The benefits of groups that provide cognitive stimulation for people with dementia

'Cogs clubs' offer mental exercise, music, movement and friendship for their members, and respite for carers. Founder Jackie Tuppen evaluates their success

Abstract

Government policy (Department of Health 2009) recommends early diagnosis, intervention, support and care for people with dementia and their carers. The National Institute for Health and Clinical Excellence (2006) emphasises the need for a non-pharmacological, structured, group cognitive stimulation intervention for people with mild to moderate dementia. Cognitive stimulation therapy (CST) is one such intervention.

This article describes the development of 'Cogs clubs', a non-pharmacological intervention based on CST, from their inception to the present day. Initial evaluation found that the clubs met government policy and clinical guideline recommendations while being an acceptable intervention for facilitators, individuals and their carers.

Keywords
Cognitive stimulation, dementia, group interventions, mental health

Correspondence
jackie.tuppen@hotmail.co.uk

Jackie Tuppen is a nurse independent specialist practitioner, Broadstairs, Kent

Date of acceptance
September 5 2012

Peer review
This article has been subject to double-blind review and has been checked using antiplagiarism software

Author guidelines
www.nursingolderpeople.co.uk

DEMENTIA IS a syndrome that may be caused by a number of illnesses in which there is progressive decline in multiple areas of function. The National Service Framework (NSF) for Older People (Department of Health (DH) 2001) reported that approximately 600,000 people in the UK had dementia and projected that by 2026 the figure would be 840,000. However, the incidence of dementia appears to be increasing. The Alzheimer's Society (2011) suggests that the number of people with dementia in the UK will reach 940,000 by 2021 and more than 1.7 million by 2051.

The NSF (DH 2001) recommended that older people who have mental health problems and their carers should have access to effective diagnosis, treatment and support. However, some commentators suggest that comparatively low numbers of individuals are diagnosed early with dementia, possibly because clinicians identify potential hazards with early diagnosis such as anxiety, stigma and depression (Iliffe *et al* 2003).

More recently, the National Dementia Strategy (NDS) (DH 2009) recommended that public and professional awareness of dementia should be improved; that early diagnosis would enable early intervention and that care and support should be in place for the person with dementia and their carers.

Standard 7 of the NSF (DH 2001) included a recommendation that non-pharmacological management strategies be used in the treatment of dementia, such as mental exercise. This was supported by the National Institute for Health and Clinical Excellence (NICE) (2006), which stated that people with mild to moderate dementia, that is, those with a typical Mini Mental State Examination score (MMSE) of more than 12 (DH 2001), should be given the opportunity to participate in a structured group cognitive stimulation programme, irrespective of any pharmacological treatment.

Group intervention

Cognitive stimulation therapy (CST) is a non-pharmacological group intervention. It was developed after a systematic review of the effectiveness of reality orientation (Spector *et al* 2000), reminiscence therapy (Woods *et al* 2005) and psychosocial therapies for dementia (Aguirre and Orrell 2010). The most effective elements of these therapies were combined by Spector *et al* (2006) to create CST.

The efficacy and cost effectiveness of CST have been reported by a number of authors (Spector *et al* 2003, Knapp *et al* 2006). A recent systematic review identified a plethora of research that supports the use of CST for optimising individuals'

Pictured: (far right) Jackie Tuppen, founder of Cogs Clubs; and (left) members enjoying some of the many activities on offer

cognitive function (Yuill and Hollis 2011). CST is recommended for people with mild to moderate dementia. It involves 14 group sessions of themed activities that are run as a two-hour session, twice a week, over seven weeks.

The group is usually run by two trained facilitators with eight to ten participants. The themed activities provide ideas for people to help them maintain their cognitive abilities and aim to maximise their potential by building on strengths and developing relationships.

Recognising that CST is a time-limited intervention, Orrell *et al* (2005) conducted a pilot study to evaluate the effectiveness of maintenance CST which involved 16 further weekly sessions, following on from CST. The results suggested that benefits in cognition from the intervention might be maintained for nearly six months.

Local mental health teams in an area of East Kent offer CST and maintenance CST but they are time limited. When this intervention ends there is no alternative cognitive stimulation for individuals with early dementia.

The Alzheimer's Society (2011) reported that, before diagnosis, carers had limited access to formal and informal support and services. In the author's experience, even with a diagnosis there was a lack of support for people with mild dementia. At various support groups, people with dementia and their carers were trying to find the support they needed. Typical comments included: 'Where can we go, he is not ready for a day centre', 'CST has finished – now what?', and 'she needs some motivation, some stimulation'. Carers were also asking for a break, typically 24 hours or less, to give them some respite. These comments confirm further the findings of the Alzheimer's Society (2011) report that people with dementia and their carers 'highlighted independence, being active and engaged, and socialising as of key importance to people with dementia'.

