A randomized, controlled study of an Alzheimer's caregiver skills training program

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Abstract

This study was an attempt to improve the quality of the relationship between dementia caregivers and their loved ones by decreasing the gap between caregivers' expectations and patients' actual functional abilities and by teaching supportive skills. Although a group of 49 caregiver-patient dyads were recruited, the outcome measures of only those dyads (47) that completed the week seven session were used for analysis. Half of the dyads were randomized to an intervention group and the other half to a waiting list. The intervention group (N = 24) completed a four-session caregiver training program in which caregivers first watched investigators administering to their loved ones the Texas Functional Living Scale and later progressed to helping their loved ones by appropriate cueing to perform the tasks involved. Comparisons were made between baseline scores, scores at seven weeks, and scores at the end of 17 weeks on the congruence between caregiver estimates and patients' actual performance on the Independent Living Scale and measures of cognition, function, preillness quality of relationship, caregiver mood, feeling of self-efficacy, and several other measures.

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We were not able to increase the congruence between caregiver estimates and patients' actual performance and found no change in any other measure. We did find the expected relationship between depression and caregiver sense of self-efficacy.

Key words: Alzheimer's disease, caregiver training, relationships, expectations, patient performance

Introduction

Efforts to assist caregivers of persons with Alzheimer's disease (AD) have included nonspecific support groups, counseling, skills training, and combinations of these approaches. Although anecdotal reports suggest participant satisfaction, empirical studies have shown equivocal or modest benefits on caregiver burden, psychological well-being, mood, and caregiver coping abilities.[1] A partial explanation for the relative ineffectiveness of these interventions may be discrepancies between the extent of patients' functional impairment and caregivers' awareness and expectations.[2] Discrepancy between caregiver ratings and direct measurement of activities of daily living (ADL) skills in AD patients is well documented.[3] Thus, techniques learned in general education seminars or individual counseling for caregivers may be misapplied, to the frustration of patient and caregiver alike. It is also assumed that by having been taught supportive techniques, caregivers are able to apply them effectively. They are not taught, for example, to take advantage of patients' procedural memory, which is typically more intact and available for enhancing function in learned tasks.[4,5] Although rehabilitation strategies focus on helping individuals compensate for impairment by focusing on preserved abilities and accommodating tasks to ability, family caregivers are not trained to view tasks in such

a manner. Teaching caregivers how to break tasks into smaller steps and to offer cues to assist patients with tasks could benefit patients as well as their caregivers.

Because skills-training approaches appear the most robust among caregiver-focused interventions, we developed an interactive program to help caregivers objectify AD patients' functional abilities and to instruct them by demonstration and practice with their loved ones on cueing in areas of deficit. We then planned to measure changes in the congruence of caregiver-rated and performance-based measures of instrumental ADL (IADL) skills. We hypothesized that our intervention, by helping caregivers develop a more realistic view of patients' function, would increase their sense of competence and lessen their depressive symptoms.

Methods

We used the caregiver and patient versions of the Independent Living Scale (ILS)[6] as our measure of congruence between caregiver expectation and objective patient performance. Our educational tool was the Texas Functional Living Scale (TFLS).[7]

We recruited 49 caregiver-patient dyads from the community and from retirement and assisted living facilities. Of the 49 caregiver-patient dyads recruited, we enrolled 47. Subjects had been diagnosed with various dementing illnesses (primarily AD) according to established clinical criteria. Participants were community dwelling, mildly to moderately cognitively impaired, and had a consistent caregiver. Participants maintained on psychotropic medications and/or cognitive enhancers had been on stable doses for at least one month before enrollment.

Instruments/materials

Mini-Mental Status Examination

The Mini-Mental Status Examination (MMSE) is a widely used measure of global cognitive abilities whose psychometric properties have been well documented.[8] Scores range from 0 to 30.

Independent Living Scale

The ILS[6] is a well-known 70-item measure that assesses IADLs in five domains: memory/orientation, money management, management of home and transportation, health and safety, and social adjustment. We constructed a parallel informant version (ILS/I) that required caregivers/proxies to rate a patient's ability to complete each ILS task with and without various cues and prompts. Scores range from 0 to 140.

Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory-MCI version

The 24-item Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory-MCI version (ADCS-MCI)[9] is an informant-rated measure of IADL skills (e.g., ability to use the telephone, handle money) and basic ADL skills (e.g., feeding). Reliability and validity are excellent. Scores range from 0 to 69.

Texas Functional Living Scale

The TFLS[7] is a performance-based measure of IADL skills (e.g., telling time, making change, using the telephone) developed for use with demented patients. Good reliability and validity have been shown in AD. Scores range from 0 to 52.

