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Effect of a training programme to reduce stress in carers of patients with dementia

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Abstract

Objective—To reduce the psychological stress and improve the skills in coping of people who care for relatives with dementia.

Design—Assessment and suitability of carers by questionnaire; assessment of patients and carers in a hospital outpatient clinic; allocation to groups according to date of application to study. Linkage of groups of four carers and programme coordinator by telephone conference calls over 12 months after programmes. Reassessment at three, six, 12, and, for those in the "wait list" group, 18 months.

Setting—The programmes were conducted in the psychiatry unit of a Sydney teaching hospital.

Subjects—Eligible patients were less than 80 years old, had mild to moderate dementia, and lived at home with their carer. Of the 96 patient-carer pairs in the study, 33 were in the dementia carers' programme group, 31 were in the memory retraining group, and 32 were in the wait list group.

Interventions—Carers in the dementia carers' programme received training in coping with the difficulties of looking after patients with dementia while the patients had sessions in subjects such as memory retraining. In the memory retraining programme patients were admitted and received the patient component of the carers' programme while their carers had 10 days' respite. In the wait list group carers waited six months before undertaking the carers' programme.

Main outcome measures—Effect of the programmes on carers' general health questionnaire scores and the rate of placement of patients in institutions.

Results—At 12 months' follow up the carers' programme had resulted in significantly lower psychological stress among carers than the memory retraining programme (mean (SD) general health questionnaire scores at 0 months were 6.31 (6.23) and 3.60 (6.25) respectively, and at 12 months were 4.69 (5.58) and 7.40 (9.39); $p < 0.05$.) In the wait list group distress scores remained stable, even after the carers and patients had undertaken the carers' programme. Patients deteriorated over 12 months regardless of group allocation, but at 30 months, allowing for patients who died and could not be included in the analysis, 65% of patients in the carers' programme group were still living at home compared with 26% in the memory retraining programme group.

Conclusion—The intensive intervention pro-

gramme described for carers of patients with dementia can reduce the psychological morbidity of the carer and delay the placement of the patient in an institution without increasing the use of health services by either patient or carer.

Introduction

Dementia is an unremitting burden¹ that leads to the carers of people with the condition becoming demoralised,² isolated,³ and psychologically distressed.^{4,6} Interventions to ease the plight of carers are needed, but empirical studies of such interventions have been sparse.

Intervention techniques have included attempts to enhance carers' skills in coping by cognitive behavioural approaches, training in problem solving, and educational therapy⁶⁻⁹; meditative relaxation^{6,7,9}; training in social skills^{6,10}; supportive counselling of individuals and groups or families, or both^{8,10}; and management of stress.¹⁰ The following outcomes were reported: reduced family burden^{8,10}; decreased psychological morbidity^{8,10}; increase in carers' knowledge about dementia¹⁰; and increased assertiveness and tolerance.⁹ But these studies have various limitations: they comprised small numbers of subjects^{6,7,9}; there was no follow up^{6,8,10}; interventions were limited⁶⁻¹⁰; there was a "floor effect" of low psychological morbidity of carers before training⁹; and the outcome of patients was not evaluated.⁶⁻¹⁰

We sought to overcome these methodological difficulties by designing an intervention programme for carers living at home with a relative with dementia. Our aim was to reduce distress and improve the quality of life for both patients and carers and to reduce the rate of placement of patients in institutions. In designing a package of appropriate interventions we took into account factors known to influence carers' psychological distress.³ We reasoned that if we could modify these factors we would enhance our ability to reduce carers' psychological morbidity. We designed the dementia carers' programme, a highly structured 10 day residential training programme for patients and carers but aimed principally at carers and evaluated it against two control interventions.

Subjects and methods

SUBJECTS

Subjects were recruited by referral or publicity. Of the 96 carers, 40 indicated that they had entered the

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study on their own initiative, 16 were referred by local doctors, 15 entered the study through the Alzheimer's Disease and Related Disorders Society, eight after media publicity, and 17 through other sources.

Eligible patients were less than 80 years old (for follow up purposes) and had mild to moderate dementia, defined as Diagnostic and Statistical Manual type III dementia. They lived in a private home with a supporter, could understand English, did not wander, and were not aggressive. Mild to moderate dementia was defined as an activity of daily living score of zero or one.¹¹ Subjects were told that there were two treatment programmes but that if they wished to participate in the trial they would have to agree to accept whichever one they were allocated to. They were also told that neither programme offered a cure but that both offered the possibility of improvement in function.

