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Cognitive Stimulation Therapy for Brazilian people with dementia: examination of implementation' issues and cultural adaptation

Bertrand^{1,2}, Elodie, Naylor¹, Renata, Laks^{3,4}, Jerson, Marinho³, Valeska, & Spector⁵,
Aimee, Mograbi^{*1,6}, Daniel C.

1 – Department of Psychology, Pontifical Catholic University of Rio de Janeiro, Rio de Janeiro, Brazil

2 – Department of Psychology, Universidade do Grande Rio (Unigranrio), Duque de Caxias, Brazil

3 – Institute of Psychiatry, Federal University of Rio de Janeiro, Rio de Janeiro, Brazil

4 – Post Graduation Translational Biomedicine Programme, Universidade do Grande Rio (Unigranrio), Duque de Caxias, Brazil

5 – Division of Psychology and Language Sciences, University College London, London, UK

6 – Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

Elodie Bertrand

Department of Psychology, Pontifical Catholic University of Rio de Janeiro (PUC-Rio);
Department of Psychology, Universidade do Grande Rio (UNIGRANRIO)

Rua Marquês de São Vicente 225, Edifício Cardeal Leme, 2º Andar - Sala 201, Gávea, Rio de Janeiro, RJ, Brazil, CEP: 22451-900

+55 21 998132963.

Renata Naylor

Department of Psychology, Pontifical Catholic University of Rio de Janeiro (PUC-Rio)

Rua Campos sales, 116, 202/bl 1., Tijuca, Rio de Janeiro, TJ, Brazil, CEP: 20270-270

+55 21 993526182

rpbnaylor@gmail.com

Valeska Marinho

Institute of Psychiatry, Federal University of Rio de Janeiro (UFRJ)

Rua Dois de Dezembro, 38/802. Flamengo, Rio de Janeiro, RJ, Brazil, CEP: 22220-040

+55 21 2205-0529

vm@valeskamarinho.med.br

Jerson Laks

Institute of Psychiatry, Federal University of Rio de Janeiro (UFRJ); Post Graduation
Translational Biomedicine Programme, Universidade do Grande Rio (UNIGRANRIO).

Av. Nossa Sra. de Copacabana 749/802, Copacabana, Rio de Janeiro, RJ, Brazil, CEP
22050-00,

+55 21 999865794

jersonlaks@gmail.com

Aimee Spector

Department of Clinical, Educational and Health Psychology, University College London
1–19 Torrington Place, London WC1E 7HB, UK

+44 020 7679 1844

a.spector@ucl.ac.uk

Daniel Correa Mograbi

Department of Psychology, Pontifical Catholic University of Rio de Janeiro (PUC-Rio);
Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's
College London (KCL); Institute of Psychiatry, Federal University of Rio de Janeiro
(UFRJ)

Rua Marquês de São Vicente 225, Edifício Cardeal Leme, 2º Andar - Sala 201, Gávea, Rio
de Janeiro, RJ CEP: 22451-900

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Abstract

Objectives: The prevalence of dementia has been increasing particularly in developing countries. However, people with dementia (PwD) in Brazil are currently offered no psychosocial treatment upon diagnosis. Cognitive Stimulation Therapy (CST) that originated in the UK has proven benefits on cognition and quality of life in PwD. We investigate the possible issues for the implementation of CST for the Brazilian population and its cultural appropriateness.

Method: Individual interviews and focus groups were conducted with PwD, their caregivers and health professionals (n=37). Data were recorded and transcribed, before being analyzed using Framework Analysis.

Results: Regarding the issues for implementation of CST in the Brazilian population, two main themes emerged, “Barriers” and “Facilitators”, along with nine subthemes. Overall, the activities and materials were seen as being appropriate for use with the Brazilian population, some minor changes were suggested.

Conclusions: The results indicate that CST is appropriate for use in the Brazilian population, only some cultural adaptations are necessary. In the stakeholders’ opinions, CTS intervention is needed in Brazil, due to the lack of treatment options for PwD in developing countries.

Keywords: dementia, Cognitive Stimulation Therapy, Brazilian population, cultural adaptation

Introduction

Increases in life expectancy worldwide have led to growing numbers of people with dementia (PwD) (Ferri et al., 2005). The prevalence of dementia has been increasing particularly in developing countries, with an estimated number of 1.6 million PwD in Brazil (ADI, 2005). In this context, interventions that can ameliorate the symptoms of dementia and improve quality of life are research priorities, but dementia care provision is still limited in lower and middle income countries (ADI, 2005). Indeed, PwD in Brazil are currently offered no psychosocial treatment upon diagnosis.