Pilot

A wide range of people with dementia can benefit from CST because it is adaptable and it can be offered longer term. It can be run by facilitators who are not professionally trained but may have experience of working with older people or people with dementia (Spector *et al* 2006). Recognising this, the author sought to develop a structured programme based around cognitive stimulation and music, which volunteers could use to provide a day of stimulation. This proposal was supported by colleagues practised in delivering group programmes and carers who had requested more support. At the suggestion of one of the carers a local resource centre was approached to run a pilot, with the author, to help identify positives and negatives of the programme.

Permission was granted by the centre and at the end of the pilot, participants, carers and facilitators wanted to continue. After discussion it was agreed that the members would split into two groups: one to start a club at the resource centre and the other to start another club in a neighbouring town. Both clubs started in July 2011 and the name 'Cogs club' was adopted.

Cogs make things go round. If they become rusty, oil or grease lubricates them. The aim of a Cogs club is to oil the 'cogs' of the brain through cognitive stimulation, and oil the body's joints through movement to music. In the author's experience older people have been heard to talk about their cogs not working so well or their brains being 'rusty', so the name appeared to resonate with them and did not hold any stigma.

Club members

Cogs clubs are for people with mild to moderate dementia, who may or may not have had previous contact with medical professionals. Members were originally referred from secondary mental health services and would have had a MMSE score of 26 to 30, and additional presenting features indicative of cognitive impairment. They would have already completed CST with professionals. Referrals to new clubs have come from word of mouth, GPs and social services. As new clubs open, information, presentations, referral and eligibility criteria are given to local mental health teams, GPs and social services as requested.

People who are vision or hearing impaired benefit less from the club because sessions involve listening, discussion, reading and writing. In addition, members should be mobile enough to take themselves to the bathroom and manage any medication needed during the day. Members should want to come to the club – they are not 'placed' at the club. A club is a place of connectedness, where people have opinions and views that are acted on. It is hoped that people will talk about their Cogs club in the same way that they might talk about their bridge or gardening club.

Clubs provide the opportunity to recall and develop new skills and transfer these skills to activities at home. They provide a supportive and relaxed space in which to be creative. Individuals are encouraged to participate in purposeful activity to develop or maintain independent living skills, while building confidence in their ability to engage in these activities.

The clubs run in the same structured way as CST, using a themed activity each week. Individuals with dementia appreciate routine and structure and they can be sensitive to changes in their surroundings (Desai and Grossberg 2001, Khan *et al* 2005). Facilitators have observed that the structured approach helps members recognise where they are and what is expected of them from week to week. This in turn appears to have created a sense of security that has encouraged them to return.

Cogs clubs are not viewed as therapy. They are run by volunteers rather than professionals and instead of two hours' occupation, the club offers five hours of activity, stimulation and music for the person with dementia, while providing a day of respite for carers. The volunteers are vetted by the organisation hosting the club. This includes having a Criminal Records Bureau check and obtaining references. The clubs capture the adaptability of CST to provide extended 'maintenance' groups that only end for members when they want to leave or they are unable to participate meaningfully.

A typical day

Cognitive stimulation, music, reminiscence and orientation are part of the usual routine. These interventions have been found to improve participants' sense of wellbeing (Spector *et al* 2000, Woods *et al* 2005, Salimpoor *et al* 2011, Spector *et al* 2011). Using researched and validated interventions enables the clubs to address the sixth objective of the NDS (DH 2009); that is, providing flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia.

Four main sessions make for a full day with regular breaks. The first hour is about meeting and greeting each other, having a discussion about the name of the club, singing, orientation to time and place and sharing news items. This first session ends with tea and a comfort break.

The second session is always an activity based on CST, such as sounds, categorising objects or word association. This is followed by a light lunch because a large meal would not be conducive to the first session of the afternoon, which is movement and music. Depending on members' abilities, this involves a mix of seated exercise, standing, walking and miming to familiar songs.

Encouraging members to take part in some gentle physical activity after lunch gets oxygen to circulate to the brain (Heyn *et al* 2004) and therefore best prepares them for the last session of cognitive stimulation, which is usually a board concentration game, such as Scrabble. The day ends with each member being given a summary of the day's activities, which is discussed over a cup of tea.

Practical aspects

The size of the group is an important consideration when working with individuals who may be experiencing memory difficulties. Therapeutic group theory suggests that optimum numbers for groups are between eight and ten (Roark and Roark 1979, Gupta 2005).