DESIGN

Carers who applied to enter the trial were asked to complete and return a set of questionnaires. Suitable patients and carers were then assessed in a hospital out-patient clinic by a psychiatrist independently of and before group allocation. The diagnosis of dementia was confirmed by investigation if necessary or by checking on previous reports if these were available. Allocation to programmes was decided by sequentially allocating subjects according to the date of their postal application. Those in the "wait list" group were told that there would be a delay until a place in a treatment group was available for them, and they were reassessed six months later, before starting the carers' programme. All subjects were asked to return for interview and reassessment at three, six, 12, and, for those in the wait list group, 18 months. Some participants living in distant rural areas were excused from the three months' follow up but were asked to return self report questionnaires. A sample size of over 30 for each of the three groups was calculated as necessary for an intervention of moderate power (estimate 0.6) to produce a relevant effect size (estimate 0.67) for α at 0.05.¹²

THE DEMENTIA CARERS' PROGRAMME

This was conducted in the psychiatry unit of a Sydney teaching hospital to which cohorts of up to four patient and carer pairs were admitted at a time. Groups of four were chosen for logistical reasons and to enable the development of small self help groups. The programme was directed mainly at alleviating difficulties associated with being the carer of a person with dementia; the problems were categorised as psychological distress^{3,4}; isolation and lack of support^{3,13}; lack of assertiveness and apprehension about new roles^{7,8,10}; a poor marital relationship¹⁴; lack of information about diagnosis, management, prognosis, domiciliary and welfare services, legal and financial matters, and safety and organisation in the home¹⁵; and poor skills at coping.^{7,9} The techniques used in the programme included didactic education, group therapy, training in management skills, assertiveness training, discussion of "re-rolling," extended family therapy sessions, training in techniques for managing problems, basic principles of behaviour modification, and use of activities.

For patients the programme comprised specific sessions in memory retraining, reminiscence therapy, environmental reality orientation, and general ward activities. They had their physical and psychiatric state reviewed, and treatment was offered if indicated. After the programme telephone conference calls linking groups of four carers and the programme coordinator initially took place fortnightly, decreasing over 12 months to four and then six weekly, with two of the final telephone conferences being arranged by the coordinator but held in her absence, the plan being to

encourage cohorts of carers to become self supporting.

In the memory retraining group up to four patients with dementia were admitted at a time without their partners and received the patient component of the carers' programme while their carers had 10 days' respite. In the wait list group patients and their carers waited six months before undertaking the carers' programme. Both control groups had telephone conference calls for 12 months after intervention, as described for the carers' programme.

ASSESSMENT

Patients were assessed on the two scales described by Blessed *et al*—the orientation information memory concentration scale¹⁶ (range 0-37; 37=maximum cognitive functioning) and the dementia scale¹⁶ (range =0-27; higher scores indicate worse function)—and on the mini-mental state examination¹⁷ (range 0-30; 30=maximum cognitive function, <17 indicates important deterioration); the 21 item problem behaviour check list¹⁸ (range 0-42; 0=no problems, 42=all problems occurring frequently); the activities of daily living¹¹ (range 0-6; 0=completely independent, 6=completely dependent); the instrumental activities of daily living¹⁹ (range=1-4; 1=complete independence, higher scores indicate increasing dependence); the 21 item Hamilton rating scale for depression²⁰ (range 0-64; >16 indicates important depression); the geriatric depression scale²¹ (range 0-20; >10 indicates possible depression); and the clinical dementia rating scale for dementia²² (range 0-3; 0=healthy, 3=severely demented).

CARERS

Carers completed the general health questionnaire²³ (range 0-30; those with scores >4 probably were significantly depressed) and the Zung depression scale²⁴ (range 20-80; ≥ 40 indicates important depression) and were rated on the Hamilton depression rating scale. They were asked to keep a health diary of all the health care visits made and medications taken by them and the patient over the 12 months of follow up. They were also asked to keep a record of all visits to day centres and any days in residential care. Completion of the diaries was encouraged at the regular telephone conference sessions. Demographic data on all participants were collected and included the position on the Congalton scale for socioeconomic class²⁵ (range 1-7; 1=highest status occupation, 7=lowest).

