivery of CST)*	"I was running face-to-face sessions before they started [vCST]. Face-to-face CST was great.. my group ran with eight members, six to eight, consistently. So, I had a huge group coming every Friday. It was amazing, they could form more connections, and turn taking is a little bit easier… It's a little harder like you with the Zoom." Group leader 2 - India
	Innovation Design *(Need for marketing)*	"It doesn't have much publicity. If it wasn't for chance, if this person hadn't put us in, I wouldn't have made it. So, I think in terms of dissemination it could be broader" Caregiver 4 - Brazil
Outer setting	Critical incidents (*COVID pandemic)*	"It was COVID and people are falling sick… even the facilitators are sick, at some point" Group leader 1 - India
	Local attitudes (*Dementia awareness)*	"In Brazil, I think it's a cultural thing to think that dementia symptoms it's part of a natural aging… So, when older people, and people living with dementia… come to a doctor to be evaluated they sometimes don't have mild symptoms anymore". Group leader 2 - Brazil
	Local attitudes *(Traditional focus on medical model)*	"People weren't aware of psychosocial interventions for dementia prior to this. They had very different model for working with people with dementia". Decision maker 1 - India
	Local conditions *(Access to technology)*	"Most of the people that we had in the groups were from the south eastern region. And that's kind of a more developed region financially… I think today most people in Brazil have access to internet. Maybe not their computer, but maybe cell phones and something like that." Group leader 3 - Brazil
Inner setting	Structural characteristics – Work infrastructure *(Staff availability)*	"When we think of scaling it up, we might have to do it first of all in institutions where there is enough manpower of mental health professionals to deliver the CST… dementia care in India is still mental health care and we're still very under-resourced as far as manpower is concerned". Decision maker 2 - India
Individuals	High level leaders – Capability *(Lack of dementia awareness)*	"Some of the policymakers, who we interviewed at the beginning [in previous stakeholder engagement] weren't even aware of the issues relating to dementia". Decision

		maker 1 - India
	Intervention deliverers – Capability *(Basics in clinical skills needed)*	“I think we if we didn't have the training, it would be very hard to just come to the groups… I didn't have any contact [with people with dementia] before.” Group leader 3 - Brazil
	Intervention recipients – Capability *(Sensory impairment and computer literacy)*	“So, one challenge was delivering it virtually. My mother was not able to hear very well. Now she has a hearing aid, she has the headphones but still that was a part of a problem of communication.” Caregiver 5 - India “I don't know how to use the computer (laughs).” Person with dementia 10 - Brazil
Implementation process	Assessing needs – Innovation recipients *(Severity of dementia)*	“If you have some difference in severity of dementia, because the activities demand something, and maybe it can be boring for who is not so severe.” Group leader 4 - Brazil
	Assessing needs – Innovation recipients *(Baseline assessments)*	“The first is, I think, the baseline evaluations were very long, and that was kind of hard on the, not on the people with dementia, but on their family members, the caregivers” Group leader 3 - Brazil
	Reflecting & Evaluating – Implementation *(Lack of long term follow up)*	“One question that most people with dementia their caregivers made was, if it was possible to have more than 14 sessions. So maybe adapting the maintenance CST for the virtual program. I think it would be a suggestion for the future.” Group leader 1 - Brazil

Key barriers related to the five CFIR domains are as follows:

- **Innovation.** The majority of group leaders highlighted challenges with virtual delivery of CST in terms of facilitating a group effectively, meeting individual needs and supporting participants with the video-conferencing platform. Many leaders reflected on the comparative ease of facilitating a group in-person. These issues are outlined in detail in the 'Acceptability' section. Finally group leaders and caregivers highlighted the need for marketing to raise awareness of vCST
- **Outer setting.** Whilst COVID-19 necessitated and possibly facilitated virtual delivery of CST, staff and participant illness during the pandemic was a barrier to group delivery and attendance. Staff at both sites reflected on a lack of dementia awareness, resulting in participants presenting later to clinical services, which is a barrier to recruiting participants with mild-to-moderate dementia. Similarly, group leaders and decision maker reflected on a lack of awareness of psychosocial interventions for dementia, with the medical model tending to prevail. Finally, in both sites it was highlighted that access to technology is a barrier to involvement.
- **Inner setting.** The limited availability of mental health personnel was highlighted as a barrier to the wider scale-up of vCST in India.
- **Individuals.** People with dementia and caregivers faced barriers to taking part in vCST, including a lack of computer literacy and sensory impairment which impacted engagement. Organizational decision-makers in India reflected on the lack of dementia awareness within high-level policy makers.
- **Processes.** One group leader reflected on the length and burden of the baseline assessments on people with dementia and caregivers. Many people with dementia and caregivers expressed a wish for the vCST groups to continue beyond the 14 sessions. At the NGO in India it was possible to follow-up with patients on the caseload,

however group leaders in Brazil wished to be able to continue to support participants and caregivers.

INSERT TABLE 4

Discussion

We found that it was feasible and acceptable to deliver CST virtually in Brazil and India. We recruited 91% of the target sample and were able to run 17 vCST groups. Attrition was low (6.78%) and attendance was moderate, with 52.5% of participants attending all 14 sessions. This is in contrast to a previous trial of face-to-face CST in Brazil, where attrition was similar (6%) but attendance was high (mean=12.8 sessions, median=14 sessions) [39]. In India, a previous pilot of face-to-face CST in Chennai, attrition was higher with three out of nine participants dropping out [16]. However, these comparisons should be interpreted with care due to small sample sizes and the impact of COVID-19 in both countries.

Outcome measure completion was slightly lower than the target of 75%, with 67.8% of participant dyads completing all follow-up outcome measures, which suggests a possible measurement burden. Small improvements across all quality of life domains were observed in people with dementia. All results should be interpreted with care, as the study was uncontrolled. Any changes cannot be ascribed to the vCST intervention specifically, and the impact of COVID-19 and consequent social isolation may have played a role in changes pre- and post-intervention.

There were some differences in the barriers and facilitators to implementation across the two sites. vCST was delivered in an NGO in Chennai, where participants could be recruited from the patient caseload. In Brazil, vCST was delivered through a university and recruitment took place from the community, and memory clinics and NGOs who were partnered with the study. Despite staff turnover as a barrier to implementation in the NGO in

India, decision-makers reflected that it would be possible to build CST or vCST into services due to its compatibility with current ways of working. This may have been more of a challenge in the university setting in Brazil, where there is no patient caseload or clinic infrastructure. However, there is scope to build partnerships with community organizations and clinics to recruit participants. Upskilling trainee psychologists to deliver vCST in Brazil also presents a low-cost and scalable solution to implementing vCST in a university setting. Similar solutions have been used for other psychosocial interventions for dementia in other countries [40,41].

A major barrier in both sites was access to technology and computer literacy. This issue was also highlighted in studies of vCST in UK settings [23,24]. A survey of the digital divide in India found that just 38% of households are digitally literate [42]. Access is higher in Brazil, where 80% of households have internet access [43]. In both countries, digital access intersects with age, gender, education level, and ethnicity [42, 43,44]. Whilst virtual interventions provide service access to those living in geographically isolated locations, the digital divide is greater in rural areas; in Brazil, 53% of the rural population have internet access compared to 88% in rural areas [43], and figures are lower overall in India where 31% of the rural population use the internet, compared to 67% the urban population [42]. To overcome barriers to technology access in India, tablets were loaned to participants from the NGO, which required sufficient funding and resources. To address issues related to digital literacy, group leaders provided mock vCST sessions to familiarize participants with the video-conferencing platform, a co-leader was available specifically for technology support, and groups sizes were smaller which meant that all participants could be viewed on the screen at once (average 3.6 participants compared to 6-8 according to the original CST protocol [12]).

