

Paper Title: Cultural Adaptation of Cognitive Stimulation Therapy (CST) for Chinese People with Dementia: Multicentre Pilot Study

Running Head: Cultural Adaptation of Cognitive Stimulation Therapy (CST) in Chinese

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Key Points:

- A Hong Kong version of Cognitive Stimulation Therapy (CST-HK), an evidence-based therapy developed in UK, was devised with slight cultural adaptations following multidisciplinary stakeholders' opinion.
- A similar proportion of people with dementia achieved no cognitive deterioration after CST-HK as in UK research, suggestive of a number-needed-to-treat of 6, in community and residential care settings. Feasibility was good per group facilitators and family caregivers, and as reflected in the low attrition and high attendance rates.
- Key cultural themes identified were: (1) conservatism/cautiousness that hinders opinion sharing; and (2) pragmatism that is shown in a preference of practical activities and rewards over non-goal-oriented ideas exchange.
- We recommend amendments of CST for Hong Kong Chinese by embedding discussions in cooperative group tasks that require verbal exchange of objective facts, and by using tangible/visible rewards as an engagement strategy.

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Abstract (250/250)

Objective: Ageing of the Chinese population will drive the continued surge in dementia prevalence. Empirically tested non-pharmacological interventions developed in western cultures may be implemented in Chinese. Cognitive Stimulation Therapy (CST) originated in the UK has proven benefits on cognition and quality of life in people with dementia. We investigated the feasibility and cultural appropriateness of CST in Hong Kong Chinese.

Methods: Mixed methods research was conducted following the Formative Method for Adapting Psychotherapy. A culturally adapted CST-HK, developed involving multidisciplinary stakeholders, was tested in a pilot multicentre study in people with mild dementia (n=30) receiving community or residential care. Changes in cognition and quality of life were measured. Opinions from family caregivers and group facilitators (n=25) were collected through focus groups and in-depth interviews for understanding the appropriateness of CST-HK. Feasibility were explored.

Results: After receiving CST-HK, 54% of participants achieved outcome of no cognitive deterioration, and 23% showed clinically meaningful improvement. Family caregivers and group facilitators expressed good acceptance of CST, with a low attrition (13%) and high attendance rate of CST-HK sessions (92%). Key cultural issues identified are (1) less active opinion sharing in group discussions due to conservatism/cautiousness; and (2) preference of practical activities with reward/recognition over pure discussion due to pragmatism.

Conclusions: CST-HK is feasible and culturally appropriate in Hong Kong Chinese. Further amendments can be made to ensure language use and enjoyment, with potential implications on effectiveness. We have provided a systematically developed culturally adapted protocol for larger-scale implementation and research in Chinese populations.

Cultural Adaptation of Cognitive Stimulation Therapy (CST) for Chinese People with Dementia: Multicentre Pilot Study

Introduction

Chinese population will drive the continued surge in dementia prevalence (Prince, Guerchet, Prina, & Alzheimer's Disease International, 2013). The estimated number of people with dementia in mainland China, Hong Kong, and Taiwan was 8.4 million in 2012, projected to increase to 20.8 million by 2030 (Wu et al., 2013). Effective interventions applicable in this population are urgently needed. Research on dementia, however, is sparse in southeast Asia in general (Prince et al., 2015).

Implementing evidence-based interventions developed in western countries with cultural adaptation can be a responsive and cost-effective approach (Hwang, 2009). Cognitive stimulation therapy (CST) is a non-pharmacological intervention recommended in UK guidelines and by the Alzheimer's Disease International (NICE, 2011; Prince, Bryce, Ferri, & Alzheimer's Disease International, 2011). The prototypical CST program involves engaging the person with dementia in enjoyable cognitive activities delivered in a small group led by dementia care personnel (Spector et al., 2003).

