Cognitive Stimulation Therapy (CST) for dementia

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Six PhDs
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Emerging from the shadows

- 1980s no drugs, little known on psychosocial interventions
- 1996 Orrell and Woods - editorial
- poor evidence - a challenge
  - poor design
  - few RCTs
  - poor defined interventions
  - variety of outcome measures
  - lack of theory
  - confusion about what is a therapy

1999 INTERDEM founded
2015 INTERDEM Academy founded
Early detection and timely INTERvention in DEMentia
International collaboration

- INTERDEM network - 20 European countries
- 40+ Universities

- INTERDEM Academy 120+ PhD and Postdoc researchers
INTERDEDEM Academy

- Travel exchange fellowships (travel and relocation costs) PhD students and post doc researchers 3 months in another INTERDEDEM research centre.

- A biannual programme for students/researchers
  - seminars to discuss work with peers and senior academics.
  - expert workshops & masterclasses to develop research ideas and expertise in the methodology of psychosocial research.

- 1\textsuperscript{st} summerschool in Maastricht 2015 - 21 students
- 2\textsuperscript{nd} summerschool in Nottingham 2016 - 29 students

- INDUCT study 15 new PhD positions across Europe
Progress

• psychosocial interventions rigorously developed and evaluated
• studies following MRC guidance on complex interventions
• randomised controlled trials improving cognition (Spector 2003), activities of daily living (Graff 2006), mood (Teri 2003) and behaviour (Livingston 2005).
• interventions can delay nursing home placement - counselling and support for carers and people with dementia (Spijker 2008, Mittelman 2006)
• psychosocial interventions in long term care (Vernooij-Dassen 2010) benefits for behaviour management, cognitive stimulation and physical activity.
new generation psychosocial interventions in dementia

Nine principles:
• Theory of action and model – agent of change/outcomes
• Evidence used in development
• High quality evaluation – major RCT/systematic review
• Unitary intervention – clearly defined
• Evidence of effectiveness on key outcomes
• Appropriate outcomes (cognition, behaviour, mood, ADL institutionalisation, quality of life)
• Cost effective
• Scalable – training/manual/resources
• Transferable – across care systems/countries
Biopsychosocial model of dementia

- Need to have active model not just of decline
- Excess disability and how to reduce it
- Practical tool
- Fixed factors (history or risk factors)
- Tractable factors (amenable to change)
- Trajectory from start of ageing process to death
Figure 1: The Biopsychosocial model

Psychosocial Fixed factors e.g.
- Education / IQ
- Previous life events
- Personality

Psychosocial Tractable factors e.g.
- Mental stimulation
- Reaction to life events
- Mood
- Social psychology
- Personal psychology
- Environment

Psychosocial Interventions e.g.
- Cognitive intervention
- Reminiscence therapy
- Social interventions
- Multi-sensory stimulation
- Carer support
- Respite care

Ageing Process
- Start of organic change
- Mild cognitive impairment
- Expression of dementia
- Diagnosis of dementia
- Increasing dependency
- Institutionalisation
- High dependency
- End of life care
- Death

Potential Function

EXCESS DISABILITY

Actual Function

Biological Fixed factors
- Age
- Health prior to dementia
- Genetic factors
- Sensory abilities

Biological Tractable factors:
- Physical health
- Sensory impairment
- Falls
- Exercise

Biological Interventions
- Cholinesterase inhibitors
- Other medication, e.g. antidepressant medication
- Medication for physical illness

TIMELINE
Cognitive Stimulation

• Distinguish from cognitive training and cognitive rehabilitation (Clare & Woods, 2004)

• Cognitive stimulation:
  – Targets cognitive and social function
  – Has a social element – usually in a group or with a family care-giver
  – Cognitive activities do not primarily consist of practice on specific cognitive modalities
• People with mild/moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme ... provided by workers with training and supervision ... irrespective of any anti-dementia drug received ...’
NHS Institute for Innovation & Improvement: Oct 2011

• “An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia”.

