Institution:
10007857 – Bangor University

Unit of Assessment:
04

Title of case study:
Cognitive stimulation – an effective intervention to improve quality of life and cognition in people with mild to moderate dementia

1. Summary of the impact (indicative maximum 100 words)

There are very few evidence-based psychological interventions for people with Alzheimer's disease and other dementias. Of these, cognitive stimulation has the strongest evidence-base. Developed by Bob Woods (Bangor University) and Martin Orrell (UCL) in the late 1990s, the approach has proven effective in maintaining both cognitive function and quality of life. Recommended in guidelines around the world for use with people with mild to moderate dementia as the major evidence-based non-pharmacological intervention, it has assisted literally thousands of people with dementia and their carers globally to have a better quality of life both before and since 2008.

2. Underpinning research (indicative maximum 500 words)

Psychological interventions for people with dementia have been described for over 50 years, but the research focus has been largely on developing pharmacological approaches. Studies of psychological approaches have been very limited by comparison, with small sample sizes and a lack of rigorous methodology making health service commissioners reluctant to fund their implementation.

In 1996, Prof. Bob Woods moved to Bangor University from UCL to take up the first UK Chair in Clinical Psychology with Older People. In a sustained collaboration with Prof. Martin Orrell (at UCL), Woods' programme of research set out to evaluate the effectiveness of psychological interventions for people with dementia, producing evidence of comparable quality to that from trials of the emerging pharmacological interventions. This joint programme of work has had several components underpinning the impact achieved:

1) *Intervention development*: an intervention had to be designed and standardised so that it could be delivered consistently and reliably, whilst maintaining respect and dignity. In order to build on the best of what had gone before, we undertook two systematic reviews, published in 2000 by the Cochrane Collaboration, on Reality Orientation (an early cognition-based approach from the USA) **[3.1]** and Reminiscence Therapy. From the effective components of these, coupled with 20 years of experience of these approaches brought to the team by Bob Woods, a new intervention called 'cognitive stimulation therapy' (CST) was developed, offering a standardised programme of group sessions, within a person-centred framework of respect and individual choice.

2) *Feasibility*: the new approach was next tested for feasibility in a small-scale study, and the programme and treatment manual adapted and adjusted accordingly in the light of patient and staff feedback **[3.2]**.

3) *Outcome measures*: to enable comparison with drug trials, standard cognitive function measures were used. However, for the approach to be clinically useful it needed to also demonstrate an impact on the person's well-being and quality of life (QoL). Accordingly, we evaluated the use of a then-new QoL self-report measure for people with dementia from the USA **[3.3]** and showed its applicability and validity in the UK.

4) *Effectiveness and cost effectiveness*: following the previous steps, a rigorous randomised controlled trial of CST, with a parallel health economic evaluation, could then be undertaken. At the time this was one of the largest trials of such an approach in the world **[3.4, 3.5].** It demonstrated that CST produced potentially cost-effective improvements in QoL and cognitive function.

5) *Mechanisms*: these positive results led to further exploration of mechanisms of change, especially as QoL and cognitive function tend to be unrelated in people with dementia. Further analyses indicated that cognition mediates the improvements in QoL **[3.6]** and highlighted areas of cognition showing most change.

6) *Wider implementation*: in 2012, we completed the first Cochrane review of cognitive stimulation with people with dementia **[3.7]**, indicating that Bangor/UCL findings in relation to improved cognition and well-being are replicable by research groups internationally.

7) Further development of CST continues, with National Institute for Health Research funded trials of maintenance CST (the effects of 8 months of treatment) and of individual, family-care delivered CST.