Cognitive Stimulation Therapy (CST) is a 14 session group intervention for PwD developed in the UK. It aims to mentally stimulate people through complex psychological techniques (including implicit learning, multi-sensory stimulation) embedded in structured group activities, such as word association and current affairs. It has a robust evidence-base, significantly improving cognition and quality of life (Orrell et al., 2014; Spector et al., 2003) and is the only non-drug intervention recommended to treat cognition by UK NICE guidelines (National Institute for Health and Clinical Excellence, 2006). It is endorsed by Alzheimer's Disease International, used in over 24 countries globally and translated into at least eight languages.

To facilitate CST implementation in other cultures, adaptation guidelines have been developed (Aguirre et al, 2014) with an approach involving stakeholders in the cultural adaptation process. This 'bottom-up' approach consists of five phases, namely, (i) generating information and collaborating with stakeholders; (ii) integrating the generated information with clinical and theoretical knowledge; (iii) reviewing and revising; (iv) pilot testing; and (v) synthesizing stakeholder feedback and finalizing. This adaptation process should precede a feasibility study, which will use a randomized controlled trial design.

The present study was performed to understand the possible issues for the implementation of CST for the Brazilian population and its cultural appropriateness by interviewing stakeholders. Two complementary formats were used for the interviews: focus groups and individual interviews. As highlighted by previous studies (Harmer & Orrell, 2008; Thorgrimsen et al., 2003), the use of individual interviews allows the participants to express freely their opinions regarding the program. Moreover, based on the fact that PwD frequently present deficits in short-term memory, individual interviews appeared more

appropriate for this population (Murphy, Killick, & Allan, 2001). The aim of this study was to identify any practical issues that might affect the delivery of the program, and to gather data about the quality and appropriateness of the activities presented in the translated manual, which would inform the development of further drafts of the materials.

Methods

Semi-structured interviews were conducted to assess the cultural appropriateness of the CST program in Rio de Janeiro (Brazil), including possible issues for its implementation. The quality of the first adaptation of the CST material was also discussed. Two complementary formats were used: focus groups and individual interviews.

Recruitment

Health professionals taking part in the focus groups were recruited from invitation, including staff from the hospital where a CST feasibility RCT is being conducted and other clinical services. Caregivers were recruited from the same hospital or from a caregivers' association.

Individual interviews were conducted with PwD and caregivers who consented to take part in the feasibility study and were randomly allocated to the control group, not being exposed to the intervention.

Procedure

Both focus groups and individual interviews were audio-recorded and were then transcribed verbatim.

Focus groups

Two focus groups with multidisciplinary health professionals, including psychiatrists, geriatricians, neuropsychologists and nurses (n=9) and two focus groups with caregivers of PwD (n=15) were conducted. Each group was attended by two members of the research team, one of whom took on the role as facilitator and led the group discussion, while the other observed the group and made notes to supplement the audio data collected. The interview schedule was developed in a semi-structured style, guided by a series of pre-determined focus points (Table 1). A description of the general principles of CST was

given, with each session of the program being presented in more detail. The participants discussed the feasibility of the activities suggested and the need of adapting the material for the Brazilian elderly population. Each group lasted approximately 90 minutes in total.

PLEASE INSERT TABLE 1 HERE

Individual interviews

PwD and their caregivers (n=13) were invited to participate to individual interviews, which were conducted separately by one member of the research team. Each interview lasted approximately 20 minutes. After being provided with a description of the CST program, both PwD and their caregivers were invited to discuss the possible facilitators and barriers that could affect the implementation of the program.

Analyses

The transcripts of the focus groups and the individual interviews were analysed using Framework Analysis (Ritchie & Spencer, 1994). Five key stages were followed: (i) Familiarization; (ii) Thematic framework identification; (iii) Coding; (iv) Charting; and (v) Mapping and Interpretation. First, two researchers read all transcripts in order to become familiar with the broad themes expressed. Then, identified themes were compiled and refined leading to a coding key, which included broad themes and sub-themes. Transcripts were then categorized and charted accordingly. Finally, mapping and interpretation was realized to map the factors which might affect the implementation of the CST program in Brazil. 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; project ref: 57019616.5.0000.5263).