• Analysis focused on cost of providing CST.

• Combining health care cost savings and QoL improvements, behavioural interventions generate a net benefit of nearly £54.9 million per year.
CST & maintenance CST programme

Making a difference

The manual for group leaders

An evidence-based group programme to offer maintenance cognitive stimulation therapy (CST) to people with dementia.

Volume 1 & 2

Includes DVD with filmed sessions

The Journal of Dementia Care
CST trial  (Spector et al., 2003)

The programme

1) 14, 45 minute sessions (2 x week, 7 weeks)

2) Participants asked to give a group name

3) RO board

4) Sessions begin with warm up exercise

5) Bridging between sessions, consistency in time, place, participants and facilitators

6) Presenting sessions in a fun and stimulating way
CST Key Principles

• Orientating people sensitively / when appropriate
• Information processing and opinion rather than factual knowledge -> implicit learning
• Multi-sensory stimulation
• Flexible activities to cater for group’s needs and abilities
• Using reminiscence (as an aid to here-and-now)
• Building / strengthening relationships
CST trial (Spector et al., 2003)

- 23 centres (18 care homes and 5 day care)
- A multicentre Randomised Controlled Trial (RCT)

Attrition Rate: n = 201, n = 168 at follow up

Significant improvement in the primary outcome measures cognition and quality of life

Improvement in QoL mediated by improvement in cognitive function

Numbers needed to treat for cognition = 6 similar to AChEIs
Treatment and Control Groups - differences between baseline and follow up: Cognition (n=201)

MMSE
p=0.04

ADAS
p=0.01

change
treatment
control

MMSE
p=0.04

ADAS
p=0.01

change
treatment
control
Treatment and Control Groups -

differences between baseline and
follow up: Quality of Life (n=201)

change

QOL

p=0.03

-1

-0.5

0

0.5

1

1.5

treatment

control
Cost-effectiveness (Knapp et al., 2006)

CST is more cost-effective than usual activities using both outcome measures:
• Incremental cost-effectiveness ratio: £75.32 per additional point on MMSE (111 euros), £22.82 per point on QoL-AD (33.2 euros)
• Donepezil had larger cost per incremental outcome gain (AD2000, 2004)

Conclusions: Small costs outweighed by larger gains likely that decision makers will see CST as cost-effective.

Limitations – short time span, mainly focused on people in residential care
Cochrane Review 2012
Woods, Aguirre, Orrell, Spector

- 15 trials, 407 treatment and 311 controls participants
- Length of intervention varied: 1 to 24 months
- MMSE difference at follow up = 1.74 points ($Z = 5.57$, $p < 0.00001$)
- Holden Communication Scale SMD = 0.47 ($Z = 3.22$, $p = 0.001$)
- Wellbeing/QoL SMD = 0.38 ($Z = 2.76$, $p = 0.006$)
- Depression (GDS) SMD = 0.34 ($Z = 1.88$, $p = 0.06$)
- No benefits to ADL, behaviour, or carers measures
Development of the MCST trial programme

1. Identifying the evidence
2. Identifying the theory
3. Modelling

Methods
Outcome
Draft versions

Evidence based
Cochrane Review

Qualitative Methods
Consensus Conference
Focus Groups
Delphi Survey

Development Steps (Craig 2008)

Final MCST programme

Draft version 1 → Draft version 2 → Draft version 3 → Draft version 4
Maintenance CST development

• Extract features of research trials which had demonstrated effectiveness
• New themes: Useful tips (caring from oneself, memory tips, use of calendars, alarms) and Visual Clips from Requena (2007) and Olazaran (2004)
• 24 sessions based on the CST and MCST pilot plus new identified studies
• Presentation of the draft version 1 in a consensus conference to develop draft version 2 of the manual.
Modelling the programme
9 Focus Groups
(Aguirre et al., 2010)

• 17 people with dementia, 13 staff and 18 family carers
• Inductive thematic analysis to examine user perceptions of the Maintenance CST programme
• Mental stimulation highly valued by PWD, vital to keep healthy and active.
• Most family carers and staff very positive towards cognitive stimulation programmes BUT some concerns:
  - When use it or lose it doesn’t apply
  - Concerns about loss of confidence, anxiety, sense of inferiority.
Positive agreement was found among 14 themes and suggestions were made for the 5 remaining themes.