Based on the diverse needs of people with dementia, coupled with their varying ability to attend

regularly, it is suggested that a memory group could have up to 12 members, with an anticipated average attendance of around ten each session. However, the size of a Cogs club is also dependent on the size of venue, facilities, ratio of volunteers to members and members' physical needs.

Costs vary from venue to venue, depending on the overheads. Members' subscriptions range from £8 to £22 for their day, which includes refreshments and a light lunch. The cost compares favourably with day care costs in this area of East Kent, which anecdotally range between £30 and £60.

The clubs do not have to be facilitated by paid staff experienced in dementia care. Volunteers with some experience of working with older people can also act as facilitators, and if they have experience of working with people with dementia this is an added bonus. When a new club starts, depending on the skills and abilities of facilitators, they are supported by presentations about CST and dementia, delivered by the author, alongside training on the job.

Evaluation

Carers and facilitators were asked to complete a questionnaire three months after the clubs started in 2011. They were advised that completion was voluntary and anonymous. The aim was to evaluate the clubs' effectiveness at providing cognitive and social support for people with mild dementia and respite for carers. CST literature (Spector *et al* 2006) suggests that observation is an effective and useful tool to record each member's response to and involvement in sessions. The outcome of these observations follows the questionnaire results.

Eight out of nine carer questionnaires were returned, giving a return rate of 88 per cent. The majority of the results and comments were positive; most of them indicating that they had benefited from a period of respite.

Nine out of 12 facilitator questionnaires were returned, giving a return rate of 75 per cent. The majority of results and comments were positive. Most of the facilitators stated that they had benefited from the clubs. They mentioned gaining insight, understanding and appreciation of others' situations. Some were satisfied by helping others and some thought the clubs had helped the facilitators themselves to stay active.

The positive evaluation indicated that the clubs were meeting carers' needs for respite and that carers and facilitators wanted them to continue.

Observation For the purposes of evaluation and with their consent, the author observed one club of six members for a day. They were advised

Cogs club aims to oil the 'cogs' of the brain through cognitive stimulation and oil the body's joints through movement to music

that their participation would be anonymous, they could opt out at any time and it would not affect their relationships with other members or facilitators. The tool for recording observations was an adaptation of the form for monitoring progress taken from the Making a Difference manual for CST (Spector *et al* 2006). The original form was developed for monitoring each member's response and involvement in a CST session. A CST session is only two hours long whereas a Cogs club is five and includes time for socialisation which should also be monitored, hence the adaptation.

Each member was rated on four areas: interest, communication, enjoyment and mood throughout the day. As with the original tool, members were rated on a scale of A to E, with B and D reflecting ratings in between the descriptions given:

- A = no interest, communication, enjoyment or low mood.
- C = shows some interest, response, enjoyment, some signs of good mood.
- E = shows great interest, communicating well, great enjoyment and appears happy and relaxed.

The Ramsgate club is facilitated by two teams of three working on a fortnightly rota. It was chosen for observation because the facilitators were new to this type of intervention. It was expected that the results would help them to see how effective their interventions were.

Observing members showed a positive response from all in all four areas – interest, communication, enjoyment and mood. All of them were observed to be showing a great interest, were communicating well, were greatly enjoying the activities and were happy and relaxed throughout the day. This was a positive result for the Ramsgate facilitators who had no experience of working with people with dementia.

The evaluation confirmed that enjoyment and an element of fun are important components of the day. Facilitators have observed and reported to the author that laughter appears to reduce distressing emotions and helps members to relax, reduces stress and enables them to stay focused and accomplish more.

Before and since the evaluation, members have continued to be positive about their participation. They have told facilitators that the club is 'the best thing that's happened to me'. Members are happy about the day and often comment that they have 'not had so much fun for ages', 'this is the only place

I can go to be normal' and 'it's good to be integrated again not isolated'. Carers have also commented on how a person is 'more helpful at home' or 'more interested in old hobbies'. One couple returned to doing an active sport together.

Conclusion

There are six clubs in Kent, run by a variety of organisations which indicates the versatility of the programme. A care home and Age UK have discovered how, through this activity, they are able to provide a seamless service to people with dementia; that is, they are providing a facility that stimulates people with mild to moderate dementia and, at the same venue, they provide another facility that provides stimulation commensurate with a diminishing level of impairment as and when needed.

