Aging & Mental Health
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/camh20

The impact of Cognitive Stimulation Therapy groups on people with dementia: views from participants, their carers and group facilitators
Aimee Spector a , Charlotte Gardner b & Martin Orrell c
a Research Department of Clinical, Educational and Health Psychology, University College London (UCL), London, UK
b South London and Maudsley NHS Trust (SLaM), Lewisham Mental Health for Older Adults Service, London, UK
c Department of Mental Health Sciences, University College London (UCL), Charles Bell House, Riding House Street, London, UK

Available online: 04 Jul 2011

To cite this article: Aimee Spector, Charlotte Gardner & Martin Orrell (2011): The impact of Cognitive Stimulation Therapy groups on people with dementia: views from participants, their carers and group facilitators, Aging & Mental Health, DOI:10.1080/13607863.2011.586622
To link to this article: http://dx.doi.org/10.1080/13607863.2011.586622

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: http://www.tandfonline.com/page/terms-and-conditions

This article may be used for research, teaching and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan, sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
The impact of Cognitive Stimulation Therapy groups on people with dementia: views from participants, their carers and group facilitators

Aimee Spector*, Charlotte Gardnerb and Martin Orrellc

aResearch Department of Clinical, Educational and Health Psychology, University College London (UCL), London, UK; bSouth London and Maudsley NHS Trust (SLaM), Lewisham Mental Health for Older Adults Service, London, UK; cDepartment of Mental Health Sciences, University College London (UCL), Charles Bell House, Riding House Street, London, UK

(Received 2 December 2009; final version received 27 April 2011)

Objectives: Cognitive Stimulation Therapy (CST) can lead to significant improvements in cognitive function and quality of life for people with dementia. This study sought to investigate whether improvements found in clinical trials were also noted by people with dementia, their carers and group facilitators in everyday life.

Method: Qualitative interviews and focus groups were conducted with people attending CST groups, their carers and the group facilitators. Data were recorded and transcribed, before being analysed using Framework Analysis.

Results: Two main themes emerged, 'Positive experiences of being in the group' and 'Changes experienced in everyday life', along with seven sub-themes. The overall experience of attending CST was seen as being emotionally positive and most participants reported some cognitive benefits.

Conclusions: The findings lend further support to previous quantitative findings, as well as providing information about the personal experience of CST.

Keywords: CST; dementia; qualitative

Introduction

Cognitive Stimulation Therapy (CST, Spector et al., 2003) is a brief, group intervention for people with dementia. It involves 14 sessions of themed activities which draw on several principles including implicit learning and person centred care. A previous clinical trial showed that CST led to significant benefits in both cognition and quality of life, as well as a trend towards an improvement in communication (Spector et al., 2003). The degree of cognitive benefit was comparable with cholinesterase inhibitor drugs and it was found to be cost effective (Knapp et al., 2006). CST is the only non-drug intervention recommended by government guidelines (National Institute for Health and Clinical Excellence [NICE], 2007) for the treatment of cognitive symptoms in dementia. Subsequent studies (Matsuda, 2007; Orrell, Spector, Thorgrimsen, & Woods, 2006) have also noted benefits.

Although the cognitive benefits of CST are well-established, the mechanisms of change remain unclear (Spector, Thorgrimsen, Woods, & Orrell, 2006). It is thought to provide an optimum learning environment, with the continuity and consistency between sessions supporting the formation of memories. Key principles include using implicit learning rather than explicit teaching and a focus on opinion rather than facts. These aim to build on the strengths of people with dementia, reducing the chance of failure and increasing confidence. Positive reinforcement of questioning, thinking and interacting may also lead to a more positive self-evaluation, increasing communication and the use of cognitive skills in daily life (Spector et al., 2003). A re-analysis of the data (Spector, Orrell, & Woods, 2010) found a significant improvement in the language subscale of the Alzheimer Disease Assessment Scale-Cognitive (Rosen, Mohs, & Davis, 1984), suggesting that CST might have stimulated language through generating opinions and creating new semantic links through categorisation.

The use of qualitative methods in supporting randomised controlled trial evaluation of complex interventions is recommended by the Medical Research Council (MRC, 2008) to aid the establishment of long-term and real-life effectiveness of interventions. Qualitative methods have been used to successfully evaluate support groups for dementia (Mason, Clare, & Pistrang, 2005; Morhardt & Menne, 2001) and for gaining an understanding of the experience of living with early-stage dementia (Steeman, De Casterle, Godderis, & Grypdonck, 2006). Mason et al. (2005) found that having a facilitated opportunity to talk with other people with dementia led to people feeling better understood by their peers, feeling more confident talking and attending more to discussions.