STATISTICAL METHODS

We used repeated measures of analysis of variance, with the multivariate model for comparing outcome; one way analysis of variance to compare groups at entry into the trial; and survival analysis^{26,27} to compare how many in each group were not placed in institutions. Four interaction comparisons were planned to determine whether there were differences in the amount of change over six and 12 months between those in the carers' training group and those in the memory retraining group and between those in the carers' training group plus those in the wait list group and those in the memory retraining groups. In addition, we compared the effect of any intervention in the first six months of the carers' programme plus any in the memory retraining programme with the effect of no intervention (the wait list group).

Results

In all, 101 pairs of patients and carers entered the trial. Three of the 36 pairs in the carers' programme had insufficient follow up data and one of the 32 patients in the memory retraining group changed carers during the follow up period. The data from these

four pairs were not included in the analyses. Two pairs in the wait list group completed intake and pre-training assessments but elected not to proceed with training. Their data from the initial two assessments were included in the analyses at 0 to 6 months but not subsequently (when theirs were recorded as missing data). All patients and carers who began programmes completed them.

Thus there were 33 pairs in the carers' programme with sufficient follow up data, 31 in the memory retraining programme, and 32 in the wait list group. Of the 96 carers, 44 were men, 89 were spouses, four were siblings, and three were children of the patients; 30 out of the 87 with data belonged to the Alzheimer's Disease and Related Disorders Society. The carers mean (SD) age was 67.7 (8.2) years.

Of the 96 patients (50 of whom were men), 70 had probable Alzheimer's disease, 19 had multi-infarct dementia, and seven had other causes of dementia. The average patient was 70.2 (6.5) years (range 49-79 years), had had 10.4 (3.6) years' education, and had mild to moderate dementia (clinical dementia rating scale score 1.1 (0.5)). Patients had a mean duration of dementia of 3.8 (3.8) years at entry into the trial and there was no significant difference among the groups. Sixteen patients were from social classes I or II^a; 52 were from classes III, IV, or V; 25 were from classes VI or VII; and the data for three patients were missing. There were no significant differences among the three groups for carers or patients in any sociodemographic variable or initial measure of outcome at entry into the trial.

The carers' general psychological morbidity as judged by their scores on the general health questionnaire were lower after the carers' programme (fig 1): differences were significant at 12 months (5.03; $p<0.05$). There were no significant differences at six months when comparing the carers' programme and wait list groups or the carers' programme plus the memory retraining groups with the wait list group.

The results from the wait list group indicate that merely waiting six months did not influence psychological stress as reflected by general health questionnaire scores. Apart from being slightly more demented on the clinical dementia rating scale (mean 2.7 (1.6) *v* 2.2 (1.2); $p<0.05$), the patients in the wait list group at the time of their intervention (that is at six months after intake) were not significantly different from the patients in the carers' programme group at their intake (at zero months) with regard to carers' age and general health questionnaire score or patient scores on the mini-mental state examination, scales of Blessed *et al*, problem behaviour check list, and geriatric depression scale. We therefore combined the results of follow up

FIG 1—Mean general health questionnaire scores for carers in the three programme groups. Standard deviations of each group at zero, three, six, and 12 months respectively were 6.2, 5.8, 6.2, and 5.6 for the dementia carers' programme group; 6.3, 7.1, 8.4, and 9.4 for the memory retraining group; and 6.1, not available, 6.6, and 7.7 at 18 months for the wait list group

FIG 2—Survival curve showing percentage of patients not placed in an institution over time in the three programme groups

after intervention in the carers' programme group (from 0 to 12 months) with those in the wait list group (from 6 to 18 months) for further comparison with the memory retraining group. Over the six months after training the combined groups of carers receiving the training programme showed a trend of reduced general health questionnaire scores compared with the group of carers not receiving training—that is, those in the memory retraining group ($F=3.01$; $0.05<p<0.10$). This trend became significant 12 months after training ($F=6.69$; $p<0.01$).