Neuropsychiatric Inventory

The Neuropsychiatric Inventory (NPI)[10] is a widely used brief caregiver-rated measure of behavioral disturbance in 10 domains including delusions, hallucinations, dysphoria, agitation, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep, and appetite disturbances. Respondents are asked to rate the frequency, severity, and degree of caregiver distress for each behavioral domain. Scores range from 1 to 114.

Finding Meaning through Caregiving Scale

The Finding Meaning through Caregiving Scale (FMTCS)[11] is a 43-item measure that assesses caregivers' sense of Loss/Powerlessness (LP), Provisional Meaning (PM) (ability to find positive meaning through caregiving), and Ultimate Meaning (UM). Good reliability and validity have been demonstrated. We used the LP and PM subscales.

General Self-Efficacy Scale

The General Self-Efficacy Scale (GSE)[12] is a 10-question self-administered scale, which assesses subjective coping ability. Scores range from 10 to 40.

Relationship Attribution Measure

The Relationship Attribution Measure (RAM)[13] measures with eight items the types of attributions that caregivers make for the spouses' negative behaviors. Scores range from 48 to 288.

Geriatric Depression Scale

The Geriatric Depression Scale (GDS, self-administered version)[14] is a frequently used 15-item version of the 30-item GDS[15] that quantifies depressive symptoms in elders. Scores range from 0 to 15.

We hypothesized that there would be no change in patients' cognitive function or function in daily life as reflected by the MMSE, ILS, or ADL scores, but that caregivers would feel more empowered (FMTCS LP scale), feel better able to cope (GSE), and would be less depressed (GDS).

Procedures

Using forms approved by the University of Texas Southwestern Institutional Review Board, informed consent was obtained from patients and caregivers. Participants were randomly assigned to the intervention group (IG) or control group (CG). At baseline, patients were administered the MMSE and ILS. Caregivers were administered the caregiver version of the ILS and TFLS, NPI, and the ADCS-ADL scales. Caregivers also completed the GDS, GSE, and the FMTCS.

Interventions were initiated one week after baseline and were individualized based on the functional level of the patient and the coping level of their caregiver. There were four weekly skills-training sessions conducted by the second author; caregivers progressed from observer to active participant. In Session 1, the TFLS was administered to the patient while observed by the caregiver. In Session 2, the TFLS was readministered with the addition of breaking tasks into smaller steps, as well as other visual, auditory, tactile, or multimodal cues and prompts to facilitate improved performance. Caregivers were told that the goal was for patients to complete as many of the IADL tasks as independently as possible, but that assistance should be rendered when patients seemed unable to proceed on their own. In Session 3, the caregiver administered the TFLS, using facilitative prompts and cues as appropriate. The study coordinator offered suggestions and input as needed to assist caregivers in cueing specific tasks. Session 4 integrated the experience of the previous three sessions. Individualized suggestions to enhance communication and specific strategies to facilitate cueing on ADL were reviewed. Practical advice regarding home safety and information about community resources, companion service agencies, and other home health services was offered. CG participants and their caregivers were placed on a waiting list for the IG and provided information about community services and resources.

At week seven, all baseline measures were readministered to CG and IG patients and caregivers. Ten weeks later (week 17), repeated evaluation was conducted.

Statistical analyses

Descriptive statistics were reported as means and standard deviations for normally distributed, continuous data and proportions for categorical/dichotomous data. Independent sample t-tests were conducted to examine baseline measures between the CG and IG.

Mixed-model analyses of variance (ANOVAs) with one between-subjects factor (CG versus IG) and one within-subjects factor (repeated measures) were used to assess the effect of the intervention program on caregivers' sense of confidence, quality of life, and level of depression. A second series of mixed-model ANOVAs was conducted to assess the impact of the intervention on patient's IADL skills, quality of life, and behavioral status. Finally, for the primary analysis, a repeated-measures ANOVA with one between-subjects factor (CG versus IG) was conducted on IADL congruence scores—the difference between caregiver ratings of IADL skills and patients' performance score (ILS/I total score versus ILS total score)—to assess the stability of caregivers' perception of patients' functional capabilities. If any measure was found to have significant group differences at baseline, a mixed-model analysis of covariance (ANCOVA) was conducted with the baseline measure as the covariate. The intention to treat principle (last measure carried forward after the first week) was used if scores at 17 weeks were missing. Additional analyses were performed with no substitution of missing values and results were found to be similar. SPSS version 12.0 (SPSS Inc., Chicago, IL) and SAS version 9.1 (SAS Institute, Inc., Cary, NC) were used to perform all analyses. Statistical significance was set at $p < 0.05$.