3. References to the research (indicative maximum of six references)

* indicates outputs that were returned in RAE2008; citation counts refer to ISI Web of Knowledge (October 2013) unless otherwise noted

1. Spector A, Davies S, Woods B, Orrell M. (2000). Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomized controlled trials. *Gerontologist,* 40(2):206–212. DOI: 10.1093/geront/40.2.206. (52 citations)

2. Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can Reality Orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia. *Neuropsychological Rehabilitation, 11*(3/4), 377-397. DOI: 10.1080/09602010143000068. (33 citations)

3. Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de-Madariaga-Lopez, M., Woods, R. T., & Orrell, M. (2003). Whose quality of life is it anyway? The validity and reliability of the Quality of Life - Alzheimer's Disease (QoL-AD) Scale. *Alzheimer Disease and Associated Disorders, 17*(4), 201-208. DOI: 10.1097/00002093-200310000-00002. (166 citations in Google Scholar)

4. ***Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry, 183*, 248-254. DOI: 10.1192/03-23. (151 citations)

5. Knapp, M., Spector, A., Thorgrimsen, L., Woods, R.T., Orrell, M. (2006). Cognitive Stimulation Therapy for people with dementia: cost effectiveness analysis. *British Journal of Psychiatry*, 188, 574-580. DOI: 10.1192/bjp.bp.105.010561. (47 citations)

6. ***Woods, R.T., Thorgrimsen, L., Spector, A., Royan, L., & Orrell, M. (2006). Improved quality of life and cognitive stimulation in dementia. *Aging & Mental Health,* 10, 219-226. DOI: 10.1080/13607860500431652. (30 citations)

7. Woods B, Aguirre E, Spector AE, Orrell M. (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD005562. DOI: 10.1002/14651858.CD005562.pub2. (9 citations)

4. Details of the impact (indicative maximum 750 words)

CST is recommended and widely used within the UK and internationally.

Current UK guidelines recommend the widespread implementation of CST. The National Institute for Health and Clinical Excellence Guidelines (**5.1**), which set the standards for practice in the NHS in England and Wales, state that CST groups should be made available to all people with mild to moderate dementia, irrespective of any anti-dementia medication prescribed. This is the strongest recommendation in the guideline relating to non-pharmacological therapies, and, as this was a joint guideline with the Social Care Institute for Excellence, also applies to the social care context. Although originally published in 2006, these guidelines have been reviewed in 2011-2012 and *continue to stand as current best practice*. In Scotland, the Scottish Intercollegiate Guidelines Network (**5.2**) national clinical guideline on dementia similarly recommends cognitive stimulation, and in its booklet for patients with dementia (revised 2011) states: “You should be offered cognitive stimulation as part of your treatment.” Other influential bodies that advocate CST include, in the

UK, Alzheimer's Research UK (**5.3**) and, at an international level, Alzheimer's Disease International (ADI). CST was strongly endorsed in ADI's World Alzheimer's Report (2011) for the early stages of dementia (**5.4**). This report, available in English, Chinese, Arabic, German and French, has far-reaching influence and impact and helps to influence health and social care policy worldwide, increasing awareness of the challenge of Alzheimer's disease and dementia to society.

CST is not a cure for dementia, but the small changes in cognitive function (especially in language) and quality of life consistently identified in research studies can make a difference in everyday life: "…CST was a lifeline for us – the group restored her confidence. She felt she was doing something to help herself…" (Daughter of person with dementia attending CST groups – Mail on Sunday, December 13, 2011). Our studies have shown that the differences in cognitive function are of the same order of magnitude as those associated with the currently available medication. The cost-effectiveness of CST is a powerful argument for its implementation. Our primary economic evaluation (3.5) indicated CST is more cost-effective than usual care when looking at benefits in cognition and quality of life. Beyond this, the NHS Institute for Innovation and Improvement published an economic evaluation in 2011, concluding that CST could save the NHS over £54.9 million per annum over the use of anti-psychotic medication (**5.5**).

A variety of measures show that CST is now in wide use.
A National Audit Office Report in 2007 (**5.6;** the most recent relevant report) stated that structured group cognitive stimulation for dementia was used regularly by 36% of community mental health teams in England in early stage dementia, by 33% in mid stage and by 20% in late stage dementia. This translates to CST being used in 2013 by over 200 teams in England, assuming a modest 25% growth over this period. CST is offered to people with dementia, for example, in NHS Trusts in Camden and Islington, Cardiff, Cornwall, South Essex, Norfolk and Waveney, Northampton and Nottingham amongst many others. The 'Dementia Tsar' for England (National Clinical Director for Dementia, Department of Health), Professor Alistair Burns has commended cognitive stimulation (**5.7**) for use in a variety of settings.

