

An evaluation of cognitive stimulation therapy sessions for people with dementia and a concomitant support group for their carers.

Jan Bailey, Paul Kingston, Simon Alford and Louise Taylor Faculty of Health and Social Care, The University of Chester, UK.

Edward Tolhurst, Faculty of Health Science, Staffordshire University, UK.

Abstract

This research aimed to ascertain the impact of a pragmatic Cognitive Stimulation Therapy course of ten sessions on the cognitive function of people living with dementia and whether attending a concomitant carers support group was beneficial to carers.

A mixed method quasi-experimental approach was adopted, data was collected pre and post intervention. The quantitative arm utilised three validated questionnaires rated by the carers. Qualitative data was collected via semi-structured interviews with carers regarding their perceptions of the impact of Cognitive Stimulation Therapy and the carers support group

Quantitative data analysis found no statistically significant differences within or between groups. The qualitative data demonstrated that carers perceived Cognitive Stimulation Therapy had some benefits for the people living with dementia, especially social benefits. Carers also perceived that attending the carers support group was beneficial for them in terms of gaining a better understanding of dementia, developing coping skills and having peer support.

The study was limited in scale and further research with a larger sample, using direct measures of the impact of Cognitive Stimulation Therapy with people living with dementia and supplementary research exploring which characteristic of carers support groups are effective would be worthwhile.

Keywords

Dementia, Cognitive Stimulation Therapy, carers, support, burden

Introduction

In 2012 the World Health Organisation (WHO) estimated that there were 25.6 million people living with dementia (PWD), projecting an increase to over 70 million by 2030 (WHO 2012). Prince et al. (2013) suggest the number of PWD will double every ten years. Clearly, these projections have implications for health and social care provision, and the carers of PWD. Moreover, at the time of writing, the diseases that cause dementia remain incurable (The Alzheimer's Society 2015; Lawrence 2014); therefore it is crucial to explore how the quality of life (QOL) of PWD and their carers can be sustained or improved.

Cognitive Stimulation Therapy (CST) as described by Clare and Woods (2004) and Spector, Orrell and Woods (2015) usually takes the form of fourteen twice weekly group sessions involving reminiscence, discussion and activities designed to improve cognitive and social functioning of PWD and is recognised as an effective intervention for cognitive symptoms in people with mild to moderate dementia. Indeed, CST is the only non-pharmacological intervention recommended by the National Institute for Health and Care Excellence (NICE). Research evidence also supports the efficacy of CST. CST has been shown to be comparable to cholinesterase inhibitor drugs (Spector et al. 2003); evidence regarding the impact of CST in conjunction with pharmacological therapies is also encouraging. An evaluation of a six month programme of CST, delivered to people with Alzheimer's disease who were stabilized on donepezil for at least three months was undertaken by Onder et al. (2005). Compared with a control group receiving donepezil only, measured on the Mini-mental State Examination (MMSE) (Folstein, Folstein & McHugh 1975), the combined treatment group showed a statistically significant benefit. Research focussing on interventions delivering CST alone also support its utility for people with mild to moderate dementia; for example, Sizer, Twamley and Jeste (2006).

There is growing evidence that, in addition to facilitating cognition, CST may produce other outcomes. In addition to improved memory and alertness, social and emotional benefits have been evidenced in CST participants (Spector Gardner and Orrell 2011). A systematic review of fifteen studies (718 participants), suggests that CST enhances QOL, communication, and interpersonal interactions (Woods, Aguirre, Spector & Orrell 2012). A large, multi-centred, controlled trial showed a significant improvement in CST participants' language compared with controls (Spector, Orrell & Woods 2010).

CST and the carers of people living with dementia

Dementia can be overwhelming for the families of PWD; evidence suggests that caring for a PWD is sometimes more stressful than caring for physically frail older people (Pinquart & Sorensen 2003). Indeed, Schoenmakers, Buntinx, and Delepeleire's (2010) systematic review reports higher rates of depression amongst those caring for PWD. Carer breakdown is not only harmful to the individual but has wider structural effects, especially for health and social care provision. Research shows that when PWD co-reside with carers they are thirty times less likely to enter residential care (Banerjee et al. 2003). Carer well-being is, therefore, crucial to the individual, the PWD, and wider society.

Support for the carers of people living with dementia

Recognition of carer stress and breakdown, suggests it is sagacious to provide support for carers. It could be hypothesised that, should CST lead to improvement in cognitive function for the PWD, there may be a concomitant impact on their carer(s)' quality of life. Marriot, Donaldson, TARRIER and Burns (2000) report a randomised control trial exploring an intervention involving stress management, coping techniques and carer education for the carers of people with Alzheimer's Disease. Compared with controls, they found a reduction in distress and depression in the carers, as well as improvements in the behaviour of those people living with Alzheimer's.

However, the evidence regarding the efficacy of carer support is equivocal. In a review of forty studies evaluating carer interventions, Cooke, McNally Mulligan, Harrison and Newman (2001) found that social interventions, such as support groups and social activities, improved carer wellbeing in 60% of cases, with a smaller impact on carer burden, 54% of controlled studies with a cognitive component (cognitive problem solving, cognitive therapy, cognitive skills) improved carer wellbeing, and 50% showed reduced carer burden. Individual behaviour management technique training of six or more sessions effectively ameliorated carer depression (Selwood, Johnston, Katona, Lyketsos and Livingston 2007). Teaching coping strategies in groups was also effective; however group supportive sessions were ineffective in improving carers' psychological symptoms. In a review of forty-four interventions, Thompson et al. (2007) found limited evidence of the efficacy of psycho-educational group interventions on carers' depression.