Carers and staff rated using money and current affairs very low - felt using money could be a sensitive topic and current affairs was a theme people with dementia wouldn't relate to.

In contrast people with dementia expressed a great interest in the using money theme and in the news.
Maintenance CST vs. CST

Randomised 272

8 to 10 Participants
CST group A

8 to 10 Participants
CST group B

Randomised 236

8 to 10 participants
TAU

8 to 10 participants
MCST

BASELINE ASSESSMENT

7 WEEKS CST

Twice a week (14 session)

BASELINE ASSESSMENT 2

3 MONTH Follow Up

24 WEEKS MCST

Once a week (24 session)

6 MONTH Follow Up
CST Predictors of change

• 272 recruited to CST groups as first stage of Maintenance CST Trial and 236 completed 7 weeks
• Improvement 1.09 MMSE points ($p < 0.001$), ADAS-Cog 2.34 points ($p < 0.001$)
• Improvement 1.85 DEMQOL points ($p < 0.003$)
• Female gender was associated with higher improvement
• use of ACHEIs did not alter improvement
Maintenance CST Trial – results

• 236 participants (123 MCST/123 CST only)
• After 6 months MCST
  – Quality of life better QoL-AD \( p = 0.03 \)
• After 3 months MCST
  – Quality of life better (proxy)
    DEMQOL \( p = 0.03 \), QoL-AD = 0.01
  – ADCS-ADL better \( p = 0.04 \)
• People on ACHEIs did significantly better on cognition if MCST rather than on CST only
CST mechanisms of change

- Qualitative study of experiences of the people attending CST groups, carers & group facilitators (N=34)
- Data analysed using Framework Analysis
- Two main themes: 'Positive experiences of being in the group' & 'Changes experienced in everyday life'
- Experience of CST seen as being emotionally positive
- Most reported some cognitive changes.
- Findings support the mechanisms of change suggested by the previous RCT of CST.
- Spector, Gardner, Orrell 2011
# Maintenance CST implementation in practice

**Amy Streater – study overview**

<table>
<thead>
<tr>
<th>Title</th>
<th>STANDOUT trial</th>
<th>MONOU trial</th>
<th>Observational study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Aim</strong></td>
<td>To assess the effectiveness of staff training &amp; outreach support</td>
<td>To assess the implementation in practice of CST &amp; outreach support</td>
<td>To assess the effectiveness of CST in practice</td>
</tr>
<tr>
<td><strong>Participants</strong></td>
<td>Qualified &amp; non qualified dementia care staff</td>
<td>Qualified &amp; non qualified dementia care staff</td>
<td>People with dementia</td>
</tr>
<tr>
<td><strong>Expected number</strong></td>
<td>120</td>
<td>120</td>
<td>100</td>
</tr>
<tr>
<td><strong>Actual number</strong></td>
<td>175</td>
<td>66</td>
<td>89</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td>Yes</td>
<td>Variable</td>
<td>Variable</td>
</tr>
<tr>
<td><strong>Outreach</strong></td>
<td>50%</td>
<td>50%</td>
<td>Variable</td>
</tr>
<tr>
<td><strong>Assessment schedule</strong></td>
<td>Baseline, 6 &amp; 12 months</td>
<td>Baseline, 6 &amp; 12 months</td>
<td>Before &amp; after CST and after maintenance CST</td>
</tr>
</tbody>
</table>
Outreach support queries

15 uses of outreach supporting across 35 centres raising 21 queries relating to:

group participation, inclusion criteria, practicalities, delivery of the programme, group facilitation. After CST, activity theme and general queries.