Although the self-reported improvements in quality of life suggest that wider changes may occur, the extent and nature of these changes are unknown. This study aims to investigate how the experiences of CST groups are expressed in the day-to-day life of a person with...
Method

Sample

A total of 38 participants were recruited through three existing CST groups run in London and the South-East. These included community-dwelling people with dementia participating in the group (17), their carers (14) and staff facilitating the groups (7). All the participants with dementia had Alzheimer’s, with the exception of one who had Lewy Body dementia. Their mean age was 82 years and mean baseline Mini Mental State score (MMSE, M.F. Folstein, S.E. Folstein, & McHugh, 1975) was 21, indicating mild dementia. Five were male and 12 were female. In the carer group, 11 were relatives, one was a friend, one a neighbour and one a paid carer. All three groups were run in day care settings, two were run by (National Health Service) NHS staff and one by a charitable organisation.

Inclusion criteria

Group members were deemed eligible for inclusion if they met the inclusion criteria as set out in the previous CST trial (Spector et al., 2003). These stipulated that they (a) met the DSM-IV criteria for dementia (American Psychiatric Association, 1994), (b) scored between 10 and 24 on the Mini Mental State Examination (MMSE), (c) had some ability to communicate and understand communication, (d) were able to see and hear well enough to participate in the group, (e) did not have a major physical illness or disability which compromised participation and (f) did not have a diagnosis of a learning disability. Carers were considered eligible for inclusion in the study if they had at least once weekly face-to-face contact with the person with dementia for whom they were named as carer. Group facilitators had received training in CST and/or were experienced at running similar groups.

Procedure

Ethical and research governance approval was received from the Leicestershire, Northamptonshire and Rutland Research Ethics Committee. Following British Psychological Society guidelines on obtaining consent, an information sheet was provided to all potential participants and consent was obtained in a subsequent CST session. This provided time for participants to discuss the study with their carers. The procedure included focus groups (lasting approximately 30 min) and individual interviews (lasting 15–60 min). Separate focus groups were run for people with dementia, their carers and staff. Focus groups and individual interviews were led by Clinical Governance, who is a Clinical Psychologist. The interview schedule included some open questions about the general impact of the group, and questions focusing on specific areas (memory, language, mood, communication, functional abilities and sociability). The same question sets were used for group participants, carers and facilitators, with the exception of small adjustments where appropriate. Within a week of the final session, individual semi-structured interviews were carried out with each group participant and carer. All participants took part in the focus groups as well as the individual interviews. All materials were either video recorded (focus groups) or audio recorded (individual interviews), and was then transcribed verbatim. All data were collected within 2 weeks of the final CST session.

Data analysis

All focus groups and individual interviews were analysed using Framework Analysis (Ritchie & Spencer, 1994), which aims to elicit an individual’s experience of an event through a number of distinct but interconnected stages of analysis. There are five key stages: (i) Familiarisation, (ii) Identifying a thematic framework, (iii) Indexing, (iv) Charting and (v) Mapping and Interpretation. In the first stage, the transcripts were read through thoroughly in order, for the researcher, to become familiar with the broad themes expressed. These were then compiled and refined leading to a coding key, which included broad themes and sub-themes. Each transcript was then categorised using the coding key, and codes were continually re-assessed and re-interpreted. A chart of themes and sub-themes was then developed and further modified until the dominant themes emerged. The focus group responses were divided up into each individual participant’s response and, for the purposes of analysis, were grouped in the same chart as their respective individual interviews. Comparisons were drawn between the themes identified from the participants, carers and group facilitator’s interviews.

Results

Across the three groups (people with dementia – P, carers – C and facilitators – F), two main themes and seven sub-themes were identified (Table A1 in Appendix). There was agreement across all three groups for six of the sub-themes. The seventh sub-theme was identified by participants and carers.

Theme 1: Positive experience of being in the group

Sub-theme: Positive feelings

There was a consensus amongst CST participants that being in the group was enjoyable and fun. This was supported by carers and facilitators’ observations.
Participants often reported that they looked forward to attending the group every week and were sorry that the group was ending. The majority felt that attending the group made them feel more positive, relaxed and confident, and that they wanted to continue with the group. Carers reported that participants remained confident for the remainder of the day on which the group was held.