Results

Summing the focus groups and the individual interviews, a total of 37 persons were interviewed. Two themes and nine sub-themes were identified consistently across the interviews (Table 2). Illustrative quotes are provided for each sub-themes.

PLEASE INSERT TABLE 2 HERE

Theme 1: Barriers

Sub-theme: More work for the caregivers

Both health professionals and caregivers of PwD said that one of the barriers for the implementation of the program is that it will entail more work for the caregivers.

“It’s essential to have collaboration from the family because we would be giving more work to the caregivers” (health professional)

“What can be difficult for the family is to find somebody who has (the) time to bring the patient to the intervention site.” (caregiver)

Sub-theme: Patients’ motivation to go to CST

Participants identified the lack of patients’ motivation to participate in the program as one barrier for the implementation of CST in Brazil. This is linked to the barrier “More work for the caregiver” considering that, if the patient is not willing to go, the caregiver will need to convince the PwD to participate in CST.

“(…) to take them away from home, to make them get up from the couch (…) he does not want to leave the house” (caregiver)

“As the principal barrier, I identify the fact that the patient does not have the initiative to participate (…) in relation to the patient’s motivation.” (health professional)

Sub-theme: Frequency of sessions

There was a consensus among participants that the frequency of the sessions would be a barrier for the implementation of the CST in Brazil. This barrier is also link to the first barrier identified (“More work for the caregiver”), due to the fact that, in Brazil, PwD will almost always have to go to the intervention site with the help of a caregiver.

“[about] the frequency of this program, I believe we would have some problems to get people with dementia to come” (health professional)

Sub-theme: Distance from patient’s neighborhood

Participants, especially caregivers, reported that PwD generally live far from the intervention site and considered this a potential barrier to the implementation of CST in Brazil.

“I live far from here, if I had to bring my wife I would depend on my two sons-in-law, if either is free, to bring me here, but if they’re not, I would have to rent a car to come??.” (caregiver)

“We are living far away (...) The distance is a big barrier for me. (...) So it is complicated for my sister to bring me here.” (PwD)

“The travel from the patient’s house to the IPUB, they are relying on someone to bring them there, because nobody is going alone. There is also a financial problem, we are dealing with people from the IPUB, so we are dealing with persons... financially... they do not have money, so...” (health professional)

Sub-theme: Cognitive stimulation uncommon for PwD

The participants explained that one barrier to the implementation of the CST in Brazil is that cognitive stimulation therapy is not commonly offered to PwD in this country. There is a lack of information around treatment options, and health professionals, based on caregivers’ demands, usually treat dementia using pharmacological interventions only.

“The caregiver’s demand is not for cognitive stimulation, the caregiver’s demand is for patient’s silencing. Doctors meet the caregiver’s demand and they also believe that once dementia begin there is nothing else to do other than giving a pharmacological treatment for the person to stay calm.” (health professional)

“Basically, in our culture it is a little... the Brazilian society is not yet open for this kind of things [about cognitive stimulation]” (caregiver)

Theme 2: Facilitators

Sub-theme: Have the caregivers’ support

PwD and health professionals agreed that it is essential to have the caregiver’s support to facilitate the implementation of the CST for the Brazilian population.

“We have to count on the caregivers’ help. They are the ones who will take the people with dementia there, give their support, stimulate the people with dementia to go to the clinical service” (health professional)

“To facilitate for me to come here? The only thing is that my sister has to agree.”
(PwD)

Sub-theme: Have two sessions per day (once a week).

There was a clear consensus amongst participants that having the two weekly sessions on the same day would facilitate the implementation of the program. Indeed, due to some Brazilian characteristics (e.g. PwD leaving far from the intervention site or lack of secure transportation for PwD or financial difficulties), limiting the number of travels to participate weekly to the CST was considered a facilitator.

“I think that for Brazil’s reality, for the kind of people with dementia that come here (...) they live far from here and can’t afford coming twice a week, (...) so I think it would be more productive to have the intervention once a week.” (health professional)

“I think once (a week) would be good because... less, less work... less time wasted... I would come once a week” (caregiver)

Sub-theme: Give the caregivers something to do while they wait for the sessions to end.