3 centres signed up to the online forum
No statistically significant difference in the proportion of CST groups run in the intervention group compared to the TAU group ($p=.458$).
Staff maintenance CST results

<table>
<thead>
<tr>
<th>Intervention</th>
<th>No CST</th>
<th>CST only</th>
<th>MCST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outreach support n=35 (%)</td>
<td>17 (49)</td>
<td>6 (57)</td>
<td>12 (34)</td>
</tr>
<tr>
<td>No outreach support n=28 (%)</td>
<td>16 (57)</td>
<td>4 (14)</td>
<td>8 (29)</td>
</tr>
</tbody>
</table>

There is a statistically significant difference with more maintenance CST groups run in the outreach support group compared to TAU group (p=.011)
Secondary outcome measures

Approach to dementia, job satisfaction, controllability of challenging behaviour, sense of competence, learning transfer, barriers to change and dementia knowledge

No difference
Staff focus groups

Four focus groups (n=15) were conducted with staff who had run the maintenance CST programme to gain their views on the implementation of the programme and the outreach support options.

Used inductive thematic analysis to gather descriptive exploratory data.

Themes:
Perception of maintenance CST programme, therapeutic value for the service user, perceived barriers, facilitator skills, perception of support, CST adaptations, quality of materials.
Observational study (n= 89)

Routine use of CST in practice with minimal outcomes

Cognition and quality of life remained unchanged over the duration of the study.

**When excluded participants scoring 25 or above on the MMSE.**
Significant improvement in cognition after CST (p=.04)
No difference between BL and after maintenance CST.

Quality of life remained unchanged.


**Comparison with a control group**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Spector (2003) control mean change (SD) [N]</th>
<th>Current study mean change (SD) [N]</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>-0.4(3.5) [70]</td>
<td>1(4.6) [47]</td>
<td>t = 2.04; p = 0.04</td>
</tr>
<tr>
<td>QoL-AD</td>
<td>-0.8(5.6) [70]</td>
<td>-1.4(9.3) [46]</td>
<td>t = 0.08; p = 0.94</td>
</tr>
</tbody>
</table>

Conducted as no control group for this study. Meta analysis comparison of mean change in CST groups compared to control group (Spector et al., 2003). 1.4 point increase on MMSE for CST programme. Quality of life unchanged.
Development of Individual Cognitive Stimulation Therapy

- 75 individual cognitive stimulation sessions
  - Delivered by the family carer
  - for 30 minutes, 3 times a week, over 25 weeks

Sessions aim to:
- Provide mental stimulation
- Each individual CST session consists of a themed activity, i.e. being creative
- iCST is guided by therapeutic principles, avoiding direct memory questions, focusing on opinions rather than facts
Development of iCST: Initial Consultations

iCST Manual - Pilot Draft
- First Round of Consultations with Carers and Professionals
  - Based on 2 previous Manuals

Main findings of Initial Consultations
- Adapt similar layout & reduce overall length
- Simplify, provide simple instructions
- Relate to every day life
- Emphasize on ‘togetherness’
- Ensure it is engaging
Development of Individual Cognitive Stimulation Therapy

What resources are provided as part of iCST?

The iCST Manual & iCST Activity Workbook
– Providing a guide to iCST and each session
– iCST sessions are accompanied by paper based activities

The ‘iCST Toolkit’
• Resources such as magnifying card, playing cards, dominoes, World/UK map, stationery
• iCST Carer’s Diary

iCST Support
• Carers receive training & continuous support in delivering iCST
Aims

1. To evaluate the iCST Manual & Activity Workbook - via an online survey in order to reach consensus on:
   - overall quality & layout
   - language, font size and amount of information presented
   - variety and clarity of activities proposed
   - likelihood of successful engagement

2. Who completed the online survey?

Experts in dementia care:
- Family carers
- NHS/Voluntary/Private Sector professionals
- Academics/Professionals with experience using CST
Evaluation of the iCST Manual