Most people with dementia were reliant on caregivers' technical support to use the

video-conferencing technology, and in some cases, caregivers remained present throughout the groups. This raises a key issue for those without caregivers, who could be systematically excluded from taking part in virtual psychosocial interventions. If vCST were implemented as a dyadic intervention, this could improve caregivers' awareness of dementia and person-centered approaches, which is important given the limited number of dementia awareness programmes in LMIC settings [45]. However, it could also negatively impact the engagement of the person with dementia, as a proposed mechanism of action of CST is the supportive learning environment, where people with dementia support each other without judgment or embarrassment [46]. If vCST is delivered dyadically, we recommend that participants are briefed at the start of the programme to set expectations about the carers' level of involvement in the vCST sessions, and that people with dementia are provided with opportunities to take part in activities and discussions alone. Further research could explore the impact of dyadic delivery on outcomes for people with dementia and their carers.

Limitations

In both sites, it is likely that the sample was unrepresentative of the broader population of people living with dementia and their carers. Specifically, in Brazil, the majority of the sample was White (79.5%) which does not reflect the majority Black and mixed Brazilian population. The majority of participants were from the urban region of southeast Brazil, though the remote method of recruitment did enable participation from areas outside of this region, which are underserved in terms of research and clinical services. In India, all participants were recruited from the same region, and were already attending clinical services which may have resulted in a sample skewed to those with the means to access services.

Online delivery may result in a self-selecting sample, who are more likely to be educated to a higher level, and more affluent than the broader population. The mean number

of years of schooling for our sample was 11.5 in Brazil and 13.0 in India. This compares to a national average of 2.5 in Brazil and 1.4 in India for the population aged 25 and over in 1970 and 1971 respectively [47] – though there is huge regional variation in education levels in both countries. To overcome issues related to digital exclusion in India, tablets were loaned to those who needed them. However, in Brazil, people without access to their own technology were excluded.

In terms of the qualitative component, the majority of themes and quotes from a participant perspective were collected from caregivers rather than people with dementia. This is because cognitive impairment affected their recall of sessions. Despite this, caregivers and group leaders reflected on the perceived participant experience of vCST sessions. Interviews took place with all caregiver dyads from India, but only those from the first two vCST groups in Brazil due to staff availability. However, the reflections from group leaders and organizational decision-makers relate to all vCST groups. Interviews with group leaders and decision-makers were carried out in English by a UK-based researcher who was not a member of the immediate research team. This was to limit response bias and encourage honest and critical feedback, however it limited the interview to people who speak English and may have compromised representation of non-English speakers.

Finally, the vCST intervention was tested in two sites, a university in Brazil and an NGO in India. Though this resulted in lessons for implementation which could be explored in other sites and countries, we acknowledge the limited generalizability of these findings.

Future research

To date, vCST has only been trialed within a pandemic context. Whilst this was acceptable to participants during a time of social isolation, many caregiver dyads and group leaders expressed a desire for CST to take place in-person. Future research could explore the feasibility of vCST outside of the pandemic context, perhaps specifically targeting those who

cannot access in-person services due to limited mobility, health issues or geographically isolation.

Additionally, although there is a strong evidence base for in-person CST, we do not know if the benefits to cognition and quality of life are conferred to the same level over virtual delivery. A recent feasibility study of vCST has shown that a full-scale randomized controlled trial is warranted (In press Spector, 2023).

Conclusions

The 14-session vCST programme for people with dementia was successfully trialled in a university setting in Brazil, and an NGO in Chennai, India. vCST offered a feasible alternative to in-person groups during the period of pandemic restrictions with potential benefits to quality of life, but there were barriers related to technology access and computer literacy. Outside of the pandemic context, vCST could be provided to people with dementia who are geographically isolated, or who have mobility or health difficulties.

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Conflicts of interest

AS offers Cognitive Stimulation Therapy (CST) training courses on a consultancy basis.