Both health professionals and caregivers said that providing some kind of entertainment to the caregivers while they are waiting for the PwD would facilitate the implementation of the intervention. Indeed, due to the distance between the PwD’s home and the intervention site, the caregivers would have to wait for the patients there.

“If it were me, I would have to be around, I could bring my knitting material and I would be completely entertained doing it, but, also, a movie would be good” (caregiver)

“What are we going to do with the caregivers while the patients are in the intervention? (...) I think that we could do psychoeducational groups with them.” (health professional)

Sub-theme: Group activities

Participants, especially caregivers of PwD, said that one facilitator of the implementation of the CST is that it is a group activity.

“In my opinion, the fact that the activities are made in group facilitates the stimulation, because one can help the other, there are more interactions” (caregiver)

“[about] the bonds they are creating with the other participants, they start to attend the group weekly, this also stimulates, like “you are going to see you friends there”.” (caregiver)

Adaptation of the sessions and materials

Based on their opinions, modifications were made. Most of the activities suggested in the original CST manual were kept. However, some of the materials for these activities were adapted (e.g. faces of famous Brazilian people or typical Brazilian foods). See Table 3 for a detailed description of the cultural adaptations made in the CST for the Brazilian population.

PLEASE INSERT TABLE 3 HERE

Discussion

Summary of the results

The present study aimed to evaluate the feasibility of the CST program in the Brazilian context by understanding the possible barriers and facilitators for the implementation of the program. The results suggested that there was a consensus among health professionals, PwD and their caregivers regarding the factors that can facilitate or difficult the delivery of the CST in the Brazilian population. Indeed, two themes (i.e. Barriers and Facilitators) and nine sub-themes were identified consistently across all the interviews.

Interpretation of findings

Participants reported that the frequency of the sessions could be a barrier for the adherence to the treatment. Indeed, PwD would have to rely on their caregivers to bring them to the intervention site, in part because most of them are living far from there. This point was also highlighted by the participants as a principal barrier to the patients' participation. As pointed by Gratao et al. (2010), most of the caregivers in Brazil are daughters, within an age range in which they have several work and personal life commitments, or elderly spouses. Therefore, having the PwD taking part in the CST program would indeed lead to more work for the caregiver, who is frequently stressed and overwhelmed by the act of caring for a demented family member (Etters, Goodall, & Harrison, 2008). To facilitate recruitment, it should be important to emphasize to the caregivers that studies showed an improvement of cognition in PwD after the CST intervention (Aguirre, Woods, Spector, & Orrell, 2013) and that this improvement could lead diminished caregiver burden. Based on these issues raised by the participants, we suggest that the two weekly sessions of the CST

should be performed on the same day following the structure: first session of 45 minutes, break of 15 minutes, second session of 45 minutes.

As a facilitator, health professionals and caregivers of PwD reflected on the possible activities that should be offered to the caregivers while they are waiting for the session to end. Indeed, due to characteristics of the Brazilian context already discussed (e.g. patients living far from the intervention site and/or lack of secure transportation for PwD), the caregivers would have to bring the patients to the intervention site and wait for them until the end of the session. However, to avoid biasing the feasibility study, it was decided that no specific activity would be provided for caregivers. Nevertheless, for an eventual larger scale implementation of CST in Brazil, intervention sites should be aware that offering activities to caregivers while PwD receive the program could increase adherence to the treatment. Indeed, studies showed that combined intervention programs for both the caregiver and the PwD are effective, especially in improving the general mental health of both the caregiver and the PwD (Smits et al., 2007).

Finally, participants said that CST is not commonly offered to PwD in Brazil, in part because of the lack of information regarding treatment options for PwD and that could limit the implementation of CST in the Brazilian context. Therefore, before larger scale implementation of the program, an awareness and information campaign regarding dementia and its treatment options might be initiated, especially targeting caregivers of PwD. In fact, this campaign, by increasing awareness regarding the efficacy of cognitive stimulation for PwD, could also lead to stronger support from caregivers in order to deliver the program. Indeed, participants of the present study highlighted that it would be essential to be able to count on caregivers' support for the CST implementation in the Brazilian context.

Regarding the different activities and the material presented in the CST manual, health care professionals and caregivers of PwD responded positively and suggested some adaptations. Only minor changes were made in order to address cultural issues, such as removing some activities which are uncommon in Brazil (e.g. gardening) and using material reflecting the Brazilian population reality (e.g. typical Brazilian sweets in the session "Childhood").