‘Well first thing it was fun, because nobody, well it was serious but it was enjoyable, yes it was enjoyable... There was an awful lot of laughing.’ (P)

‘Its made me a bit more confident, you know at the beginning I was a bit hesitant to say much, well you just think well if I’ve got something to say then I’ll say.’ (P)

Sub-theme: Listening to others and feeling able to talk
Most participants said that the group provided an opportunity to hear each other’s views, which was interesting and provided an opportunity to broaden their outlook on life. This made them feel as if they had achieved something. Carers and facilitators also echoed this idea in their interviews.

‘I’ve had feedback about how much she’s been involved, what she’s given to the group and how much she’s talked and participated and chatted with other people and I just think that’s brilliant. It is short lived but just for that moment that hour and half or whatever its been superb you know, knowing that mums been interested enough to give her views and share her views and listen to other people.’ (C)

‘... it was just good to be able to go and discuss the things so you felt that at least you’d done something you know I wasn’t wasting my time.’ (P)

Some participants reflected on the contrast between the CST groups and feelings of loneliness and a passive state of mind when at home.

‘Well yes you get other peoples point of view. If you are by yourself at home all the time you haven’t got anyone to discuss anything with. Well its better than stagnating at home saying nothing to anyone all day isn’t it’. (P)

Sub-theme: Sharing a diagnosis
People felt supported in that they shared a common difficulty. For some this was defined as a dementia diagnosis and for others, ‘memory problems’.

‘Yes the trouble shared is a trouble halved as they say, yes, you think there’s other people out there and geographically not far away could be next door, So yeah I think it helped all of us to know that we’re on the same boat on the same road, yes that was a very good part of it.’ (P)

Sub-theme: Supportive/non-threatening
Most participants said that the CST groups were a non-threatening and supportive environment, which fostered a sense of togetherness and friendship. Participants were able to support each other and also felt supported by the group facilitators.

‘It was like that you could feel yourself becoming close to people, it’s a nice feeling. That’s what I feel anyway and you never felt threatened.’ (P)

‘Well the first enter everybody is smiling that is main thing. Cause if you see one face, is smiling everybody, no one short...’ (P)

Theme 2: Impact on everyday life
Benefits in everyday life were reported by 83% of the people with dementia and 79% of carers. The group facilitators’ reports of impact were limited to observed differences from session to session or feedback that they had received from carers. Three main sub-themes emerged.

Sub-theme: Finding it easier to talk
Participants reported that they enjoyed the conversational aspect of the CST groups and felt that they were able to talk more easily in the group environment. Also, a third of carers said that their relatives were showing improvements in their verbal skills outside the CST groups, more willingness to engage in conversation and more fluency in conversations.

‘She’s clearer on the telephone. Clearer I suppose in the way she holds the conversation it’s not that she speaks differently it’s just that the flow of the conversation is a little easier.’ (C)

Some carers stated that the person did not talk much about what happened within the sessions, which they described as frustrating.

‘He wasn’t always able to tell me, he perhaps couldn’t usually say exactly what they were doing but you know, just get an idea if someone’s been enjoying themselves and had a good time.’ (C)

Sub-theme: Improvement in memory
The group participants reported memory improvements and half reported either a specific improvement in retaining new information or a non-specific memory improvement. Most facilitators reported an improvement in the participants’ memory of the structure of the CST groups, activities from previous CST sessions and awareness of time. One in three carers noticed a more general memory improvement in the person with dementia.

‘Yes remembering the recent events have been a lot more simple and a lot more logical than it was, certainly.’ (P)

‘...she seems to be retaining more information. And she’s able, although its sometimes difficult for her to trawl and drag up the information, she seems to want to do it a bit more and she’ll store some information. Say for example my son has told her something, when
we had a weeks holiday and my son told her something, when she had a conversation with me the following week when I came home, she was able to remember what he’d said and exact dates, things that were happening things that they were doing in my daughter in laws family, that she hadn’t before. (C) ‘They seem to remember sometimes things that we were doing before, for example one of them remembered we were planting or doing some gardening the week before’. (F)

Sub-theme: Improvement in concentration and alertness

Most participants reported that they were concentrating more and noticed a subsequent improvement in memory. They also felt that the action of talking in the group facilitated remembering.

‘Well it always makes a change when you have to concentrate on something it’s more helpful for your memory. . . I think it makes you concentrate more in everything you’re doing really.’(P)

‘No, I think yeah there was improvement I mean with X it was very noticeable even within sessions that she wouldn’t be that focused and by the end she’d be concentrating more. Yeah I think with all of them actually there was quite an increase in concentration’. (F)

Most carers reported improvement in terms of the person with dementia’s concentration skills, as well as a change in their alertness and brightness. There was also a consensus that participants were engaging in more activities such as personal care, conversations and watching television.