A meta-analysis has shown evidence of benefits on cognition and quality of life (QoL) for people with mild-to-moderate Alzheimer's disease (Woods, Aguirre, Spector, & Orrell, 2012), with general stabilization or slight improvement observed in CST versus decline in control groups. The estimated number needed to treat (NNT) for clinically important cognitive improvement ranged from 6 to 14 (Onder et al., 2005; Spector et al., 2003). Based on a systematic review of cholinesterase inhibitors (Livingston & Katona, 2000), improvement can be conceptualized as (1) no

deterioration or (2) an increase of 4 points or above as measured using the Alzheimer's Disease Assessment Scale – Cognition (ADAS-Cog). Previous studies have reported that 45% to 50% of CST participants showed no deterioration and 19% to 30% showed an increase on ADAS-Cog (Onder et al., 2005; Spector et al., 2003).

From an implementation science perspective, interventions with documented effectiveness can nevertheless become ineffective in real-world practice because of implementation gaps. In-context pilot and small-scale implementation studies are needed before large-scale application of empirically tested interventions (Gaglio & Glasgow, 2012). These implementation gaps likely exist when translating an intervention to different cultures. Cultural appropriateness is important for creating meaning and motivating engagement in the intervention, particularly for older adults who tend to internalize cultural values (Fung, 2013). The Cognitive Stimulation approach is rooted in western cultures, which was originated in France (Breuil et al., 1994), with the standard CST protocol developed in the UK (Spector et al., 2003), and recently adapted in Italy (CST-IT) (Capotosto et al., 2016). Initial experience of applying CST in Asia has been gained in a Japanese pilot study, where some cultural modification has been made to the session content (e.g., word games); results in cognition, mood, and aspects of QoL were promising (Yamanaka et al., 2013). Building upon the Japanese experience, broader cultural issues common to Asian populations including Chinese can be further explored to enhance intervention design and application. For example, language promotion through group discussion appears to be a key mechanism of CST (Spector, Orrell, & Woods, 2010). It is yet unclear whether and how intervention elements of CST are compatible with Asian values, such as social harmony (Hwang, 2006).

To facilitate CST implementation in other cultures, adaptation guidelines have been developed (Aguirre, Spector, & Orrell, 2014) based on the formative method for adapting psychotherapy (FMAP) (Hwang, 2009), an approach involving stakeholders in the cultural adaptation process. This “bottom-up” approach consists of five phases, namely (1) generating information and collaborating with stakeholders; (2) integrating the generated information with clinical and theoretical knowledge; (3) reviewing and revising; (4) pilot testing; and (5) synthesizing stakeholder feedback and finalizing.

Groundwork has been completed to adapt CST in a Chinese population in Hong Kong. Briefly, themes on potential implementation gaps were generated in a workshop involving multidisciplinary stakeholders (n=105) with background in social work, psychology, occupational therapy, physiotherapy, speech therapy, and nursing from various settings, including community and residential care units of non-governmental organizations, government departments, hospitals, and academia. Years of experience in dementia care ranged from 6 months to 30 years in dementia care (Wong, 2015). These themes were used to inform a draft version of the group CST for Hong Kong Chinese (CST-HK) for testing and finalizing.

This study investigates the feasibility and cultural appropriateness of CST-HK.

Methods

A mixed method design was used. A multicentre pilot research was conducted to test feasibility of CST-HK. A qualitative study was performed to understand the cultural appropriateness of CST-HK.

In the quantitative study, we recruited people with dementia in community and residential care units of three major non-governmental organizations (NGOs) providing dementia care services in Hong Kong. All NGO staff involved in delivering CST-HK

received a half-day training conducted by the first author. Group leaders included both professionals and allied healthcare workers, who understand and follow the key principles of CST. All facilitators had experience in dementia care and group programmes. The CST-HK was modified from the standard CST protocol (Spector et al., 2003), with small groups of persons with dementia receiving 14 sessions of group activities (2 sessions/week, approximately 45 minutes/session). A group size of 6 to 8 was determined with reference to the CST manual (Spector, Thorgrimsen, Woods, & Orrell, 2006), review on Cognitive Stimulation (Woods et al., 2012), opinions from multidisciplinary stakeholders (Wong, 2015), and a local dementia group activities program (Wong et al., 2015). The CST groups were conducted in activity rooms within the elderly centres and residential care homes. Modifications were made in the draft CST-HK (Table 1) to activities not applicable in the Hong Kong Chinese culture (e.g., word games involving alphabets). Baseline and post-intervention assessments on cognition and QoL were conducted by independent researchers with background in psychology.