Patients initially had mild to moderate dementia, and this became progressively worse over the 12 months of the trial. The rates of decline were roughly linear (table) and equivalent across groups. Patients

Mean (SD) scores in various tests of cognitive function for patients with dementia at allocation to one of three intervention groups (zero months) and at three, six, and 12 months' follow up

Test	No of months			
	0 (n=94.6)	3 (n=53.8)	6 (n=84.8)	12 (n=71.91)
Clinical dementia rating scale	1.1 (0.5)	Not available	1.5 (0.9)	1.7 (0.9)
Mini-mental state examination	17.1 (6.5)	15.9 (6.9)	16.2 (7.3)	15.2 (7.6)
Orientation information memory concentration test ¹⁶	20.8 (8.5)	19.7 (8.3)	19.4 (8.9)	18.4 (10.0)
Dementia scale ¹⁶	7.0 (2.9)	7.0 (3.6)	8.2 (4.3)	10.4 (5.4)
Problem behaviour check list	6.3 (5.6)	8.1 (6.2)	9.8 (7.2)	11.4 (8.0)
Instrumental activities of daily living	2.3 (0.8)	2.6 (0.7)	2.6 (0.8)	2.9 (0.8)
Activities of daily living	0.3 (0.6)	1.1 (1.4)	1.1 (1.4)	1.7 (1.7)

were not depressed clinically; fewer than six at any assessment over the 12 months had a Hamilton score >16 , and their mean Hamilton and geriatric depression scale scores remained low and stable over time.

There was a pronounced divergence in the number of patients being placed in institutions in the different groups at a census undertaken 40 months after the programme began (fig 2). Patients in the dementia carers' programme and the memory retraining programme were followed up for an average of 29 months, and patients in the wait list group were followed up for an average of 19 months. To allow for the different times of entry into the trial survival at home was analysed pragmatically²⁶ with the SPSS-X survival program. This analysis allows for patients who die at home and are therefore not eligible to be placed in an institution.

When the three groups were compared over the full period of the study the Lee-Desu statistic²⁷ of 6.19 indicated significant differences ($df=2$; $p<0.05$). When the carers' programme and memory retraining programme groups were compared the Lee-Desu statistic of 6.90 ($df=1$; $p=0.01$) indicated a significantly higher rate of survival at home for patients

whose supporters had had early training. There had been more deaths at the time of the census in the memory retraining group: 10 patients had died (one at home and nine in institutions) compared with five in the carers' programme group (three at home) (χ^2 with Yates's correction=1.6). In the wait list group two patients had died (one at home) by the time of the census.

Discussion

The most striking finding was the much lower rate of placement of patients with dementia in institutions, mainly nursing homes, when carers had been through the training programme. It cannot be assumed that avoiding placement in an institution is necessarily desirable, even though supporters usually wish for the patient to be at home for as long as possible. Whether the patient's living at home would lead to more distress for carers compared with his or her placement in an institution, as has been reported,²⁸ and greater costs of professional services while the patient is at home compared with those in an institution would have to be weighed up carefully.

The dementia carers' programme did not delay institutionalisation of the patient at the expense of the morbidity of the carer. On the contrary, it reduced psychological morbidity as measured by the general health questionnaire. This difference became more pronounced at 12 months' follow up, suggesting a long term effect for the programme. (No differences were found in ratings of depression in carers among groups or over time. Low initial depression scores [mean (SD) Zung depression score 34.8 (8.9); n=94 and Hamilton depression score 6.7 (5.2); n=88], however, may have precluded any such benefits from the carers' programme.)

The increased rate of retaining the patient at home was not likely to be at the expense of increased usage of the health service. Over the first 12 months after training there were no differences between the patients or carers in the carers' programme and the memory retraining programme in how often they attended consultations or took drugs.

It could be argued that the carers' programme was not necessarily beneficial and that the important results emerged as a result of the memory retraining group's deterioration over time; perhaps carers in the memory retraining group were disappointed by their patient's lack of improvement. It may have been that after the 10 days' respite afforded by the memory retraining programme carers became more keenly aware of the extent of their burden. Another explanation, which we favour, is that the general health questionnaire scores of the memory retraining group were approaching their expected level of morbidity. Thus in an earlier survey of members of the Alzheimer's Disease and Related Disorders Society we found that the mean general health questionnaire score was 7.3,¹ which is similar to that described by Gilleard.⁴

We concede the weakness of setting α at 0.05, given the number of comparisons. To correct for the possible increase in the rate of type 1 errors associated with the four planned comparisons a conservative procedure would be to set α at 0.05/4=0.0125. As many variables may affect carers' psychological morbidity,⁵ our power analysis estimates were optimistic and numbers of subjects too small. When the number of subjects was increased by combining both groups of carers who had received training the difference in general health questionnaire scores between them and untrained carers over 12 months was significant at the $p<0.01$ level.