These are also positive indicators for people with dementia and their carers when looking to the future. For example, many have told the author that they do not want to think about residential care. However, if an individual has been attending a club in a residential home and then there is a crisis, it is much easier to suggest the person spends a night at the club – where they have fun and are known – than it is to suggest they go into an unfamiliar residential home.

The evaluation and the opening of more clubs are indicators of their success. Referrals from primary and secondary care professionals, support from voluntary groups, individuals, people with dementia and their carers indicate that this is an acceptable intervention at all levels. The evaluation has shown that the clubs are meeting the need for cognitive stimulation as recommended by NICE (2006).

This article has shown how the clubs link to government policy by accessing important areas of the NDS (DH 2009) and the Carers Strategy (DH 2010). In doing so, they:

- Improve public and professional awareness of dementia.
- Provide a non-pharmacological early intervention for those with mild to moderate dementia.
- Provide research-based high quality support for the person with dementia and their carer.
- Give carers a break from caring to sustain their role as carers.

Conflict of interest
The author of this article is the founder of Cogs clubs

Acknowledgements
The author wishes to thank Dr Aimee Spector and Professor Bob Woods, CST founders and Julia Burton-Jones, Dementia UK for their advice and support

References

Aguirre E, Orrell M (2010) Cognitive stimulation therapy for dementia. *Healthcare Counselling and Psychotherapy Journal.* 10, 3, 22-26.

Alzheimer's Society (2011) *Support. Stay. Save. Care and Support of People with Dementia in Their Own Homes.* Alzheimer's Society, London.

Department of Health (2001) *National Service Framework for Older People.* DH, London.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy.* DH, London.

Department of Health (2010) *Recognised, Valued and Supported: Next Steps for the Carers Strategy.* DH, London.

Desai A, Grossberg G (2001) Recognition and management of behavioral disturbances in dementia. *Primary Care Companion to the Journal of Clinical Psychiatry.* 3, 3, 93-109.

Gupta A (2005) Group therapy for psychiatric disorders: an introduction. *Mental Health Reviews.* www.psyplexus.com/mhr/group_therapy.html (Last accessed: October 30 2012.)

Heyn P, Abreu B, Ottenbacher K (2004) The effects of exercise training on elderly persons with cognitive impairment and dementia: a meta-analysis. *Archives of Physical Medicine and Rehabilitation.* 85, 10, 1694-1704.

Iliffe S, Manthorpe J, Eden A (2003) Sooner or later? Issues in the early diagnosis of dementia in general practice: a qualitative study. *Family Practice.* 20, 4, 376-381.

Khan D, Gwyther L, Frances A *et al* (2005) *Treatment of Dementia and Agitation: a Guide for Families and Caregivers.* http://alzheimer.ucdavis.edu/careg/media/pdf/dementiahandout.pdf (Last accessed: October 30 2012.)

Knapp M, Thorgrimsen L, Patel A *et al* (2006) Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis. *British Journal of Psychiatry.* 188, 574-580.

National Institute for Health and Clinical Excellence (2006) *Dementia: Supporting People with Dementia and their Carers in Health and Social Care. Clinical guideline 42.* NICE, London.

Orrell M, Spector A, Thorgrimsen L *et al* (2005) A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. *International Journal of Geriatric Psychiatry.* 20, 5, 446-451.

Roark A, Roark E (1979) Group structure: components and effects. *Journal for Specialists in Group Work.* 4, 4, 186-197.

Salimpoor V, Benovoy M, Larcher K *et al* (2011) Anatomically distinct dopamine release during anticipation and experience of peak emotion to music. *Nature Neuroscience.* 14, 2, 257-262.

Spector A, Davies S, Woods B *et al* (2000) Reality orientation for dementia: a systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist.* 40, 2, 206-212.

Spector A, Thorgrimsen L, Woods B *et al* (2003) Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry.* 183, 248-254.

Spector A, Thorgrimsen L, Woods B *et al* (2006) *Making a Difference: An Evidence-based Group Programme to Offer Cognitive Stimulation Therapy (CST) to People with Dementia.* Hawker Publications, London.

Spector A, Gardner C, Orrell M (2011) The impact of cognitive stimulation therapy groups on people with dementia: views from participants, their carers and group facilitators. *Aging & Mental Health.* 15, 8, 945-949.

Woods B, Spector A, Jones C *et al* (2005) Reminiscence therapy for dementia: a review of the evidence of effectiveness from randomised controlled trials. *Cochrane Database of Systematic Reviews.* Issue 2.

Yuill N, Hollis V (2011) A systematic review of cognitive stimulation therapy for older adults with mild to moderate dementia: an occupational therapy perspective. *Occupational Therapy International.* 18, 4, 163-186.