In the qualitative study, group facilitators and family caregivers of people with dementia who have received CST-HK were invited to participate in focus groups or in-depth interviews. The focus groups and interviews were conducted by independent researchers with background in social work following a pre-defined interview guide. Data collection was continued until the point of data saturation has been reached.

The Human Research Ethics Committee for Non-Clinical Faculties at The University of Hong Kong has approved the studies and all participants have provided informed consent.

Participants

Participants in the pilot quantitative study were 30 persons with dementia recruited from existing dementia service units of three local NGOs. Recruitment was done by screening and inviting all eligible service users of the NGO units. The inclusion/exclusion criteria were guided by those used in the initial CST study (Spector et al., 2003), with additional criteria on cognitive performance level to minimize sample heterogeneity in this small sample pilot study:

- a clinical diagnosis of dementia made by a medical doctor;
- a Chinese Mini-Mental State Examination score (Chiu, Lee, Chung, & Kwong, 1994) between 18 and 23;
- able to communicate and understand communication;
- see and hear well enough to participate in a meaningful assessment; and
- absence of any major physical illness or disability that affect CST participation.

In the qualitative study, participants were trained CST-HK facilitators (n=12) and family caregivers (n=13) who provided care for the person with dementia in this study on a regular basis (≥ 8 hours/week).

Measures

Cognition was measured using the ADAS-Cog (Rosen, Mohs, & Davis, 1984). This is a cognitive test commonly used in clinical trials for people with dementia. It contains 11 questions with a range of score from 0 to 70. A higher score denotes worse performance. Cognitive improvement was defined as a change in score of ≥ 0 point (no deterioration) or an increase of ≥ 4 points comparing post-intervention with baseline score (Spector et al., 2003).

Quality of life was measured using the Quality of Life in Alzheimer's Disease (QoL-AD) (Logsdon, Gibbons, McCurry, & Teri, 2002). It contains 13 items which can

be rated as poor, fair, good, or excellent. The sum score can range from 13 to 52. A higher score indicating better QoL. Proxy (family caregiver) rating was used in this study. The QoL-AD has good consistency, validity, and reliability and is recommended in a European consensus (Moniz-Cook et al., 2008).

The interview guide for group facilitators included questions on overall acceptance, observed participant response for each CST session, and suggested alternatives; the interview guide with family caregivers explored their observed acceptance and response of the person with dementia.

Data Analysis

In the quantitative study, the percentage of people with cognitive improvement was calculated based on ADAS-Cog criteria (Livingston & Katona, 2000); NNT was estimated with reference to a previous study (Spector et al., 2003). To investigate the changes in cognition and quality of life following the intervention, paired-samples *t* test was used to compare baseline and post-intervention ADAS-Cog and QoL-AD scores. In the qualitative study, framework analysis was used in view of its advantage of an explicit analytical process and the deductive *a priori* reasoning (Pope, Ziebland, & Mays, 2000), to allow investigation into the effect of known cultural factors on CST implementation in Chinese. We followed the five-step process in framework analysis, namely (1) familiarization; (2) thematic framework identification; (3) coding/indexing; (4) charting; and (5) mapping and interpretation (Ritchie & Spencer, 1994). Two reviewers read all transcripts and identified recurrent themes independently to reduce researcher bias (Pope et al., 2000). Identified themes were synthesized into an analytical framework. Transcripts were then coded and charted accordingly. Mapping and interpretation was led by the first author (GW) with support from the second and third

authors (OY and AZ), who reviewed subheadings and research notes to search for patterns and structures (Ritchie & Spencer, 1994) to map the range and nature of cultural issues affecting CST.

Results

Quantitative Study

Baseline characteristics of the patients and caregivers are summarized in Table 2. Patients were 8 men and 22 women aged 81.5 (s.d.=5.9) years old. They had on average 3.4 (s.d.=4.1) years of education, with a large proportion (n=19, 63.3%) having never received any formal education. The majority (n=25, 83.3%) were being cared for by a child or child's spouse. Their baseline ADAS-Cog and QoL-AD scores suggested mild impairment and fair-to-good QoL. Four patients were not available for post-intervention assessment due to change in care setting, health and other personal reasons (attrition rate 13%). Mean attendance rate of the CST sessions was 92%.