Is the layout appropriate?
91.66%

Is there adequate variety in the activities?
83.33%

Likelihood of enjoyment of activities?
75%

Amount of information presented?
75%

24 experts
Evaluation of the iCST Activity Workbook

Is the layout appropriate?
100%

Is there adequate variety in the activities?
87.5%

Likelihood of enjoyment of activities?
79.17%

Amount of information presented?
95.83%
iCST Evaluation & Revision

**Aim:** To evaluate in depth the iCST Package and revise according to experts:

**Key comments/revisions**

- **Specify the level of difficulty for each of the activities**
  - This will enable carers to see the difference between each activity clearly

- **Reduce Introduction to iCST**
  - Abridged form with key points will be useful for carers

- **Provide examples of how carers could start each session**
  - Variation in ‘warming up’
iCST Revision of Materials

Useful comments by experts, people with dementia, and carers

Key comments and revisions

✔ Emphasise on positive aspects of iCST
  ❖ This will empower carers involved in the programme
✔ iCST needs an emphasis on both the family carer and the person with dementia and should be person centred
✔ Describe the purpose and content of activities as an opportunity for discussion
✔ Focus on images in the iCST sessions, as ‘images are less threatening than words”
iCST Carers’ Feedback

Support for Family Carers

- Most carers report that they will need limited support in delivering iCST

- 76% prefer to be trained at home

- Most carers report that they have been able to engage successfully with their relative in iCST
iCST Carer Support

Key areas of support for family carers in main RCT

✓ Carers will receive the following types of support

- **A Set-up visit**
  - Home based training with an opportunity to ask questions about iCST
- **Telephone support** (preference for weekly support)
- **Two home visits** after completion of 50% of the iCST sessions and at the end of iCST
- **Training protocol** in place to ensure consistency in training
- **Treatment protocol** in order to guide researchers

✓ **Treatment Adherence Reporting** following previous models emphasizing the need to specify *treatment implementation*
iCST Main RCT

Centers: London (Coordinating Centre)
   Bangor
   Hull
   Manchester

✓ On the basis of a feasibility exercise 4 new centres have joined iCST
   ✤ North Devon, Lincolnshire, Norfolk & Suffolk, and Dorset NHS Trust

✓ Main RCT commenced in London on the 4th of April 2012
   ✤ Local Training Day in London on the 30th of March
   ✤ Bangor commences assessments end of April 2012
   ✤ Training for all centers: May 2012
   ✤ Remaining centers start from June/July 2012
Randomisation
N=356

Allocated to iCST
N=180

iCST follow up 1 at 13 weeks
N=142

iCST follow up 2 at 26 weeks
N=134

Allocated to TAU
N=176

TAU follow up 1 at 13 weeks
N=146

TAU follow up 2 at 26 weeks
N=139
Referred/screened \((n = 1340)\)

Baseline Assessment & Randomisation \((n = 356)\)

Follow-up 1 - 13 weeks assessment \((n = 288)\)
68 losses
52 withdrawals (including 4 deaths)
16 agreed to follow up 2

Follow-up 2 - 26 weeks assessment \((n = 273)\)
Further 31 dyads withdrew (4 deaths)
83 withdrawals overall
retention rate 77\%, attrition rate was 21\% excluding deaths
(predicted rate in updated sample size calculations)

No difference between centres at FUP2 \(p = 0.33\)
### Perception of allocation at 26 weeks