Conversely, a review of 127 interventions with carers of PWD found an immediate effect on carer burden, depression, subjective wellbeing, ability/knowledge and perceived symptoms (Pinquart & Sorensen 2006). However, eleven months post-intervention the effect for subjective wellbeing and perceived dementia symptoms was lost; although longer interventions had more impact on depression. There was also evidence of gender differences; outcomes for depression were more significant for females. Pinquart and Sorensen propose, therefore, that individually tailored interventions will be more effective.

A key issue highlighted by research is that, due to differences in quality between interventions and the measures adopted in studies, additional evidence regarding the efficacy of carer interventions is needed (Woods, Aguirre, Spector & Orrell 2012).

The current study

This study was commissioned by a third sector organisation (TSO) and employed a quasi-experimental approach to evaluate a CST intervention for PWD, and a support group programme (CSG) for their carers. Both interventions consisted of ten, parallel two-hour sessions, delivered over a five-week period in separate rooms. Ten sessions were utilised rather than the typical fourteen sessions for pragmatic reasons, these were related to the cost of delivering sessions which was determined by the commissioners' of the service and difficulties with carers and PWD committing to attend fourteen sessions.

The CST involved reminiscence sessions, as examples, about fashion, childhood and music, discussions about current affairs, hobbies and places and activities such as handling money and budgeting.

The CSG sessions included education about dementia and how it affects behaviour and cognition, information on how to handle issues such as repeated questions, and opportunity for peer support and discussions. Additionally, each CSG session began with feedback on the previous week's CST session.

Unfortunately, staff delivering the CST sessions to PWD were unable to collect data, reporting that participants were unable to provide the necessary input. Thus, PWD did not participate in the research.

The aims of the study reported in this paper were to evaluate:

- the impact of the CST sessions on PWD, and
- the impact of a carers support group on their carers.

Methods

A mixed method approach was taken to evaluate both the CST and CSG sessions. Quantitative data were collected via the following questionnaires administered to the intervention and control group carers (quasi-experimental approach):

The quality of life – Alzheimer’s Disease, family member or care-giver (QOL-AD) (Logsdon, Gibbons, McCurry & Teri, 2002) was scored by carers thus providing a proxy assessment of the PWD’s QOL. Scores range from 13 to 52; low scores indicate poorer QOL. AOL-AD has been shown to be reliable with caregivers, as well as patients with values ranging from 0.83 to 0.90, whilst validity of patient and caregiver has been found to be more modest ($r = -0.41$ to -0.65) (Logsdon et al., 2002).

- The Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen & Griffin 1985) was completed by carers to rate their satisfaction with life. Scores range from 1 to 35; low scores indicate low satisfaction. Satisfaction with life scale has been reported to have a two month test- retest reliability of 0.82, whilst validity has been reported as $r = 0.68$ (Diener et al 1985).
- Burden Interview (BI) (Zarit, Reever & Back-Peterson 1980) was completed by carers to rate how burdened they felt. Scores range from 21 to 105; high scores indicate higher burden. The Burden Interview has been shown to be reliable and valid as a measure of response by care givers with scores of $r = 0.83$ and $r = 0.71$ respectively (Majerovitz, 1995; Zarit & Zarit 1990).

The aims were to identify whether there was any difference in scores on each measure pre and post the CSG and CST sessions that could be attributable to the interventions.

The qualitative arm of the research had two aims:

1. to explore carers’ perceptions of the outcomes of the CST,
2. to explore the opinions regarding the CSG sessions of those carers who attended (intervention group).

Data was collected via semi-structured interviews with carers.

The pre-intervention interview questions explored carers' experience of caring, how they felt CST could help the PWD and asked them to describe their "typical day". The post-intervention questions asked about the convenience and effectiveness of the CST and whether carers had noticed any changes in the PWD, how any changes had impacted on their relationship with the PWD as well as seeking feedback about the CSG sessions.

Quantitative and qualitative data were collected before CST and CSG sessions commenced and after the last scheduled session, at either participants' homes or session venues, both types of data were collected at the same time.

One CST group facilitator gave intervention group carers feedback regarding their relatives' participation in the sessions and their interaction with other PWDs.

Recruitment

Participants were recruited by the TSO and were a convenience sample of individuals, PWD and/or their carers who had approached them for support. All recruited PWD attended CST sessions. A control group of carers did not attend CSG sessions. Allocation to intervention or control group was not randomised instead this was prescribed by the geographic location of the CST sessions.

Ethical issues

Ethical approval was provided by the University of Chester, Faculty of Health and Social Care Ethics Committee. All carers gave written consent prior to participating in the research; to protect anonymity participants were assigned a numerical pseudonym

Data analysis

Quantitative data was analysed using SPSS statistical software (IBM 2012). A Wilcoxon signed rank test was used to assess repeated measure (pre and post). In order to assess change between the intervention and control groups, variables signed change scores (post-test minus baseline) were generated, and analysis of covariance was performed using a Mann-Whitney U test to determine change in scores of the intervention group compared with the control group. In addition, all questionnaire scores were aggregated to identify total change in score. In each instance the data were assessed for normal distribution and where applicable

(between groups) homogeneity of variance in order to conduct independent t-test (between groups) and paired t-test (repeated measures). If the appropriate assumptions were not met then the non-parametric equivalent of the test were undertaken. All statistical tests were conducted at a significance level of 0.05.