The "Making a Difference" CST manual (**5.8**) for group leaders is used in care homes, day care centres, hospitals and community settings by family carers and staff carers, occupational therapists and nurses involved in running activities for people with dementia. The manual has been translated into a number of languages (e.g. Japanese, Spanish, Italian, German, Portugese, Dutch and Swahili). 'Making a Difference – 2', a manual for maintenance cognitive stimulation groups was published in 2011 by Hawker Publications. Over 5000 copies of the manuals have been sold (two-thirds since 2008). Training events are frequently held e.g. under the auspices of Dementia UK, in London, for example (**5.9**) with over 300 people being trained since 2009.

CST is being used elsewhere internationally, for example in Australia, Hong Kong, Italy, Japan, and New Zealand. Obtaining figures of how many people with dementia have benefitted from CST is difficult, of course, as such statistics are not routinely collected. However, in one region of Italy, Emilia Romagna, the annual report on the Regional Dementia Project indicates that 1,379 people with dementia living at home took part in cognitive stimulation in the previous 12 months. This does not include people with dementia taking part in groups in day centres or nursing homes (**5.10**). Given that there are estimated to be 36 million people living with dementia globally (750,000 in the UK), and that these figures are growing with the growth of the numbers of people surviving to live into the ages of greatest risk (80 and above), the potential for CST to continue to influence the lives of thousands of people is clear, even if it were only to reach a modest proportion of those affected. We therefore consider an estimate of 50,000 beneficiaries between 2008-2013 to be conservative.

5. Sources to corroborate the impact (indicative maximum of 10 references)

1. NICE-SCIE. *Dementia: Supporting people with dementia and their carers in health and social care: Clinical Guideline 42*. London: NICE-SCIE, 2006. (updated December 2011)
See also: http://www.nice.org.uk/nicemedia/live/10998/58965/58965.pdf for confirmation the guideline has been reviewed (2012) and continues to be current.

2. *Scottish Intercollegiate Guidelines Network(2006)* (http://www.sign.ac.uk/pdf/sign86.pdf) Patient Booklet (revised 2011): http://www.sign.ac.uk/pdf/pat86.pdf

3. *Alzheimer's Research* UK http://www.alzheimersresearchuk.org/general-treatments/ (accessed 18th March 2013)

4. Prince M, Bryce R, Ferri C. *World Alzheimer Report 2011: the benefits of early diagnosis and intervention*. London: Alzheimer's Disease International, 2011. http://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf

5. NHS Institute for Innovation and Improvement (2011). An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia. http://www.institute.nhs.uk/qipp/calls_to_action/Dementia_and_antipsychotic_drugs.html

6. National Audit Office (2007) Community Mental Health Teams for Older People: census results. http://www.nao.org.uk/publications/0607/dementia_services_and_support.aspx

7. Prof Alistair Burns, National Clinical Director for Dementia, Department of Health, England http://dementia.dh.gov.uk/cochrane-review-supportive-of-cognitive-stimulation-therapy-for-people-with-dementia/

8. Publishers of "Making a Difference" CST manual: USA (under title 'Our Time'): Freiberg Press Inc. http://www.care4elders.com/care4elders-programs-our%20time.htm UK and rest of the world and 'Making a difference – 2': Hawker Publications Ltd., http://www.careinfo.org/books/ Royalties for manuals received at Bangor University for further development of CST.

9. CST training events e.g: http://www.dementiauk.org/what-we-do/learning-partnerships-and-training/short-courses/ (accessed 18th March 2013). Also: http://www.cstdementia.com/page/training-and-events

10.Emilia Romagna Region, Italy: Regional dementia project: activities at the 31 December 2011 http://www.saluter.it/documentazione/rapporti/demenze_rapporto_dicembre2012.pdf