<table>
<thead>
<tr>
<th>Researcher rating</th>
<th>Treatment allocation</th>
<th></th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>iCST (%)</td>
<td>TAU (%)</td>
<td>Total (%)</td>
</tr>
<tr>
<td>‘Definite’ judgement: Correct</td>
<td>22 (19)</td>
<td>4 (3)</td>
<td>26 (10)</td>
</tr>
<tr>
<td>‘More likely’ judgement: Correct</td>
<td>17 (15)</td>
<td>17 (12)</td>
<td>34 (13)</td>
</tr>
<tr>
<td>Equally likely iCST or TAU</td>
<td>65 (57)</td>
<td>80 (57)</td>
<td>145 (57)</td>
</tr>
<tr>
<td>‘More likely’ judgement: Incorrect</td>
<td>10 (9)</td>
<td>31 (22)</td>
<td>41 (16)</td>
</tr>
<tr>
<td>‘Definite’ judgment: Incorrect</td>
<td>0</td>
<td>9 (6)</td>
<td>9 (4)</td>
</tr>
<tr>
<td>Total</td>
<td>114</td>
<td>141</td>
<td>255</td>
</tr>
</tbody>
</table>
Main Results

356 participants across 8 UK centres seen at baseline, 3 & 6 months

Randomised to intervention (180) or usual care (176)

At six months
no differences in primary outcomes between the intervention and the treatment as usual group

ADAS-Cog cognition: difference -0.55 (SE) 0.74; \( p = 0.45 \)

self-reported quality of life: difference -0.14, (SE) 0.50; \( p = 0.78 \)

People with dementia (iCST) improved carer relationship difference 1.77 (SE) 0.77; \( p = 0.02 \)
Improved quality of life for the carer at 6 months

Carers (iCST) higher quality of life (EQ5D) difference 0.06 (SE) 0.02; \( p = 0.01 \)

**Adherence analyses:**

Dyads completing more iCST sessions also showed lower carer depressive symptoms \( p = 0.018 \)

When number of sessions was included at first follow up: cognition (MMSE \( p = 0.104 \)) and quality of life (QoL-AD \( p = 0.084 \)) for the person with dementia close to significance.
Positive outcomes for carers

I’m glad we have iCST, it has given us a lot of help.

The programme has given me ideas I never would have thought of.

The programme has given me more tolerance.

It has taught us how to work on the things that matter, and ignore the things that don’t.

I feel like I have a purpose when spending time with dad.

I cannot say how much of a difference this has made to my relationship with my mother.

It made us realise that parts of mum’s memory work, and others don’t.

We’ve had some nice enjoyable times doing the activities together.
Positive outcomes for people with dementia

Mum is enjoying the activities

Mum’s conversational skills seem to have improved

My dad’s mood is lifted during sessions

Mum is more alert after sessions

My mum seems more confident and like her old self

Mum is enjoying the activities

My dad’s mood is lifted during sessions

Mum is more alert after sessions

My mum seems more confident and like her old self
Economic Outcomes

- costs £481 per person for paid staff to deliver
- £652 if the costs of carer time taken into account.

INTERVENTION GROUP
- health and social care costs greater £4740 iCST vs. £4670 TAU
- societal costs lower £9770 iCST vs. £10630 TAU
- Costs were not significantly different £70 (95% CI -1050, 1190)

Cost-effectiveness analyses from the health and social care perspective yielded incremental cost-effectiveness ratios of
- £300 for achieving a standardised mean difference on the ADAS-Cog
- £600 for achieving a standardised mean difference in the QOL-AD.

- health and social care cost for QALY gain for carers was £3100
- Improved quality of life for carers without significant impact on costs
MRC framework (2008) for the development of a complex intervention

Figure 1. Key elements of the development and evaluation process (Craig et al., 2008)
Cognitive Stimulation Therapy for dementia

- Cognitive and social activities in group or with family carer
- Easy to deliver using standard manuals & DVD
- CST principles also useful in practice
- Cost effective (Knapp et al 2006) and savings to NHS of potentially £54 million/year (Institute for Innovation 2011).
- Works in synergy with cholinesterase inhibitors
- Used in 65% of UK memory services
- CST website: www.cstdementia.com
- Making a difference 1/2 and DVD from http://www.careinfo.org/books/
- 25 countries using CST
- Join the CST Network - email a.spector@ucl.ac.uk