The outcomes of no cognitive deterioration and clinically meaningful improvement were achieved in 14 (53.8%) and 6 (23.1%) of the patients, with an estimated NNT of 6 and 9.9, respectively. The ADAS-Cog total score improved by 0.5 (s.e.=0.9) points, with paired-sample *t*-test suggesting no statistically significant change ($t=0.62$; $p=0.54$). Similar results were obtained using mixed-model analysis. The QoL-AD total score improved by 0.3 (s.e.=0.9) points ($t=0.34$; $p=0.74$). An item-by-item paired-sample *t*-test showed a significant improvement in "family relationship" ($p=0.03$), while the items "memory" and "living situation" showed a significant decline ($p<0.01$ and $p=0.03$, respectively).

[Insert Table 2 about here]

Qualitative Study

A total of 11 individual interviews with CST group facilitators (n=3) and family caregivers (n=8), three focus groups with facilitators (n=3, 4, and 2), and one focus group with family caregivers (n=5) were conducted (qualitative study total n=25). Table 3 shows the participant characteristics of the qualitative study. Charts of “Socioeconomic Status and Education Level”, “Language Use”, “Personality”, and “Social Boundaries and Manner” were created. Based on these charts and research notes, two key dimensions of cultural influence on CST were drawn out (Figure 1). Illustrative quotes are provided below.

[Insert Table 3 and Figure 1 about here]

Key Theme 1: Conservatism/Cautiousness

Under this theme includes collectivism, reserved personality, and social boundaries. These cultural themes posed barriers in active opinion sharing during group CST.

“In terms of communication, Chinese people cannot compare with foreigners... especially among older people. Even when they are very happy to participate, they would just sit there.” (facilitator 4, female, personal care work in day care centre)

“Some would just copy others’ answer when you ask for their opinion.” (facilitator 3, female, social worker in day care centre)

“This is perhaps related to the fact that Chinese people seldom express their opinions... Those who are more reserved would just say ‘It’s fine, that’s OK.’ ... Often we need to keep inviting them to share their views... it is more like an interview.” (facilitator 9, female, social worker in day care centre)

Reservation was particularly obvious when the discussion topic potentially involves negative family/personal history.

“They do not feel that comfortable to share too much about their family affairs... We may at most talk about their home town, or what they did for living. Usually we need to avoid touching on things about their family members, such as their siblings.” (facilitator 2, female, social worker in care and attention home)

“Their childhood can be quite miserable. For example, some of them were traded by their parents to another family as a servant.” (facilitator 7, female, social worker in care and attention home)

Key Theme 2: Pragmatism

Under this theme includes a focus on basic levels of needs (i.e., food over civil participation), preference for deeds over words, and the importance of tangible rewards and visible recognition in promoting active participation.

“They would not focus on leisure or entertainment, but would tell you how they raised their children despite all adversities.” (facilitator 1, male, social worker in care and attention home)

“Older adults in Hong Kong do not watch news that often.” (facilitator 5, male, occupational therapist in day care centre)

“Enjoying food is something older adults have in common. They are delighted whenever they can eat.” (facilitator 3, female, social worker in day care centre)

Participants were much more engaged in activities that involve actions.

“Perhaps it is because of the sense of success, after drawing [a task in the ‘Being Creative’ session] she talked more than usual.” (caregiver 2, daughter)

“I think they are happy to learn something new, activities in a practical format are more suitable for them than chatting.” (facilitator 9, female, social worker in day care centre)

“It is much easier to lead the “Being Creative” session as it allows more opportunities for the group to participate together. It is true that Chinese prefer doing than saying.” (facilitator 3, female, social worker in day care centre)

Recognition of achievement, especially tangible product or other visible records and rewards were important.