For sample size, we estimated that 40 participants (20 per group) would be needed to detect an 0.35 effect size for the mixed-model ANOVAs, with a Type I error rate of 5 percent and a Type II error rate of 24 percent for the repeated and between-subjects factors. Although this level of power is less than optimal, it was thought to be adequate for a pilot study.

Results

Of the 49 dyads enrolled in the study, 47 completed week seven and 45 completed week 17. All 24 dyads in the IG completed the four education sessions; one dyad did not complete week seven testing, and one dyad did not complete week 17 testing. The analyses presented in this paper are for the 47 dyads that completed week seven.

Participants were mostly white, and caregivers were

Table 1. Demographic characteristics of control and intervention groups

	CG		IG		Total group	
	n	**Percent**	**n**	**Percent**	**n**	**Percent**
Race of care recipient						
White	20	87.0	23	95.8	43	91.5
Hispanic	1	4.3	0	0.0	1	2.1
African American	2	8.7	1	4.2	3	6.4
Gender						
Care recipient F	11	50.0	6	25.0	17	37.0
Caregiver F	14	60.9	19	79.2	33	70.2
Relationship to care recipient						
Spouse	20	87.0	23	95.8	43	91.5
Daughter	2	8.7	1	4.2	3	6.4
Sister	1	4.3	0	0.0	1	2.1
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**
Age of care recipient (years)	23	72.7 ± 8.1	24	72.4 ± 8.1	47	72.5 ± 8.0
Education of caregiver (years)	17	15.8 ± 2.4	17	15.4 ± 2.6	34	15.6 ± 2.5
Education of care recipient (years)	23	15.2 ± 2.3	24	15.1 ± 1.6	47	15.1 ± 1.9
Number of years care recipient received care	23	3.9 ± 2.2	24	4.4 ± 3.1	47	4.2 ± 2.7
Caregiver MMSE score	23	29.2 ± 1.0	24	29.2 ± 1.1	47	29.2 ± 1.0
Care recipient MMSE score	23	19.0 ± 7.5	24	19.8 ± 6.6	47	19.4 ± 7.0
CG, control group; IG, intervention group; MMSE, Mini-Mental Status Examination; SD, standard deviation.						

primarily female spouses (Table 1). Baseline comparisons of the demographic variables for the CG and IG were nonsignificant for age of care recipient, education of caregiver, education of care recipient, and the number of years a care recipient received care. The MMSE scores for the caregivers and care recipients were nonsignificantly different for the two groups. Care recipients had MMSE scores within the impaired range, and caregivers were well within the normal range.

There were no significant differences between groups on baseline measurements (Table 2) except for FMTCS LP, on which IG scored significantly higher ($63.9 + 12.2$) than CG ($56.7 + 10.7$, $p = 0.04$).

Over the 17 weeks of the study (Table 3), no significant differences (group, time, and group by time interactions) were noted in participant MMSE scores, NPI total, and FMTCS PM. NPI total scores decreased slightly over time for both groups. Only the model covariate (baseline) was significant for FMTCS LP ($p < 0.01$). A trend was found for the mean ILS congruence score (ILS/I-ILS, $p = 0.06$) with IG caregivers making higher overestimates of the actual scores than CG. IG members were rated by caregivers as significantly more functional (ADCS-MCI, $p = 0.03$), less depressed (GDS, $p = 0.02$), and more effective (GSE, $p = 0.04$) than CG at baseline and throughout the study. None of the measures showed significant change over time.

Discussion

The goals of this study were to increase the congruence between caregivers' expectations and patients' actual functional abilities and to increase caregiver competence in supporting their loved ones' function. Table 3

Table 2. Baseline measures for control and intervention groups							
Measure	**CG**			**IG**			**t-test p-value**
	n	**Mean**	**SD**	**n**	**Mean**	**SD**	
ILS/I	23	73.30	17.06	24	77.92	17.34	0.3631
ILS	23	71.83	17.30	24	71.71	16.37	0.9810
ILS congruence (ILS/I-ILS)	23	1.48	10.35	24	6.21	16.02	0.2344
NPI total	23	12.48	11.33	24	13.29	13.90	0.8273
ADCS-MCI	23	31.65	16.24	24	36.25	14.01	0.3036
GDS	23	3.00	3.26	24	1.79	1.56	0.1176
FMTCS LP	23	56.70	10.72	23	63.87	12.23	0.0400
FMTCS PM	23	78.65	9.25	23	74.96	11.96	0.2474
GSE	23	29.83	3.74	24	31.71	4.18	0.1109
RAM	18	117.17	58.49	22	127.82	48.99	0.5344