Abbreviations

ADAS-Cog: Alzheimer's Disease Assessment Scale–Cognitive Subscale
ADCS-ADL: Alzheimer’s Disease Cooperative Study–Activities of Daily Living Scale
CFIR: Consolidated Framework for Implementation Research
CST: Cognitive Stimulation Therapy
COM-B: Capability, Opportunity and Motivation in Behavior change
DemCarES : Dementia Caregiver Experience Scale
IADL-EDR: Scale for the Instrumental Activities of Daily Living in the Elderly
LMIC: Low-income and middle-income countries
NGO: Non-government organization
vCST: Virtual Cognitive Stimulation Therapy
WHOQOL-BREF: World Health Organization Quality of Life Brief Version;
ZBI: Zarit Burden Interview

References

1. Nichols E, Steinmetz JD, Vollset SE, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*. 2022;7(2):e105-e125. doi:10.1016/S2468-2667(21)00249-8
2. World Health Organization (2017). Global action plan on the public health response to dementia 2017 - 2025. Geneva: World Health Organization. Retrieved from: https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025
3. Wimo A, Seeher K, Cataldi R, et al. The worldwide costs of dementia in 2019. *Alzheimer's & Dementia*. 2023;19(7):2865-2873. doi:10.1002/ALZ.12901
4. Bertola L, Suemoto CK, Aliberti MJR, et al. Prevalence of Dementia and Cognitive Impairment No Dementia in a Large and Diverse Nationally Representative Sample: The ELSI-Brazil Study. *The Journals of Gerontology: Series A*. 2023;78(6):1060-1068. doi:10.1093/GERONA/GLAD025
5. Lee J, Meijer E, Langa KM, et al. Prevalence of dementia in India: National and state estimates from a nationwide study. *Alzheimer's & Dementia*. 2023;19(7):2898-2912. doi:10.1002/ALZ.12928
6. Pan American Health Organization (2022). Taking the pulse of the health system's response to the needs of older persons. Situational analysis Brazil. Retrieved from: https://www.paho.org/en/documents/taking-pulse-health-systems-response-needs-older-persons-situational-analysis-brazil
7. Nakamura AE, Opaleye D, Tani G, Ferri CP. Dementia underdiagnosis in Brazil. *The Lancet*. 2015;385(9966):418-419. doi:10.1016/S0140-6736(15)60153-2
8. Calil V, Elliott E, Borelli WV, et al. Challenges in the diagnosis of dementia: insights from the United Kingdom-Brazil Dementia Workshop. *Dement Neuropsychol*. 2020;14(3):201-208. doi:10.1590/1980-57642020DN14-030001
9. Nulkar A, Paralikar V, Juvekar S. Dementia in India – a call for action. *J Glob Health Rep*. 2019;3. doi:10.29392/JOGHR.3.E2019078
10. Pickett J, Bird C, Ballard C, et al. A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *Int J Geriatr Psychiatry*. 2018;33(7):900-906. doi:10.1002/gps.4868
11. Vernooij-Dassen M, Moniz-Cook E. Raising the standard of applied dementia care research: Addressing the implementation error. *Aging Ment Health*. 2014;18(7):809-814. doi:10.1080/13607863.2014.899977
12. Woods B, Rai HK, Elliott E, Aguirre E, Orrell M, Spector A. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*. 2023;2023(1). doi:10.1002/14651858.CD005562.PUB3/MEDIA/CDSR/CD005562/IMAGE_N/NCD005562-CMP-008.05.SVG
13. Spector A, Thorgrimsen L, Woods B, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *The British Journal of Psychiatry*. 2003;183(3):248-254. doi:10.1192/BJP.183.3.248
14. NHS England » Cognitive Stimulation Therapy (CST) – summary of evidence on cost-effectiveness. Accessed October 27, 2023. https://www.england.nhs.uk/publication/cognitive-stimulation-therapy-cst-summary-of-evidence-on-cost-effectiveness/
15. International Cognitive Stimulation Therapy (CST) Centre UCL. CST by Country. Published 2023. Accessed September 15, 2023. https://www.ucl.ac.uk/international-cognitive-stimulation-therapy/cst-country