The qualitative interviews were recorded and transcribed for analysis, which was undertaken using thematic approach (Braun and Clarke 2006) to identify patterns and commonalities in the data.

Results

Twenty carers participated in the research, ten female and ten male (see table 1). Sixteen carers were spouses, four were children/children-in-law. No participants dropped out of the study.

Table 1 – Study Participants

	Intervention group carers N = 12	Control group carers N = 8
Gender	5 female 7 male	3 female 5 male

The results are presented in two parts; first the impact of CST and second the impact of the CSG.

Carers' perceptions of the impact of CST on the PWD

Quantitative data analysis

This section reports the scores from the QOL-AD (Logsdon et al 2002) for both intervention and control carer groups.

Table 2 QOL-AD score pre and post CST sessions for intervention and control group

	Intervention Group				Control Group			
	Pre (SD)	Post (SD)	Significance		Pre (SD)	Post (SD)	Significance	
Physical health	2.08(0.67)	2.08(0.52)	Z= 0.00	P= 1.00	2.29(0.76)	2.43(0.54)	Z= -0.58	P= 0.564
Energy	1.75(0.62)	2(0.60)	Z= -1.73	P= 0.08	2(0.58)	2(0.58)	Z= 0.00	P= 1.000
Mood	1.92(0.67)	2.58(0.52)	Z= -2.53	P= 0.01*	1.43(0.54)	1.86(0.38)	Z= -1.73	P= 0.083
Life situation	2.75(0.62)	2.75(0.97)	Z= 0.00	P= 1.00	3(0.58)	3(0.58)	Z= 0.00	P= 1.000
Memory	1.58(0.52)	1.67(0.65)	Z= -1.00	P= 0.32	1.29(0.5)	1.71(0.49)	Z= -1.73	P= 0.083
Family	2.92(0.52)	3(0.85)	Z= 0-.38	P= 0.71	2.71(1.11)	2.71(0.76)	Z= 0.00	P= 1.000
Marriage	2.67(0.78)	2.75(0.75)	Z= 0-.45	P= 0.66	3.14(0.69)	3(0.58)	Z= -1.00	P= 0.317
Friends	2.5(0.91)	2.67(0.89)	Z= 0-.58	P= 0.56	2.86(0.69)	2.29(0.49)	Z= -2.00	P= 0.046*
Self as a whole	2.17(0.84)	2.67(0.65)	Z=0-2.12	P= 0.03*	1.86(0.38)	2.29(0.76)	Z= -1.73	P= 0.083
Chores	2.08(0.67)	2.25(0.75)	Z= 0-.71	P= 0.48	2(1.16)	2(0.82)	Z= 0.00	P= 1.000
Fun	2.17(0.84)	2.25(0.62)	Z= -0.38	P= 0.71	1.43(0.54)	1.71(0.76)	Z= -1.00	P= 0.317
Money	2.33(0.78)	2.42(1)	Z= -0.33	P= 0.74	2(1)	1.71(0.76)	Z= -1.41	P= 0.157
Life as a whole	2.25(0.622)	2.25(0.75)	Z= 0.00	P= 1.00	2.43(0.79)	2.43(0.54)	Z= 0.00	P= 1.000
QOL-AD total	29.17(5.36)	31.42(5.76)	t = -2.58	P= 0.26	28.43(4.18)	29.14(3.39)	Z= - 0.73	P= 0.47

*P<0.05 = statistically significant

The intervention group showed statistically positive effects with an increase in the mean scores for two questions; ‘self as a whole’ (p= .034) with an increase of \bar{u} from 2.17 to 2.67 and ‘mood’ (p = .011) with an increase of \bar{u} from 1.92 to 2.58. The only statistically significant change within the control group was for ‘friends’ question (p = .046) with a reduction in the \bar{u} from 2.86 to 2.29 (see table 2).

There were no significant differences between the mean changes of the two groups (see Table 3).

Table 3 Changes in quality of life for intervention and control group

	Intervention Group	Control Group	Significance
	Mean change	Mean change	
Physical health	0 (0.43)	0.14 (0.69)	U= 36.500 P= 0.55
Energy	0.25 (0.45)	0 (0.82)	U= 34.500 P= 0.46
Mood	0.67 (0.65)	0.43 (0.54)	U= 34.000 P= 0.45
Life situation	0 (0.74)	0 (0.82)	U = 42.000 P= 1.00
Memory	0.08 (0.29)	0.43 (0.54)	U = 27.500 P= 0.08
Family	0.08 (0.79)	0 (1.16)	U = 37.500 P= 0.69
Marriage	0.08 (0.67)	-0.14 (0.38)	U = 34.000 P= 0.41
Friends	0.17 (1.03)	-0.57 (0.54)	U = 21.500 P= 0.07
Self as a whole	0.5 (0.67)	0.43 (0.54)	U = 41.000 P= 0.92
Chores	0.17 (0.84)	0 (1)	U = 39.000 P= 0.79
Fun	0.08 (0.79)	0.29 (0.76)	U = 33.500 P= 0.42
Money	0.08 (0.9)	-0.29 (0.49)	U = 28.000 P= 0.18
Life as a whole	0 (0.43)	0 (0.58)	U = 42.000 P= 1.00
QOL-AD total	2.25 (3.02)	0.71 (3.2)	t = 1.05 P= 0.310

There were no significant differences between the mean changes of the two groups.