ADCS-MCI, Alzheimer's Disease Cooperative Study ADL-MI; CG, control group; FMTCS LP = Finding Meaning through Caregiving-Loss/Powerlessness; FMTCS PM, Finding Meaning through Caregiving-Positive Meaning; GDS, Geriatric Depression Scale; GSE, General Self-Efficacy; IG, intervention group; ILS, Independent Living Scale; ILS/I, Independent Living Scale, Informant version; NPI, Neuropsychiatric Inventory; RAM, Relationship Attribution Measure; SD, standard deviation.

indicates that although there was a trend toward increased IG caregiver congruence by week seven, this trend did not continue over time to week 17. Our failure to increase congruity between caregiver perceptions and care recipients' abilities over time may have been related to the brevity of the program and to heightened expectations by caregivers. Ensuring that caregiver's expectations are realistic and appropriate regarding care recipient's true abilities can be challenging yet important. Long-term caregiver support may be a better approach. The use of a multimodal intervention including counseling and support over four years that offered coping strategies to assist caregivers in understanding care recipient's true abilities delayed nursing home placement significantly.[16]

Although we hypothesized that our intervention would help caregivers feel more empowered (FMTCS LP scale), feel better able to cope (GSE), and be less depressed (GDS), these secondary outcome measures did not show significant results in these areas. Possible explanations for this may be related to caregiver denial, coping, and preillness relationships. Our study focused on helping caregivers better understand their care recipient's level of function with ADL. Many caregivers underestimated or overestimated their care recipient's level of function. As the reality of the care recipient's actual abilities becomes more obvious to the caregiver, so too might the painful reality of the disease process, with implications of the care recipient's progressive deterioration of function. In addition, longstanding preillness relationships can affect the caregiver's ability to cope and find meaning in caregiving.[17] Feelings relating to this type of awareness of loss and relationship issues may be better served with some form of counseling and ongoing support.

As hypothesized, there was no change in patients' cognitive function or function in daily life.

Poststudy questionnaire reports showed that after completing the four educational sessions, 60 percent (28 of 47) of caregivers were surprised at patients' deficits. They generally responded by learning new ways to adapt. For example, several who found that their care recipients did not know to dial 911 developed supportive strategies for patients who were at home alone. Caregivers who had overestimated care recipients' abilities expressed relief that the patients were not purposefully unhelpful. Caregivers also found it helpful to encourage patients to do tasks within the limits of their

Table 3. ANOVA/ANCOVA results for study measures[a]

Measure	Time (week)	CG		IG		ANOVA/ANCOVA	
		Mean	Standard error	Mean	Standard error	Mean	Standard error
MMSE (participant)	1	19.04	1.49	19.44	1.43	NS	–
	7	18.55	1.53	20.75	1.46		
	17	19.05	1.53	19.13	1.46		
ILS/I-ILS	1	1.48	2.75	5.96	2.63	Group	0.0616
	7	−0.38	2.87	2.25	2.69		
	17	0.57	2.87	6.17	2.69		
NPI total	1	12.48	2.58	13.56	2.48	NS	–
	7	11.95	2.64	12.58	2.53		
	17	10.41	2.64	10.63	2.53		
ADCS-MCI	1	31.65	3.26	35.20	3.12	Group	0.0322
	7	31.05	3.33	39.08	3.19		
	17	30.64	3.33	36.21	3.19		
GDS	1	3.00	0.47	1.76	0.45	Group	0.0176
	7	2.09	0.48	1.67	0.46		
	17	2.68	0.48	1.58	0.46		
FMTCS LP[b]	7	61.52	1.62	62.14	1.69	Covariate	< 0.0001
	17	62.61	1.62	58.71	1.59		
FMTCS PM	1	78.65	2.05	72.25	2.01	NS	–
	7	75.82	2.10	74.00	2.15		
	17	76.09	2.10	75.75	2.01		
GSE	1	29.83	0.87	32.04	0.83	Group	0.0353
	7	31.27	0.89	32.54	0.85		
	17	30.77	0.89	31.79	0.85		

[a]Intent-to-Treat Principle ; [b]Baseline measures significantly different for groups. ANCOVA results are presented with means at time 7 and 17 evaluated with baseline measures as a covariate; ADCS MI, Alzheimer's Disease Cooperative Study ADL-MI; ANOVA, analysis of variance; ANCOVA, analysis of covariance; CG, control group; FMTCS LP, Finding Meaning through Caregiving-Loss/Powerlessness; FMTCS PM, Finding Meaning through Caregiving-Positive Meaning; GDS, Geriatric Depression Scale; GSE, General Self-Efficacy; IG, intervention group; ILS, Independent Living Scale; ILS/I, Independent Living Scale, Informant version; MMSE, Mini-Mental Status Examination; NPI, Neuropsychiatric Inventory; NS, Nonsignificant; RAM, Relationship Attribution Measure.

