The evaluation of individual Cognitive Stimulation Therapy (iCST) for dementia

Lauren Yates – Research assistant & PhD student
What is CST?

• 7 week group programme of activities

• Spector et al. (2003): cognitive & QoL benefits

• Recommended in the UK & internationally:

• Orrell et al (2014): Maintenance CST – No additional cognitive benefits but improved QoL

• Aguirre, Spector & Orrell (2014): Cultural adaption guidelines
What is iCST?

• One to one version of CST
• Home based, family / informal carer led
• Up to 3 sessions per week
• 20-30 minute sessions
• Themed activities eg: being creative, word games, art discussion
iCST Session Structure

Discuss orientation information (5 mins)

Discuss current news (5 mins)

Main activity (20 mins)
CST groups may not be accessible because:

- Health / mobility problems
- Local service constraints
- Not keen on group environment

iCST presents an opportunity for family carer involvement
Objectives of the research

To develop the iCST programme and materials

To evaluate the effectiveness of iCST

**Primary Outcomes:** Cognition (ADAS-Cog) & Quality of life (QoL-AD) for the person, quality of life for the carer (SF-12)
Survey
Panel of carers & professionals
Cochrane Review of CST
CST/MCST manuals
Individual cognitive therapies literature

Pre-clinical Phase

Draft 1

Phase I: Modeling

10 Individual interviews

6 Focus groups

Field testing

Phase II: Piloting

Online survey

Conference

Main RCT

n=356

ciCST vs. TAU

Phase III: Main RCT

Main RCT version

Draft 2
iCST package (research version)

Manual

Individual Cognitive Stimulation
A Manual for Carers

Activity Workbook

Our Time...

iCST
Individual Cognitive Stimulation Therapy

Activity Workbook

UCL
Main RCT design

- **iCST intervention (N=180)**
- **Set up visit**
- **Monitoring visit 1**
- **Baseline (N=356)**
- **Randomization**
- **Treatment as usual (TAU) (N=176)**
- **Follow up 1 at 13 weeks (n=288)**
- **Monitoring visit 2**
- **Follow up 2 at 26 weeks (n=273)**

12 weeks post BL
25 weeks post BL
Training visit:
• 1-1.5 hours at home
• Introduction to materials, key principles, session structure
• Role play of good/bad practice
• DVD clip of group session

Remote adherence:
• Telephone support (weekly, fortnightly, monthly)
• Questionnaires for data

Monitoring visits:
• 12 weeks pre FU1, 25 weeks pre FU2
• 30 mins- 1 hour
• Short questionnaire for carer & researcher

Carer diaries:
• Carer Diary 1 (set up – MV1) & 2 (MV1-MV2)
• Ratings of enjoyment, interest, communication & mood plus comments
Results of the trial

Person with dementia:
Better quality of relationship with carer delivering programme

Carer:
Improved health related quality of life
Fewer depressive symptoms with greater adherence

No significant differences in primary outcomes for person or carer
Reflections

• iCST could be a useful tool for carers and people with dementia. It provides an opportunity for dyads to spend quality time together, and is an aid to communication and can enhance carer health related quality of life / mood.

• Why didn’t we observe benefits? Treatment delivered as intended? 22% dyads did no sessions, 51% completed >30. Ceiling effect of cognition related to sample? Social component of group CST a key factor in impact on cognition?

• Further research might focus on the mechanisms behind group CST vs. iCST, delivery of iCST by healthcare professionals
Service users' involvement in the development of individual Cognitive Stimulation Therapy (iCST) for dementia: a qualitative study

Lauren A Yate1,2, Martin Glenn3, Anne Specord4 and Vafulia Chong5

Abstract

Background: Individual Cognitive Stimulation Therapy (iCST) is a one-to-one carer led psychosocial intervention for people with dementia, adapted from group Cognitive Stimulation Therapy (GST). It is increasingly recognised that involving service users in research is key to developing interventions and treatments that successfully address their needs. This study describes the contribution of people with dementia and carers during the development phase of the intervention and materials.

Methods: Twenty-eight people with dementia and 24 carers were consulted in a series of six focus groups and 11 interviews. The purpose of this study was to gain insight into perceptions of mental stimulation from the perspective of people with dementia and carers to ensure the materials are easy to use, liked and appropriately tailored to the needs of people with dementia and their carers and to assess the feasibility of the intervention.

Results: The importance of mental stimulation was emphasised by people with dementia. Feedback from carers was positive as a way of building on their residents' existing interests. Carers identified benefits such as improved quality of life, social and mental. The concept of iCST was well received, and both carers and people with dementia responded positively to the first drafts of materials. Feasibility issues, such as finding time to do sessions, were identified.

Conclusions: The feedback from the focus groups and interviews will be used to further develop and refine the iCST programme material in preparation for a full testing phase prior to a large-scale controlled trial (RCT).

Trial registration: ISRCTN71059915 Date of registration: 02/05/2010

Keywords: Cognitive stimulation therapy, Dementia Focus groups, Individual cognitive stimulation therapy, Individual interviews.

Background

Providing care for people with dementia is a great challenge for health and social care services across the globe [1]. The number of people affected by the disease, coupled with increasing costs, is expected to reach 115.4 million by 2050 [2]. The development of user-friendly, clinically effective conversion into services delivered to carers could improve cognition and quality of life for people with dementia, and help carers be involved in worthwhile and enjoyable activities. The Department of Health, the National Health Service (NHS) Executive, research charities and funding bodies suggest that the key to developing interventions and treatments that successfully address the needs of service users and produce results that will impact clinical practice is to involve them in research [3].

Group CST is an evidence-based psychological intervention for people with dementia [4]. Studies evaluating the effectiveness of CST consistently report that CST can improve cognition and quality of life for people with dementia [5]. Clinically and cost-effective (6), CST is recommended by the National Institute of Clinical Excellence (NICE) [7], the NHS Institute for Innovation and Improvement [8], and the Alzheimer’s Society [9]. It is delivered by a trained facilitator and is designed for use in small groups (10 to 14 people) for up to two hours per week, over an 8-week intervention period. The CST programme is divided into 10 sessions, each focusing on a different topic, such as family and friends, meals and eating, and memory.

Introduction

Clinical interventions such as psychological therapies are used in health and social services. To ensure that policy makers see the role of support and work to determine whether the intervention is more likely to be cost-effective and better developed, including those who need the intervention, whether it is delivered by a facilitator or a professional, and whether it is delivered in a group or individually. The intervention should be evaluated for its effectiveness and cost-effectiveness, and the effectiveness of the intervention should be assessed in terms of its impact on the well-being of people with dementia.
Lauren Yates (lauren.yates@ucl.ac.uk)
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