Qualitative data analysis

This section reports the qualitative data regarding carers' perceptions of the impact of CST on the PWD. Quotes from the participants' interviews are used to support the veracity of the thematic analysis; carers who participated in the CSG are annotated 'intervention'; those who did not are annotated 'control'.

Course content.

Carers were asked whether their relative had enjoyed the CST sessions, all but one confirmed that they had:

'Well I know [name] enjoyed them very much. He liked the different type of things they were discussing and they seemed to enjoy it really, very much. We could hardly get them out of the room at the end of the session; they were all talking to each other you know?' (P1 intervention)

The CST session most prominent in carers' narratives focussed on music. One felt this session enabled their relative to reconnect with his past. Another highlighted that they only discovered their relative enjoyed singing due to this session; this improved family interactions:

'...when she used to come home, she was always bouncy and full of it, and that's when we found out that she liked music. So, if nothing else for the course, then knowing that she likes to sing-a-long to so many things has really changed things for us... sometimes we are singing along to things, which is nice because we never did that really'. (P1005 intervention)

Some carers indicated that tailoring session content to individuals' interests would be useful:

'...so if there'd been like a sports section, would that have been more of interest to you? (talking to PWD)... and most people in some point in their lives have had a pet haven't they?...perhaps that might have interested [name] more'. (P6 control)

One carer suggested that, where appropriate, sessions could be more challenging:

'But you thought maybe he could have been stretched a bit more?' (Interviewer)

'I think yes, and he thought... But actually I am so pleased with this group, I really am. I didn't expect to say that after the first week, because the first week [name] said it was a bit childish, but he has carried on and he has come and he enjoyed it...' (P1 control)

Cognitive benefits.

Carers' ratings of the efficacy of the CST sessions regarding their relatives' cognitive ability varied. Of those who felt able to rate this there were different perceptions. Nine perceived no improvement:

'So have there been any changes in [name] do you think?'(Interviewer)

'... no, I can't, you know I don't see any changes at all'. (P1001 intervention)

Whereas five said that they had seen an improvement during the sessions but that this had diminished:

‘Well there was, not last week, the week before, I felt we had sort of moved on a bit, and he was doing a bit better. But this last week, he seems to have slipped back again’. (P1004 intervention)

Only three said improvements had been sustained:

‘So have you noticed some changes in [name], since he started doing them (the CST sessions)?’ (Interviewer).

‘His mood, I would say has been the greatest change... even to the way he has related to family members now. We actually went out for a social event last weekend and we went to a restaurant and he hasn’t done that in probably three years...so that was a huge step forward...he has started to take a bit more interest in the home now and has done a bit of painting... he is actually taking an interest in things again, which again, that’s a huge improvement...and he is very upbeat, he’s communicating more, he’s socialising more’. (P4 intervention)

Social benefits.

Carers appreciated the opportunity the CST sessions provided for PWD to socialise and almost all said that they had seen improvements in their ability and desire to socialise with others. . One carer disclosed that, since their relative developed dementia, they had lost friends; consequently he had become introverted. However, the CST sessions enabled him to re-engage with people and make new social connections:

‘Have you engaged in many other activities prior to this course?’ (Interviewer)

‘None at all because he wouldn’t go out, he wouldn’t socialise... he had shut down and he had become more and more withdrawn...I think because of a lot of negativity we were getting from friends and family ... he was able to connect to each one of these people and communicate again, because I think when he had cut himself off, he had stopped communicating with everybody, it brought him out again and helped him

to start to communicate with people and talk about his life. And since then he has just been so positive.’ (P4 intervention)

Irrespective of other outcomes, socialising emerged as a key aspect of the sessions, with carers reporting that their relatives had made new friends:

‘...she [PWD] made friends there as well. I mean, I think she made one very good friend in one of the other ladies there and when they parted it was “we will have to try and see one another again”’. (P1006 intervention).

That all CST participants have dementia was viewed as creating a safe environment, thus PWD were not anxious about being judged:

‘...people who are suffering with the same memory losses, my mum doesn't feel so scared to make a fool of herself or things like that.’ (P7 control)

‘... in this group obviously they all felt at ease and he felt at ease because he knew everybody was in the same situation as him...I think that's helped [name] a lot really, I think that's probably why he enjoyed it so much, he wasn't made to feel, you know, silly?’ (P2 intervention)

There was also evidence of improved relationships between the carer and the PWD for both intervention and control groups:

‘...we are interacting now, more than me trying to reach him, and me make conversation and him talk to me. He is actually talking to me first... we chat and that...’ (P1 control).

Impact on the carers

Quantitative data analysis.

This section reports data collected from carers, illustrating differences within and between the intervention and control groups' scores on the SWLS (Diener et al 1985) and the BI (Zarit et al 1980) pre and post-intervention.

Satisfaction with Life. No statistically significant changes in either the intervention and control groups; were evident (see table 4).