own abilities. Approximately 43 percent (20 of 47) of caregivers had been unaware of how many times during the day they completed thoughts or activities for patients. Approximately 28 percent (13 of 47) of patients reported that their sense of self-esteem increased after participating in the exercises. Likewise, their caregivers stated they seemed more active and animated. Alternatively, 13 percent (six of 47) of caregivers found cueing a burden. A small group of 8 percent (four of 47) of patients found the ILS testing to be very stressful; they did not like being reminded of their deficits.

Conclusion

Although our objective measures showed no increase in congruence over time between caregiver expectations and patients' abilities to perform a series of structured tasks, caregivers stated that they appreciated learning more about their care recipient's actual abilities. Education regarding communication strategies, insight into the care recipient's functional abilities, specific suggestions about ways to adapt activities to patients' abilities, and information about community support were most valued by caregivers. The results of this study suggest that although caregivers report satisfaction with participation, there is no significant lasting benefit of short term-focused caregiver interventions. The fact that a few caregivers and patients found aspects of the program upsetting further indicates that such interventions need to be individualized.

Acknowledgments

References

1. Toseland RW, Rossiter CM: Group interventions to support family caregivers: A review and analysis. *Gerontologist*. 1989; 29: 438-448.
2. Zarit KE, Toseland RW: Current and future direction in family caregiving research. *Gerontologist*. 1989; 29: 481-483.
3. Zanetti O, Bianchetti A, Trabucchi M: The puzzle of functional status in mild and moderate Alzheimer's disease: Self-report, family report, and performance-based assessment. *Gerontologist*. 1995; 35: 148-155.
4. Heindel WC, Salmon DP, Shults CW, et al.: Neuropsychological evidence for multiple implicit memory systems: A comparison of Alzheimer's, Huntington's and Parkinson's disease patients. *J Neurosci*. 1989; 9: 582-587.
5. Clare L, Wilson BA, Carter G, et al.: Intervening with everyday memory problems in dementia of Alzheimer type: An errorless learning approach. *J Clin Exp Neuropsychol*. 2000; 22: 132-146.
6. Loeb PA: *Independent Living Scales*. San Antonio, TX: The Psychological Corporation, Harcourt Brace, 1996.
7. Cullum CM, Saine K, Davis-Chan L, et al.: A performance-based instrument to assess functional capacity in dementia: The Texas Functional Living Scale. *Neuropsych Neuropsychol Behav Neurol*. 2001; 14: 103-108.
8. Tombaugh TN, McIntyre NJ: The Mini-Mental State Examination: A comprehensive review. *J Am Geriatr Soc*. 1992; 40: 922-935.
9. Galasko D, Bennett D, Sano M, et al.: An inventory to assess activities of daily living for clinical trials in Alzheimer's disease. The Alzheimer's Disease Cooperative Study. *J Alz Dis Assoc Disord*. 1997; 11(Suppl 2): S33-S39.
10. Cummings JL: The Neuropsychiatric Inventory: Assessing psychopathology in dementia patients. *Neurology*. 1997; 48(Suppl 6): S10-S16.
11. Farran CJ, Miller BH, Kaufman JE, et al.: Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *J Clin Psychol*. 1999; 55(9): 1107-1125.
12. Jerusalem M, Schwarzer R: Self-efficacy as a resource factor in stress appraisal processes. In Schwarzer R (ed.): *Self-Efficacy: Thought Control of Action*. Washington, DC: Hemisphere, 1992: 195-213.
13. Fincham FD, Bradbury TN: Assessing attributions in marriage: The Relationship Attribution Measure. *J Personality Soc Psychol*. 1992; 62: 457-468.
14. Lesher EL, Berryhill JS: Validation of the geriatric depression scale-Short Form among inpatients. *J Clin Psychol*. 1994; 50: 256-260.
15. Yesavage J, Brink T, Rose T: Development and validation of a geriatric depression screening scale: A preliminary report. *J Psychiatr Res*. 1983; 17: 37-49.
16. Mittelman MS, Roth DL, Haley WE, et al.: Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *J Gerontol*. 2004; 1: 27-34.
17. Martin-Cook K, Remakel-Davis B, Svetlik DS, et al.: Caregiver attribution and resentment in dementia care. *Am J Alzheimers Dis Other Demen*. 2003; 18: 366-374.