16. Raghuraman S, Lakshminarayanan M, Vaitheswaran S, Rangaswamy T. Cognitive Stimulation Therapy for Dementia: Pilot Studies of Acceptability and Feasibility of Cultural Adaptation for India. *Am J Geriatr Psychiatry*. 2017;25(9):1029-1032. doi:10.1016/J.JAGP.2017.04.014
17. Bertrand E, Naylor R, Laks J, Marinho V, Spector A, Mograbi DC. Cognitive stimulation therapy for brazilian people with dementia: examination of implementation' issues and cultural adaptation. *Aging Ment Health*. 2019;23(10):1400-1404. doi:10.1080/13607863.2018.1488944
18. World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support. Published online September 21, 2022. Accessed November 5, 2023. https://www.alzint.org/resource/world-alzheimer-report-2022/
19. Spector A, Stoner CR, Chandra M, et al. Mixed methods implementation research of cognitive stimulation therapy (CST) for dementia in low and middle-income countries: Study protocol for Brazil, India and Tanzania (CST-International). *BMJ Open*. 2019;9(8). doi:10.1136/bmjopen-2019-030933
20. World Bank Country and Lending Groups – World Bank Data Help Desk. Accessed April 5, 2024. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups
21. Liu KY, Howard R, Banerjee S, et al. Dementia wellbeing and COVID-19: Review and expert consensus on current research and knowledge gaps. *Int J Geriatr Psychiatry*. 2021;36(11):1597-1639. doi:10.1002/GPS.5567
22. Cheung G, Peri K. Challenges to dementia care during COVID-19: Innovations in remote delivery of group Cognitive Stimulation Therapy. *Aging Ment Health*. Published online 2020:1-3. doi:10.1080/13607863.2020.1789945
23. Fisher E, Proctor D, Perkins L, Felstead C, Stott J, Spector A. Is Virtual Cognitive Stimulation Therapy the Future for People with Dementia? An Audit of UK NHS Memory Clinics During the COVID-19 Pandemic. *J Technol Behav Sci*. Published online February 24, 2023:1-8. doi:10.1007/S41347-023-00306-5/
24. Perkins L, Fisher E, Felstead C, et al. Delivering Cognitive Stimulation Therapy (CST) Virtually: Developing and Field-Testing a New Framework. *Clin Interv Aging*. 2022;17:97-116. doi:10.2147/CIA.S348906
25. Damschroder LJ, Reardon CM, Widerquist MAO, Lowery J. The updated Consolidated Framework for Implementation Research based on user feedback. *Implementation Science 2022 17:1*. 2022;17(1):1-16. doi:10.1186/S13012-022-01245-0
26. Means AR, Kemp CG, Gwayi-Chore MC, et al. Evaluating and optimizing the consolidated framework for implementation research (CFIR) for use in low- And middle-income countries: A systematic review. *Implementation Science*. 2020;15(1):1-19. doi:10.1186/S13012-020-0977-0/
27. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*. 2011;6(1):1-12. doi:10.1186/1748-5908-6-42/
28. World Health Organization. The ICD-10 classification of mental and behavioural disorders : diagnostic criteria for research. Published 1993. Accessed September 15, 2023. https://apps.who.int/iris/handle/10665/37108
29. Morris JC. Clinical Dementia Rating: A Reliable and Valid Diagnostic and Staging Measure for Dementia of the Alzheimer Type. *Int Psychogeriatr*. 1997;9(S1):173-176. doi:10.1017/S1041610297004870
30. Proctor E, Silmere H, Raghavan R, et al. Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda. *Adm Policy Ment Health*. 2011;38(2):65. doi:10.1007/S10488-010-0319-7