Table 4 Satisfaction with Life Scale pre and post CST sessions for intervention and control group

	Intervention Group				Control Group			
	Pre (SD)	Post (SD)	Significance		Pre (SD)	Post (SD)	Significance	
In most ways my life is close to my ideal	2.92(1.88)	3.25(1.66)	Z= -0.79	P= 0.43	2.71(2.36)	3(1.83)	Z= -0.65	P= 0.52
The conditions of my life are excellent	3.08(2.02)	3.17(1.64)	Z= -0.64	P= 0.79	3(2.236)	3.29(1.89)	Z= -0.32	P= 0.75
I am satisfied with my life	3.33(1.78)	3.92(2.02)	Z= -1.61	P= 0.11	3.71(1.89)	4.43(1.27)	Z= -1.09	P= 0.28
So far I have gotten the important things I want in life	4.58(1.78)	4.5(1.73)	Z= -0.21	P= 0.84	5.29(1.113)	4.71(1.78)	Z= -1.00	P= 0.32
If I could live my life over, I would change almost nothing	3.83(1.9)	3.83(2.17)	Z= 0.00	P= 1.00	5.43(1.272)	5.14(1.57)	Z= -0.54	P= 0.59
Total satisfaction with life score	17.75(7.98)	18.75(7.88)	t = -1.01	P= 0.34**	20.14(8.275)	19.86(7.38)	t = 0.16	P= 0.88

Table 5 compares the mean change between the pre and post scores between the intervention and control group.

Table 5 Change in Satisfaction with Life Scale post-CST for intervention and control group

	Intervention Group	Control Group	Significance	
	Mean change (SD)	Mean change (SD)		
In most ways my life is close to my ideal	0.33(1.37)	0.29(1.38)	U= 26.500	P= 0.17
The conditions of my life are excellent	0.08(1.08)	0.29(1.70)	U= 34.000	P= 0.45
I am satisfied with my life	0.58(1.17)	0.71(1.60)	U= 32.000	P= 0.33
So far I have gotten the important things I want in life	-0.08(1.78)	-0.57(1.4)	U= 20.500	P= 0.05
If I could live my life over, I would change almost nothing	0(0.95)	-0.29(2.06)	U= 39.500	P= 0.82
Total satisfaction with life score	1(3.44)	-0.29(4.86)	t= 0.68	P= 0.51

No statistically significant differences were observed between the two groups.

Burden Interview.

Carers completed the BI questionnaire (Zarit et al 1980) to detect any changes in their perception of burden from caring for PWD (see table 6).

There were no statistically significant changes within either intervention or control group; although, BI scores increased for both groups. Table 7 compares the pre and post scores between the intervention and control group.

Table 6 Mean Burden Interview questionnaire score pre and post CST for control and intervention group

Question Number	Intervention Group			Control Group			Significance	Significance
	Pre (SD)	Post (SD)	Significance	Pre (SD)	Post (SD)	Significance		
Q1	3.5(1.17)	3.33(1.07)	Z= -0.63 P= 0.53	3.14(1.22)	3.57(0.79)	Z= -1.34 P= 0.18		
Q2	2.83(1.59)	3.17(1.34)	Z= -0.85 P= 0.40	2.86(1.35)	2.57(0.79)	Z= -0.45 P= 0.66		
Q3	2.83(1.47)	2.92(1.17)	Z= -0.37 P= 0.71	2.71(1.11)	2.43(0.54)	Z= -0.82 P= 0.41		
Q4	4.33(1.23)	4.08(0.9)	Z= -1.34 P= 0.18	3.57(0.98)	4.14(1.07)	Z= -1.41 P= 0.16		
Q5	3.08(0.9)	3.5(0.91)	Z= -1.67 P= 0.10	3(1)	3.29(0.95)	Z= -1.00 P= 0.32		
Q6	3.92(1.24)	4.17(0.94)	Z= -1.09 P= 0.28	4(0.82)	4.71(0.76)	Z= -1.89 P= 0.06		
Q7	2.58(1.08)	2.83(1.12)	Z= -1.00 P= 0.32	1.86(0.9)	2.29(0.95)	Z= -1.34 P= 0.18		
Q8	1.83(0.72)	2(1.13)	Z= -0.71 P= 0.48	2.14(1.225)	2(0.82)	Z= -0.58 P= 0.56		
Q9	3.5(1.24)	3.5(1.17)	Z= 0.00 P= 1.00	3.29(1.38)	3.14(0.69)	Z= -0.38 P= 0.71		
Q10	3.42(1.2)	3.5(1.31)	Z= -0.38 P= 0.71	3.71(0.76)	4.14(0.9)	Z= -1.13 P= 0.26		
Q11	3.33(1.37)	3.33(1.43)	Z= 0.00 P= 1.00	3.57(1.27)	3.43(0.54)	Z= -0.33 P= 0.74		
Q12	2.67(1.5)	2.92(1.24)	Z= -1.13 P= 0.26	3.29(1.5)	3(1)	Z= -0.54 P= 0.59		
Q13	4.17(1.40)	4.33(0.89)	Z= -0.41 P= 0.68	4.14(1.22)	4.43(0.79)	Z= -0.82 P= 0.41		
Q14	2.83(1.85)	3(1.48)	Z= -0.51 P= 0.61	3.43(1.27)	2.71(1.11)	Z= -0.17 P= 0.10		
Q15	3.92(1.17)	4(1.41)	Z= -0.26 P= 0.79	4.14(0.69)	4.29(0.95)	Z= -0.45 P= 0.66		
Q16	3.67(1.07)	3.83(0.72)	Z= -1.00 P= 0.32	3.57(1.27)	3.71(0.76)	Z= -0.38 P= 0.71		
Q17	3.58(1.31)	3.83(1.03)	Z= -1.34 P= 0.18	4.43(0.97)	4.29(0.95)	Z= -1.00 P= 0.32		
Q18	3.25(1.29)	3.33(1.16)	Z= -0.58 P= 0.56	3(0.58)	3.14(0.69)	Z= -0.45 P= 0.66		
Q19	3.25(1.22)	3.33(1.23)	Z= -0.45 P= 0.66	2.57(0.79)	3.29(1.11)	Z= -1.89 P= 0.06		
Q20	3.25(1.06)	3.17(1.12)	Z= -0.29 P= 0.77	2.71(0.95)	3.14(0.9)	Z= -1.34 P= 0.18		
Q21	3.33(1.23)	3.33(1.16)	Z= 0.00 P= 1.00	2.71(1.25)	2.57(1.4)	Z= -0.45 P= 0.66		
Burden Interview total	69.25(19.73)	71.33(18.39)	t= -0.93 P= 0.38	68(12.29)	69.43(9.85)	t= -0.59 P= 0.58		