Limitations

Limitations of the current study include the difficulty for the interviewer/moderator to have PwD and their caregivers answering specifically to the topic during focus groups and individual interviews. This issue has also been reported in other studies using qualitative methods with service users (Qazi, Spector, & Orrell, 2010; Yates, Orrell, Spector, & Orgeta, 2015). Regarding PwD, the difficulty to stay “on topic” can be explained by the deficits in short-term memory and verbal communication frequently experienced by this population (Murphy et al., 2001). The tendency of PwD’s caregivers to talk about issues other than the particular topic of discussion could reflect the need to share experiences and to talk about the caring role in general (Qazi et al., 2010; Yates et al., 2015). Despite this issue, overall collected data was informative and “off-topic” data was minimal.

Conclusion

During this study, health professionals and caregivers highlighted the need of the CST intervention in Brazil, expressing the lack of treatment options offered for PwD. Indeed, the prevalence of dementia is increasing and care provisions for PwD are still scarce, especially in developing countries (Shaji, 2009; ADI, 2005). Based on the adaptation guidelines developed by Aguirre et al. (2014), we used a bottom-up formative research method and found CST appropriate for the Brazilian population, with some minor amendment needed to address cultural issues.

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Disclosure statement

All of the authors have no financial conflicts of interests or other disclosures to report.

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Table 1.

| Focus points of the semi-structured interviews |
|--|
| Barriers and facilitators for referrals to non-pharmacological interventions |
| Relevance of the approach |
| Frequency and content of the sessions |
| Adaptation of materials and procedures |
| Validation of outcomes |

Table 2. Themes and sub-themes identified across focus groups and individual interviews.

| <i>Themes</i> | <i>Sub-themes</i> |
|----------------------------|--|
| <i>Barriers</i> | <i>More work for the caregivers</i> |
| | <i>Patients' motivation to go to CST</i> |
| | <i>Distance from patients' home</i> |
| | <i>Frequency of the sessions</i> |
| | <i>Cognitive stimulation uncommon for PwD</i> |
| <i>Facilitators</i> | <i>Have the caregivers' support</i> |
| | <i>Have two sessions per day (once a week)</i> |
| | <i>Give the caregivers something to do while they wait</i> |
| | <i>Group activities</i> |

Table 3. Cultural adaptations made in the CST for Brazil and the rationale

| Session themes | Cultural adaptation | Reasons for adaptation |
|----------------------|--|--|
| 1. Physical games | Nil | Not applicable |
| 2. Sounds | Use of familiar Brazilian songs | Adaptation of the material to the Brazilian population |
| 3. Childhood | Suggested sweets replaced with typical Brazilian childhood sweets (e.g. <i>cocada</i> or <i>paçoca</i>) | Unfamiliarity with suggested sweets |
| 4. Food | Suggested foods used as memory triggers replaced with typical Brazilian foods (e.g. <i>pudim de pão</i> or <i>mariola</i>). Names of food items to be completed replaced with typical Brazilian dishes (e.g. <i>canja de galinha</i> or <i>pão de ló</i>) | Unfamiliarity with suggested foods |
| 5. Current affairs | Removal of royal family- and of charity-related question. | Unfamiliarity with those themes. |
| 6. Faces/scenes | Use of photographs of famous Brazilian faces and places (e.g. Carmem Miranda or Sugarloaf Mountain) | Adaptation of the material to the Brazilian population |
| 7. Word associations | Suggested word associations replaced by culturally adapted phrases (e.g. “ <i>Açucar ... Pão de</i> ” or “ <i>é melhor prevenir ... do que remediar</i> ”) Use of Brazilian songs, such as famous soccer anthems. | Adaptation of the material to the Brazilian population |
| 8. Being creative | Removal of the gardening and the | Uncommon activities in the |

| | | |
|-------------------------|---|--|
| | cooking activities. | Brazilian population. |
| 9. Categorizing objects | Nil | Not applicable |
| 10. Orientation | Map of the UK replaced with a map of the city of Rio de Janeiro | Adaptation of the material to the Brazilian population |
| 11. Using money | Nil | Not applicable |
| 12. Number game | Removal of the snap game | Unfamiliarity with the snap game. |
| 13. Word game | Nil | Not applicable |
| 14. Team game | Nil | Not applicable |