31. Rosen WG, Mohs RC, Davis KL. A new rating scale for Alzheimer's disease. *Am J Psychiatry*. 1984;141(11). doi:10.1176/AJP.141.11.1356
32. Harper A, Power M, Orley J, et al. Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychol Med*. 1998;28(3):551-558. doi:10.1017/S0033291798006667
33. Galasko D, Schmitt F, Thomas R, Jin S, Bennett D, Ferris S. Detailed assessment of activities of daily living in moderate to severe Alzheimer's disease. *Journal of the International Neuropsychological Society*. 2005;11(4):446-453. doi:10.1017/S1355617705050502
34. Da Cunha Cintra FCM, Cintra MTG, Nicolato R, et al. Functional decline in the elderly with MCI: Cultural adaptation of the ADCS-ADL scale. *Rev Assoc Med Bras*. 2017;63(7):590-599. doi:10.1590/1806-9282.63.07.590
35. Mathuranath PS, George A, Cherian PJ, Mathew R, Sarma PS. Instrumental activities of daily living scale for dementia screening in elderly people. *Int Psychogeriatr*. 2005;17(3):461-474. doi:10.1017/S1041610205001547
36. Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. The Gerontologist, 20(6), 649-655. https://doi.org/10.1093/geront/20.6.649
37. Brinda EM, Rajkumar AP, Enemark U, Attermann J, Jacob KS. Cost and burden of informal caregiving of dependent older people in a rural Indian community. *BMC Health Serv Res*. 2014;14(1):1-9. doi:10.1186/1472-6963-14-207/
38. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health*. 2019;11(4):589-597. doi:10.1080/2159676X.2019.1628806
39. Marinho V, Bertrand E, Naylor R, et al. Cognitive stimulation therapy for people with dementia in Brazil (CST-Brasil): Results from a single blind randomized controlled trial. *Int J Geriatr Psychiatry*. 2021;36(2):286-293.
40. Livingston G, Barber J, Rapaport P, et al. Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial. *BMJ*. 2013;347:f6276. doi:10.1136/BMJ.F6276
41. Cheng ST, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological Interventions for Dementia Caregivers: What We Have Achieved, What We Have Learned. *Curr Psychiatry Rep*. 2019;21(7):1-12. doi:10.1007/S11920-019-1045-9/TABLES/1
42. Oxfam India (2022.) India Inequality Report 2022: Digital Divide. Retrieved from: https://www.oxfamindia.org/knowledgehub/workingpaper/india-inequality-report-2022-digital-divide
43. Nakayama LF, Binotti WW, Woite NL, et al. The Digital Divide in Brazil and Barriers to Telehealth and Equal Digital Health Care: Analysis of Internet Access Using Publicly Available Data. *J Med Internet Res*. 2023;25(1):e42483. doi:10.2196/42483
44. da Silva LF, Zitkus E, Freire AP. An Exploratory Study of the Use of the Internet and E-Government by Older Adults in the Countryside of Brazil. *Information (Switzerland)*. 2023;14(4):225. doi:10.3390/INFO14040225/S1
45. Stoner CR, Lakshminarayanan M, Mograbi DC, et al. Development and acceptability of a brief, evidence-based Dementia Awareness for Caregivers course in low- and middle-income countries. *Dementia (London)*. 2022;21(2):598-617. doi:10.1177/14713012211055316
46. Orfanos S, Gibbor L, Carr C, Spector A. Group-based cognitive stimulation therapy for dementia: a qualitative study on experiences of group interactions. *https://doi.org/101080/1360786320201746740*. 2020;25(6):991-998. doi:10.1080/13607863.2020.1746740
47. The World Bank. Databank. Education Statistics: Education Attainment. Accessed April 9, 2024. https://databank.worldbank.org/Average-years-of-schooling-of-adults-(male-and-