Regarding the patients, it was clear that the programme could not affect the relentless progression of

the dementias, most of which were of the Alzheimer's type. Whatever test was used to monitor patient state, be it of cognitive function, problem behaviours, day to day functioning, or overall severity, there was a consistent linear decline, which was similar in all three groups. Our impression, however, was that after training there was an observable improvement in the morale of patients.

The much less striking results from the wait list group are puzzling, especially given the comparable severity of the disease by all of the measures except one at the time of intervention. Perhaps carers were disappointed at not receiving immediate attention. Alternatively, it may be that the timing of such an intervention is important—earlier is better. This is supported by our impressions that carers seemed to derive more benefit and were able to use the strategies in coping in a preventive manner when they received earlier training.

We cannot yet comment on which aspects of the dementia carers' programme are effective. This would require several further studies examining its different components. One of us (HB) interviewed all of the carers after 12 months' follow up and asked which components of the training had been most helpful. No element of the programme emerged consistently as the most helpful, and virtually all elements were considered by at least some carers to be particularly beneficial. We cannot comment on which carers and which patients are most likely to benefit from such a programme: additional analyses will be required to determine further the question of specificity.

Patients in the carers' programme group were at home at least 5.2 months longer than patients in the memory retraining programme group. (This calculation is based on the conservative assumption that all patients were placed in institutions the day after the census.) This may not, however, represent any financial savings as the cost of care in an institution must be weighed against the costs of the programme and of professional support while the patient is at home. As good domiciliary care is no cheaper than good institutional care the basis for further argument must rest therefore on the quality of life for both patient and carer.

We conclude that an intensive intervention programme for carers of patients with dementia early in the course of the patient's illness has the potential to delay institutionalising the patient and reduce the psychological morbidity of the carer without increasing the use of health services.

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Acute right heart strain after crushing injury at Hillsborough football ground

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Ninety five people died from crushing injuries and asphyxiation at Hillsborough football ground in April 1989. Eighty one others were admitted to hospitals in Sheffield. Of the 18 patients who required artificial ventilation, five were transferred to this hospital for treatment and computed tomography of the head, and one further patient was admitted to this hospital. In all six men (aged 15-23) the brain scan was normal, though they had been asphyxiated by crushing and cerebral hypoxia had occurred. Five had epileptiform convulsions; one had bilateral pneumothoraces and one negative results on laparotomy. None had bone injuries. We report the effect of asphyxiation on cardiac function in these six young men.

Patients and methods

All six patients were ventilated and examined on admission. Electrocardiograms were recorded daily and echocardiograms on day one and day three or four. Blood samples were taken within the first 24 hours and on days two and three after injury to measure creatine kinase activity, including the myocardial isoenzyme and lactate dehydrogenase isoenzyme 1 activities.

In two patients the initial electrocardiogram showed a nodal rhythm and in one left axis deviation and left bundle branch block. The other four were in sinus rhythm, and by day two all were in and remained in sinus rhythm. The electrical axis was rightward ($+90^\circ$) in four patients initially, and one patient developed right axis deviation by day two.

There was a dominant R wave in V1 with an RsR pattern in two patients and this appeared by day three in three further patients. T wave inversion developed in leads V1 to V5 in three patients and resolved within two weeks.

Initial echocardiograms showed dilated and impaired right ventricles in four patients. Left ventricular function was reduced in three due to septal hypokinesia. The mean ejection fraction was 0.66 (range 0.46-0.85), becoming normal in all (mean 0.83, range 0.7-0.9). Two patients had small transient pericardial effusions, and three had persistent abnormalities of right ventricular function.

The total creatine kinase activity was appreciably raised, being compatible with muscle damage, but the cardiac isoenzyme fraction was not raised and the cardiospecific lactate dehydrogenase fraction was slightly raised in all patients (maximum 34% of total lactate dehydrogenase activity, normal $<25\%$).

Comment

In all six patients the apparent injury was similar—thoracic compression causing hypoxia, loss of consciousness, and convulsions. Unusually, there was no

Serial electrocardiographic recordings in one patient. On day one there was right axis deviation, sinus rhythm with blocked atrial premature beats and sinus arrest and nodal escape beats, partial right bundle branch block, and non-specific ST and T wave changes in V3 and V4. On day three axis is $>+90^\circ$, and there is complete right bundle branch block. There is marked T wave inversion in V1 to V5. On day 14 the axis remains at $+90^\circ$, and there is partial right bundle branch block and the T wave changes have resolved.