Table 7 Mean change in burden interview questionnaire score post-intervention

	Intervention Group	Control Group	Significance
	Mean change (SD)	Mean change (SD)	
Q1	-0.17(0.94)	0.43(0.79)	U= 26.500 P= 0.17
Q2	0.33(1.30)	-0.29(1.25)	U= 34.000 P= 0.45
Q3	0.08(1.18)	-0.29(0.95)	U= 32.000 P= 0.33
Q4	-0.25(0.62)	0.57(0.9)	U= 20.500 P= 0.05
Q5	0.42(0.79)	0.29(0.76)	U= 39.500 P= 0.82
Q6	0.25(0.87)	0.71(0.76)	U= 26.500 P= 0.13
Q7	0.25(0.87)	0.43(0.79)	U= 37.500 P= 0.68
Q8	0.17(0.84)	-0.14(0.69)	U= 34.000 P= 0.45
Q9	0(0.60)	-0.14(1.07)	U= 41.000 P= 0.93
Q10	0.08(0.79)	0.43(0.98)	U= 32.500 P= 0.37
Q11	0(0.43)	-0.14(1.22)	U= 41.500 P= 0.97
Q12	0.25(0.75)	-0.29(1.5)	U= 31.000 P= 0.32
Q13	0.17(1.19)	0.29(0.95)	U= 39.500 P= 0.81
Q14	0.17(1.12)	-0.71(0.95)	U= 22.500 P= 0.10
Q15	0.08(1.08)	0.14(0.9)	U= 40.500 P= 0.89
Q16	0.17(0.58)	0.14(1.07)	U= 38.500 P= 0.74
Q17	0.25(0.63)	-0.14(0.38)	U= 27.500 P= 0.14
Q18	0.08(0.52)	0.14(0.9)	U= 40.000 P= 0.83
Q19	0.08(0.67)	0.71(0.76)	U= 24.000 P= 0.09
Q20	-0.08(1.24)	0.43(0.79)	U= 31.000 P= 0.33
Q21	0(0.74)	-0.14(0.9)	U= 37.500 P= 0.69
Burden Interview total	2.08(7.81)	1.43(6.4)	t= 0.19 P= 0.85

No statistically significant differences were observed between the intervention and control groups.

Qualitative data analysis – carers who attended CSG

This section reports the qualitative data collected from intervention group carers. All found the CSG beneficial; citing increased understanding of the behavioural symptoms of dementia, how these change as dementia progresses, learning coping strategies and feeling able to express their feelings. Another major benefit highlighted by 75% of participants was realising they were not alone and their experience and emotions were shared by others in the group. These outcomes fall into two themes practical, benefits and emotional benefits.

Practical benefits.

Carers spoke about learning strategies for dealing with their relative's behaviour and their own responses; formally from CSG sessions:

‘Well she [facilitator] gave you little hints as to how to handle situations, you know to sort of answer things when you get all these repeat questions and whatnot. You got advice on that and there was also advice on things like, where you can have a Power of Attorney...’ (P1004 intervention)

and informally through interacting with other carers:

‘I think mainly, picking up tips from other people, ways they have dealt with things.... and just swapping tips, like having a white board and a calendar and things that you wouldn't think of yourself’. (P1003 intervention)

Feedback from the CST sessions regarding their relatives was also valued:

‘...we get feedback in our group, on how our partners have been getting on in their group. It's nice to know someone else's view when you are not in the room, how they act when you are not there. So the feedback is quite interesting’. (P1003 intervention)

Some carers were surprised by the feedback they received:

‘...It was astonishing...The fact that she was really lively and chatty and that she sang along to everything, it was like another person, and that was really interesting. So yes, you will see a side of your caree that you may not be expecting. It was nice’. (P1005 intervention)

Formal and informal learning helped carers cope better with changes in their relative with all saying they had a better understanding of dementia:

‘... and the emotional understanding of not only where [name] was at, which was extremely important...And there is a lot of anger and resentment to them, why are they behaving this way? Why are they treating me this way? What have I done that I

deserve this? Then when you are on that course and you actually hear everybody else relating similar stories, what their partners have done and you realise that they don't have control anything like what you have assumed they have got'.(P4 intervention)

'So you don't take it so personally?'(Interviewer)

'I think since the course there's probably only been two incidents that I have taken personally, that before they would have been an everyday occurrence and that has been a big change for me, I feel much more at peace, much more at ease with the situation'. (P4 intervention)

Emotional benefits.