female)/id/12d63977

Supplementary file 1: Pre- and post-intervention outcome measures by country

Outcome (range)	India								Brazil							
	Pre-intervention		Post intervention		Mean improvement (pre-post)				Pre-intervention		Post intervention		Mean improvement (pre-post)			
	n	Mean (SD)	n	Mean (SD)	n	Mean difference (95% CI)	p-value	Effect size (95% CI)	n	Mean (SD)	n	Mean (SD)	n	Mean difference (95% CI)	p-value	Effect size (95% CI)
ADAS-Cog (0-70)	15	19.50 (7.43)	14	19.43 (9.97)	14	-0.52 (-5.51, 4.47)	0.83	-0.06 (-0.58, 0.47)	44	29.70 (13.42)	39	29.89 (14.96)	39	-1.42 (-3.64, 0.80)	0.20	-0.21 (-0.52, 0.11)
WHOQOL-BREF: Physical health (4-20)	15	14.32 (2.23)	14	14.94 (2.27)	14	+0.37 (-0.65, 1.38)	0.45	+0.21 (-0.33, 0.74)	44	14.53 (3.01)	37	14.75 (2.68)	37	+0.39 (-0.42, 1.19)	0.34	+0.16 (-0.17, 0.48)
WHOQOL-BREF: Psychological (4-20)	15	13.87 (1.68)	14	13.81 (2.13)	14	-0.05 (-0.93, 0.84)	0.91	-0.03 (-0.56, 0.49)	44	14.27 (2.27)	37	15.10 (1.89)	37	+0.81 (0.15, 1.47)	0.02	+0.41 (0.07, 0.74)
WHOQOL-BREF: Social relationships (4-20)	15	14.93 (1.61)	14	14.95 (1.40)	14	+0.10 (-0.78, 0.97)	0.82	+0.06 (-0.46, 0.59)	44	15.18 (1.75)	37	15.68 (2.12)	37	+0.68 (-0.05, 1.42)	0.07	+0.31 (-0.02, 0.64)
WHOQOL-BREF Environment (4-20)	15	15.00 (2.01)	14	14.82 (1.67)	14	-0.18 (-1.27, 0.91)	0.73	-0.10 (-0.62, 0.43)	44	15.03 (1.97)	37	15.42 (1.87)	37	+0.57 (0.03, 1.11)	0.04	+0.35 (0.02, 0.68)
IADL – Cognitive domain (0-100)	15	37.65 (19.77)	14	43.97 (20.72)	14	-8.64 (-17.91, 0.64)	0.07	-0.54 (-1.09, 0.03)								
IADL – Physical domain (0-100)	15	4.20 (7.95)	14	10.57 (15.71)	14	-7.50 (-16.61, 1.61)	0.10	-0.48 (-1.02, 0.09)								
ADCS-ADL (0-78)									44	44.34 (16.55)	40	42.00 (16.44)	40	-3.18 (-5.35, -1.01)	0.005	-0.47 (-0.79, -0.14)
ZBI (0-88)	15	26.67 (12.83)	14	25.36 (13.56)	14	+1.64 (-2.79, 6.08)	0.44	+0.21 (-0.32, 0.74)	41	37.71 (19.03)	33	36.12 (18.43)	32	+1.18 (-1.63, 4.00)	0.40	+0.15 (-0.20, 0.50)
DemCarES (17-51)	12	26.83 (3.16)	14	26.93 (3.17)	12	-0.25 (-2.84, 2.24)	0.84	-0.06 (-0.63, 0.51)	41	29.56 (7.59)	32	30.41 (8.30)	31	-0.84 (-2.30, 0.63)	0.25	-0.21 (-0.56, 0.15)

Abbreviations: ADAS-Cog: Alzheimer's Disease Assessment Scale–Cognitive Subscale; WHOQOL-BREF: World Health Organization Quality of Life Brief Version; ADCS-ADL: Alzheimer's Disease Cooperative Study–Activities of Daily Living Scale; IADL-EDR: Scale for the Instrumental Activities of Daily Living in the Elderly; ZBI: Zarit Burden Interview; DemCarES : Dementia Caregiver Experience Scale.

ADCS-ADL administered in Brazil only, and IADL-EDR in India.

The positive maximum scale score is underlined.

Effect size calculated using Cohen's d (complete case analysis). No adjustments were made for multiple testing because analyses are exploratory.

Supplementary Files

Untitled.
URL: http://asset.jmir.pub/assets/25836e318e66b8a99a1249b011a6c23f.docx