“We added some elements to encourage attendance. We gave them a stamp for attending each session. They will receive a prize when they have completed 10 sessions, or all 14 sessions. This took us time, but we still recommend it as the older adults would be really happy. They would even ask for make-up sessions if they have missed a stamp.” (facilitator 5, male, occupational therapist in day care centre)

Discussion

Summary of Findings

This mixed method formative study provided evidence for the feasibility and cultural appropriateness of adapting CST in a Chinese population in Hong Kong. Results from the pilot quantitative study has showed that participants receiving group CST-HK had stable cognition. More than half of the participants achieved

the outcome of no cognitive deterioration, and nearly one in four showing clinically meaningful improvement in cognitive function. The percentage and the estimated NNT are both within range of western CST studies (Onder et al., 2005; Spector et al., 2003).

Our sample showed stable overall QoL. The improvement in family relationship may be related to the positive experience with CST, which can be shared within the family. On the other hand, this group of patients are in their early phase of disease, when caregivers are still adjusting to the changes in the person's cognition and needs, and may be more sensitive to the person's memory loss and adaptation to living environment. The decline in perceived memory functioning may reflect caregiver worries, which did not correspond to objective test results of no change. The decline in satisfaction with living situation is a common challenge in Hong Kong where living space is limited, although this is not amenable to CST.

These findings of stable cognition and QoL in general, interpreted together with the low attrition rate and high attendance rate, suggested that CST-HK is a feasible intervention in Hong Kong Chinese.

As CST can be directly integrated into existing community and residential care service settings in Hong Kong, group facilitators reported no particular difficulties in participant recruitment or retention. Only two cultural issues were identified. First, the strong social norm for conservatism and cautiousness of this generation of Chinese elders in Hong Kong may discourage open discussion in group CST. Compared with western cultures that emphasize independence and individualism, Chinese are more interdependent and tend to prioritize group over self to achieve social harmony (for a review, see Fung, 2013). The group

facilitators attributed this cultural factor to the challenges they faced in generating opinions, even when participants appeared to be enjoying the session.

Second, pragmatism was observed that selectively motivated participants in some CST sessions and engagement method. Chinese pragmatism refers to thoughts that center around practical issues, and less interest in logical reasoning or abstract theorization (Kolstad & Gjesvik, 2014). Because of the specific historical background of Hong Kong, this cohort of older Chinese in general has lower education, who have experienced war, hunger, and other adversities. The more basic levels of needs (e.g., physiological needs in Maslow's hierarchy) may have greater personal meaning to them. We found that CST sessions that involved production and food were most well received, and linking participation to a reward system was an important strategy, according to the group facilitators in our study.

Suggested Amendments to CST Program

Based on our findings, we suggest the following minor amendments to the CST program. First, to overcome conservatism/cautiousness that lead to less active opinion sharing, embedding the discussion in a cooperative group task (to achieve social harmony) that requires exchange of more objective facts (to avoid personal sharing) can be considered. Although the exact mechanisms of action in CST are still under investigation, some studies have suggested a central role of language use in the cognitive benefits (Hall, Orrell, Stott, & Spector, 2013; Spector et al., 2010). We propose amendments to align with the Chinese values of social harmony while promoting active language use. For example, verbal communication such as Chinese idioms related to wishes and good luck can be used in combination with small gifts (e.g., greeting cards) for exchange among group members.

Second, activities and techniques that draw on the Chinese value of pragmatism were effective in engaging this population. We propose to enhance this element in CST for Chinese, for example, by including more action-based tasks that also promote discussion in the process, providing visible recognition of task completion, and creating tangible products during the sessions. Token economy can be used to encourage participations.

Limitations

This study has several limitations. First, the small sample size and lack of control group of the quantitative study did not allow answering question on the effectiveness of CST-HK. Some of the sample characteristics (e.g., lower education, mild dementia, history of life adversity) may not be generalizable. We caution about interpretation of the estimated NNT, as calculation was based on control data from a previous study and the sample characteristics may not be directly comparable.

Second, the group size used in this study (6-8) is slightly larger than that used in western literature (5-7) (Woods et al., 2012). The possible influence of group size on the results are manifold (e.g., less attention for each member, greater sense of collective responsibility, and pressure to speak up) and should be interpreted in the cultural context. The effect of group size and other factors related to group dynamics (e.g., gender mix) on CST in Chinese should be further investigated.