Carers' accounts were emotionally charged. Some were dealing with a psychological loss of their spouse or parent and a consequent change to their own identity as a spouse or child. This was especially difficult for couples where previously each had adopted a traditional gendered role:

'...when it's your husband, it's very difficult because if he's always been the one to make the decisions, you know the man of the house and suddenly that's gone. There's also that massive loss you're trying to deal with all the time and learn to be the one who's the decision maker but do that in a way that doesn't undermine him... I've now started to get to a point where I actually think I've got to make these decisions myself, so that makes it very difficult being a carer of your husband. I think being a carer if it was like for my grandson I see that in a very positive way, because I know him so well and it because it's that sort of parent child relationship anyway, but doing it for my husband, I think I'm still trying to learn, sort of that transition period of becoming a carer and not a wife'. (P4 intervention)

The carers group ran in parallel with the CST sessions, this allowed carers to be 'off duty':

'I quite enjoyed it to be honest, the separation...I could just relax. I feel as if, when we go to other groups and we go as a couple, you're still part his carer', you're not separated from that. You're still looking to see, 'is he alright? Is he doing this? Is he doing that?' ` You're not relaxed. So if you're separated then you know somebody's being taken care of in the other room, that's good you can relax'. (P1 intervention)

Having discrete sessions also provided opportunity for catharsis; carers were able to express their feelings openly without fear of distressing their relatives:

‘What I liked about it was, they were in a separate room and we were in a separate room, so we could say what we thought without feeling that you had to pull back because your partner was in the same room as you, so you could say what you felt.’
(P1 intervention)

‘I really enjoyed it because it's the first time that I've ever been able to sit and talk in a group without [name]’. (P2 intervention)

The shared experience of caring for a relative with dementia and the resulting empathy emerged as crucial factors facilitating carers feeling comfortable and confident that they were not being judged:

‘What was good about that (talking to other carers)?’ (Interviewer)

‘Because you could say things, that you couldn't say to your friends, really like 'oh you know I can't bear it any longer, I am going to scream sort of thing'. You know? '[name], is driving me mad', or something like that, and that's fine’. (P1005 intervention)

This empathy also assuaged carers' guilt, as the realisation that others shared similar emotions, normalised and legitimised their feelings:

‘... also knowing that other people are in the same boat as you and you are not the only one struggling sometimes, tearing your hair out... it is something a few people have said to me, “I am not the only one now, I know that now”... because you think it's just you, you're just a terrible, impatient person, but if you know other people are slightly impatient as well it helps’. (P1003 intervention)

‘Having somebody to talk to that knows what it's about, not having to feel guilty, or what's the word? Disloyal.’ (P1005 intervention)

Discussion

This study adopted a mixed methods approach to the exploration of the impact of CST and CSG, utilising validated psychometric tools for the collection of quantitative data and in-depth one to one interviews to obtain qualitative data.

In summary, there were no statistically significant differences between the mean ratings of the intervention and control groups for the QOL-AD (proxy measure of quality of life of the PWD) (Logsdon et al 2002), the SWLS (carers' satisfaction with life) (Diener et al. 1985) or the BI (how burdened the carer feels) (Zarit et al. 1980) pre and post intervention. Some within group differences were evidenced between pre and post ratings for the QOL-AD. The authors acknowledge that some changes were not statistically significant, nevertheless we argue that these should not be ignored and it is useful to consider them in context. There was a statistical difference (improvement) in intervention group's scores for "self as a whole" and "mood" and a reduction for "friends" rated by the control group. Analysis of the qualitative interviews shows that while carers believed the PWD had enjoyed the CST sessions and they had benefitted from socialising with other PWD, only three felt there was any sustained cognitive improvement. The carers who attended CSG sessions found them valuable.

While the QOL-AD did not detect any statistically significant differences between the ratings of the intervention and control groups of carers, the intervention group ratings showed carers perceived a greater improvement in their relatives' QOL and mood. This improvement in mood contrasts with Woods et al (2012) who found no evidence of improved mood as a result of CST. Furthermore, it is interesting that, while the PWD for both groups participated in CST, the carers who participated in CSG reported a greater improvement in the PWD's mood. It can be hypothesised, that the support group may have had a placebo effect on those carers' perceptions of their relatives' QOL. However, information provided post data collection revealed that the content of the CST sessions delivered at the intervention and control sites differed. The differences were small, for example one group had sessions on fashion, food, famous faces, while the other group did not, having sessions on places, hobbies and interests instead. Nonetheless, it must be considered that this may have induced different outcomes for the PWDs and subsequently affected carers' ratings of their QOL. Moreover, intervention group carers were surprised at the positive feedback from the CST session facilitator regarding their relatives' behaviour and interaction with others during the sessions.

It can be hypothesised that this led to them re-assessing their perception of the PWD's cognitive ability, which affected their rating of their QOL.

Carers' narratives regarding the impact of CST on the PWDs' cognitive functioning showed that the majority felt there were no sustained cognitive benefits from CST. This is consistent with the failure of the QOL-AD to detect any statistically significant changes in PWDs' memory or money skills. The previous evidence regarding the efficacy of CST was based on a course of fourteen sessions. An important consideration therefore is that the CST evaluated in this study did not adhere to the usual fourteen sessions with only ten being delivered. It should be considered that fewer sessions may have impacted on the efficacy of the course of CST. Alternatively, the lack of impact on PWD's cognitive skills may reflect an actual cognitive decline in the PWD.

