Psychosocial interventions for people with dementia in the early phase
The rise of Cognitive Stimulation Therapy (CST)

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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
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
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
An evidence-based group programme to offer cognitive stimulation to people with dementia
The manual for group leaders
Aimee Spector, Lena Thorgrimsen, Bob Woods, Martin Orell
Foreword by The Journal for Dementia Care

Making a difference 2
An evidence-based group programme to offer maintenance cognitive stimulation therapy (CST) to people with dementia
The manual for group leaders
Elsa Agaku, Aimee Spector, Amy Stretzer, Juanita Hoes, Bob Woods, Martin Orell
Endorsed by The Journal of Dementia Care
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 trial (Spector et al., 2003)
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

[Bar chart showing change in MMSE and ADAS scores for treatment and control groups]
Treatment and Control Groups - differences between baseline and follow up: Quality of Life (n=201)

change

QOL

p=0.03
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

Development Steps (Craig 2008)

Evidence based
- Cochrane Review

Qualitative Methods
- Consensus Conference
- Focus Groups
- Delphi Survey

Final MCST programme

Draft versions
- Draft version 1
- Draft version 2
- Draft version 3
- Draft version 4

Methods
Outcome
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.
Focus Groups results
(Aguirre et al., 2010)

- 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 ($p=0.458$).
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)
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.
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
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%

Font used: 87.5%

24 experts
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*
Randomisation
N=356

Allocated to iCST
N=180

iCST follow up 1 at 13weeks
N=142

iCST follow up 2 at 26 weeks
N=134

Allocated to TAU
N=176

TAU follow up 1 at 13weeks
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></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

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

We’ve had some nice enjoyable times doing the activities together

The programme has given me more tolerance

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

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

It has taught us how to work on the things that matter, and ignore the things that don’t
Positive outcomes for people with dementia

- Mum’s conversational skills seem to have improved
- Mum is more alert after sessions
- My dad’s mood is lifted during sessions
- Mum is enjoying the activities
- My mum seems more confident and like her old self
- Mum is enjoying the activities
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