Third, a combined use of focus groups and individual interviews has pros and cons. While it allows for a balance between depth and breadth (Morgan, 1996) and access to private experience and public knowledge (Michell, 1999), guidelines are needed for combining data in a rigorous way (Lambert & Loiselle, 2008).

Although not noted in our qualitative finding, linguistic difference is a potentially important consideration. In Hong Kong, a substantial proportion of older adults are migrants from different parts of mainland China, and differences in dialects use (e.g., *Hakka, Hokkien*) may pose communication barriers, although the slightly different yet compatible cultures may also facilitate exchange. This should be an area of further investigation to inform understanding of cultural effects on CST.

Finally, this study did not include feedback from people with dementia; although they represent a major stakeholder in the development of CST-HK, collection of personal opinions from Chinese people with dementia is challenging as noted by the CST facilitators in this study. Future research should nevertheless include simple means of eliciting and capturing qualitative feedback from people with dementia, for example as part of the ending of each session.

Implications

Using a bottom-up formative research method, we found CST both feasible and appropriate in Hong Kong Chinese, with only minor amendment needed to address cultural issues. The systematic process of cultural adaptation described in this paper will inform finalization of a culturally adapted CST-HK for larger-scale implementation and testing.

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Table 1. Cultural adaptations made in CST-HK and the rationale

Session Themes	Cultural Adaptation	Reasons for Adaptation
1. Physical games	Nil	n/a
2. Sound	Nil	n/a
3. Childhood	Removal of school-related questions	School uncommon in this cohort of older persons
4. Food	Nil	n/a
5. Current affairs	Pictorial news and TV news clips provided as extra options to newspaper articles and magazines	High rate of illiteracy in this cohort
6. Faces / scenes	Include sets of old and recent photos of the same person / place to generate discussion	More obvious similarities in the stimuli to cater for lower ability in abstract thinking due to education
7. Word associations	Use of drawings and idioms to facilitate word association	High rate of illiteracy
8. Being creative	Nil	n/a
9. Categorizing objects	Words beginning with a certain letter replaced with words within a category	Logogram scripts instead of alphabets in Chinese
10. Orientation	Nil	n/a
11. Using money	Nil	n/a
12. Number game	Snap replaced with other number games (e.g. card or Chinese dice game)	Unfamiliarity with the snap game
13. Word game	Hangman replaced with word card game (reading out card if needed) and charades	Logogram instead of alphabets in Chinese; high rate of illiteracy
14. Team game	Nil	n/a

Table 2. Characteristics of the group CST participants at study entry

Patients (n=30)	
Age, years: mean (s.d.)	81.5 (5.9)
Female gender, <i>n</i> (%)	22 (73.3)
Education, years: mean (s.d.)	3.4 (4.1)
No formal education, <i>n</i> (%)	19 (63.3)
Work, years: mean (s.d.)	36.8 (16.8)
Duration of disease, years: mean (s.d.)	2.0 (1.5)
Living with caregiver, <i>n</i> (%)	12 (40)
ADAS-Cog score: mean (s.d.)	20.4 (1.2)
QoL-AD score: mean (s.d.)	31.3 (1.1)
Caregivers (n=30)	
Age, years: mean (s.d.)	53.7 (10.2)
Female gender, <i>n</i> (%)	25 (83.3)
Children/children-in-law	25 (83.3)
ADAS-Cog, Alzheimer's Disease Assessment Scale – Cognition	
QoL-AD, Quality of Life in Alzheimer's Disease	

Table 3. Characteristics of the qualitative study participants

CST group facilitators (n=12)	
Professional background, <i>n</i> (%)	
Social worker	6 (50.0)
Occupational therapist	2 (16.7)
Nurse	1 (8.3)
Programme worker	1 (8.3)
Personal care worker	2 (16.7)
Work setting, <i>n</i> (%)	
Community care centres	7 (58.3)
Residential care homes	5 (41.7)
Family caregivers (n=13)	
Age group, <i>n</i> (%)	
50-60 years	9 (69.2)
61-70 years	1 (7.7)
71-80 years	2 (15.4)
≥81 years	1 (7.7)
Female gender, <i>n</i> (%)	8 (61.5)
Relationship, <i>n</i> (%)	
Adult child	9 (69.2)
Spouse	4 (30.7)