Regarding the efficacy of the CSG sessions, the analysis of carers' narratives clearly demonstrates that attendees found them valuable. Nevertheless, the SWLS (Diener 1985) showed no statistically significant changes, however it would be erroneous to assume that there were not changes in score pre and post intervention. There was a small improvement in the overall SWLS score for the intervention group with a decrease in the control group score. This was not statistically significant so should be viewed cautiously, however placing it in the context of the interview data suggests that CSG may be influential in carer well-being. This is consistent with Cook et al (2001) who reported a social intervention promoted carer wellbeing and with Pinquart and Sorensen (2006) who found an improvement in both carer wellbeing and their perception of symptoms in the PWD.

However, Cook et al (2001) and Pinquart and Sorensen (2006) also reported reduced carer burden whereas in this study, even though some carers, perceived improved QOL for the PWD and showed improved ratings for their own satisfaction with life, there was a small increase in burden scores for both intervention and control groups. Although this increase was not statistically significant, it is interesting that there was a greater increase in the mean burden scores for the intervention group; there may be several explanations for this. It can be hypothesised that attending a group with other carers may have resulted in a more realistic world view of the issues faced by PWD and their carers. Alternatively, it may simply reflect actual cognitive decline in the PWD over the period of the study.

Small non-significant improvements in personal relationships were reported by the intervention group but not by the control group; again, it can be hypothesised that the CSG sessions were influential in this. The CSG sessions offered explanations for the behaviour of PWD, which facilitated carers viewing behaviour more objectively; this depersonalisation of difficult behaviour may have improved carers' perceptions of their relationship. To enable carers to deal more effectively with behaviour, coping mechanisms were also discussed during the CSG sessions. The concomitant improvement in the perception of interpersonal relationship and SWLS evidenced on this study is consistent with Selwood et al (2007) and Thompson et al (2007) who highlighted the benefits to carers of psycho-education, including teaching coping strategies.

Although previous evidence regarding social support groups for carers of PWD is equivocal - Selwood et al (2007) reporting no benefit, whereas Cook et al (2001) report benefits - this study found strong evidence from carers' narratives that they felt it was beneficial. Becoming a carer had affected some participants' personal identity with evidence that they viewed caring in terms of adopting a parental role, consequently losing their personal identity as a spouse or child. The impact of a loss of identity and social role, linked with an enforced adoption of a new unwanted identity (carer), cannot be underestimated and participants' narratives contained examples of loss, grief, resentment, and associated guilt. A valuable facet of the CSG was that the support sessions gave carers the opportunity to 'be themselves', to re-engage with their 'pre-carer identity' and interact with others as a person in their own right. The empathy group members experienced was crucial in this process, suggesting that specific groups for dementia carers would be more beneficial than a generic support group.

Limitations

An important issue is that, although the research was designed to include the input of PWD who participated in CST, the necessary data was not collected therefore information regarding the impact of CST was only available in the form of carers' perceptions, i.e. the QOL-AD and interview data. It must be considered that proxy ratings may be inaccurate, indeed there is evidence that PWD rate their QOL differently than do their carers (Moyle et al 2011). While the proxy data does have utility, the research outcomes would be stronger had it been possible to obtain data from PWD and compare between the two groups.

The study was designed to have discrete intervention and control groups, however in practise this did not occur; this is the challenge of 'real life research'. The carers who did not attend the CSG did not simply drop off their relative and leave; conversely, they congregated in a side room during the CST sessions, socialising and chatting. This confounding variable may have affected the difference between intervention and control group outcomes, i.e. reduced any difference. Indeed, it can be hypothesised that, had there been a discrete control group, a statistically significant difference between the two groups may have been observed.

The number of participants in the research was small, where this is acceptable in purely qualitative studies; it has implications for the quantitative aspect of the study. Analysis of the study data was limited to some degree by the small sample size in both the intervention (n=12) and control groups (n=7), which lacked power to detect statistical differences. Thus the failure to detect any significant difference between the groups may be due to the sample size, rather than actually indicating there was no impact of either the CST or the CSG. However, this small study has identified areas of interest worthy of further investigation to establish if the results would be statistically significant within a larger scale study, which may facilitate generalisability to a wider population

Conclusion and recommendations

While the statistical outcomes need to be treated cautiously, the findings from this research into the CST and CSG sessions are encouraging; they suggest that participating in the CST was beneficial to the PWD and the CSG sessions led to improved carer wellbeing.

Deconstructing which aspects of the CSG sessions were most effective requires further research. Adopting a more structured approach to delivery, such as incorporating education about the impact of dementia on behaviour, coping and practical skills training, as well as social support, then obtaining feedback on each session may yield useful information. The impact of CSG on the carers also requires further investigation utilising a discrete control group. Additionally, due to the need to avoid carers travelling to different locations, allocation to intervention and control groups was not randomised, it is possible that this introduced bias. Future research should, if possible, include random allocation of carers to intervention and control groups

Repeating the study, using measurement tools with the PWD, such as the MMSE (Folstein et al. 1975), to assess their level of impairment before and after CST, is required. Consideration should also be given to whether instruments selected to measure changes in carer wellbeing were the most appropriate. Additionally, it is essential that the same CST sessions are delivered to all participants.

Such future research should be undertaken with larger samples - powered for statistical accuracy - of both PWD and carers.

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