‘Mum had been more engaged with the activities they offer there... She doesn’t particularly seem to seek other peoples company I mean she tolerates people but I know for a fact that she’s been enjoying bingo and they had a singer going round singing songs from the old days and apparently mum had a whale of a time’(C)

Facilitators were less clear about possible improvements in concentration. Some felt that it varied from session to session, while others did identify particular participants who demonstrated an improvement in their concentration.

Discussion

This study aimed to investigate how the experience of CST groups might be translated into the day-to-day life for people with dementia from the perspective of people with dementia, their carers and group facilitators. The results suggested that the CST groups benefited participants’ lives in a number of ways. People reported feeling more positive, relaxed and confident following groups, a feeling of not being alone through sharing common difficulties and finding it easier to talk – both within and outside of the group (illustrated by increased fluency in conversations). There were also reports of specific improvements in memory, for example retaining new information. However, often the experienced impact of the group was non-specific. The most commonly reported cognitive changes were an improvement in concentration and alertness, described by participants and carers as a sense of being more switched on or wanting to attend to things more. The results suggested that people with dementia have clear views about particular aspects which had a positive emotional impact and made the group feel supportive and non-threatening (e.g. not feeling judged and having the opportunity to talk). They indicated that people had more motivation to engage with each other because the interaction was on their terms and at their pace. A third of carers noticed some improvement in verbal skills outside the groups, providing some support to the finding that CST stimulates language function (Spector et al., 2010).

A study of dementia support groups (Mason et al., 2005) similarly found themes of feeling understood by peers, more confidence in talking, attending/concentrating more in discussions and being in an environment where all communication was accepted and facilitated. However, the cognitive and social benefits of CST were also reported in participant’s everyday lives. In dementia, cognitive impairment may be further undermined by the associated decrease in the individual’s confidence. CST, therefore, may improve morale by helping to combat loss of confidence in a person’s abilities to communicate and improving sense of competence and morale resulting in a more active attentive mind. CST may help to restore confidence by the provision of tasks and challenges in supportive non-threatening environment.

A recent bio-psychosocial model for change in dementia (Spector & Orrell, 2010) suggests that many factors may influence the level of performance in dementia and provides a theoretical framework for understanding the effects of CST and other interventions. For example, the group may be working against a ‘Malignant Social Psychology’ (Kitwood, 1997) and so improving person-centred care. Additionally, it may be tapping into cognitive skills which are present but under-rehearsed, supporting the ‘Use It or Lose It’ hypothesis (Swaab, 1991).

Limitations include the inherent difficulty of asking people with memory problems to remember, in some detail, the experiences of the CST group sessions. This may be why people usually reported the general benefits of attending rather than specific benefits of CST activities. The study, therefore, did not provide any indication of whether people thought that some activities were more beneficial than others. There was also considerable variation in the amount of contact between carers and group participants, which may have impacted on their knowledge about the extent to which any improvements generalised to everyday life. Future research could investigate the mechanisms of change in CST in more depth, for example using detailed neuropsychological tests examining different types of memory.
Conclusion
This study has investigated the experience of CST from multiple perspectives, highlighting the importance of exploring the impact of CST using a qualitative approach. Qualitative studies in dementia are inevitably hindered by cognitive difficulties. However, this study has shown that the views of people with dementia can add to creating a credible framework for understanding group processes in CST, to support quantitative findings (Spector et al., 2003, 2010) and help explain how CST is effective in improving cognition. This provides further evidence to support the use of CST in routine practice for people with mild to moderate dementia.

Acknowledgements
We acknowledge the invaluable contributions of all the research participants who took part in this study, without whose time and reflections this research would not have been possible. We thank the facilitators of the CST groups in the NHS and CHAT for facilitating access to the groups and participants. This study formed Charlotte Gardner’s doctoral thesis for the DClinPsy at University College London.

References

Appendix
Table A1. Themes identified across focus groups and individual interviews.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
</table>
| Positive experience of being in the group | Positive feelings  
Listening to others and feeling able to talk contrasted with passivity of home  
Sharing a diagnosis  
Supportive/non-threatening* |
| Changes experienced in everyday life | Finding talking easier  
Improvement in memory  
Improvement in concentration and alertness |

Note: *This sub-theme only applied to group participants and carers.