

# THE PRINCE HENRY HOSPITAL DEMENTIA CAREGIVERS' TRAINING PROGRAMME

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## Rezumat:

**Obiectiv:** Descrierea teoriei, elementelor practice care au stat la baza unui program de training de succes al persoanelor implicate în îngrijirea pacienților; raportarea rezultatelor.

**Design:** Cercetarea s-a bazat pe un studiu controlat, randomizat, în perspectivă și pe o urmărire longitudinală de peste 8 ani.

**Serviciile în care s-a desfășurat cercetarea:** Secția de Psihiatrie din Spitalul General din Sydney, Australia

**Participanți:** 96 de persoane sub 80 de ani cu demență medie sau ușoară și persoanele implicate în îngrijirea pacienților și care locuiesc cu aceștia;

**Intervenții:** Toti pacienții au primit un program de 10 zile structurat pe antrenamentul memoriei și susținerea activității. Persoanele implicate în îngrijire, din anturaj și persoanele de pe lista de așteptare au primit un program de training de 10 zile intensiv structurat, rezidențial, susținut de follow-up-uri și teleconferințe pe o durată de un an. Cei din grupul de pe lista de așteptare au intrat în program după 6 luni. Al treilea grup a primit un răgaz de 10 zile (timp în care pacienții urmau programul lor de antrenare a memoriei) și 12 luni de sesiuni de susținere, la fel ca și celelalte grupuri.

**Principalele instrumente de evaluare:** Internarea în casele de nursing; timpul scurs până la moartea pacienților.

**Principalele rezultate:** 64% din pacienții care au fost îngrijiți de persoane din anturaj, 53% care au fost îngrijiți de persoane de pe lista de așteptare și 70% din pacienții care au primit programul de training pentru memorie au murit. Admiterea în casele de nursing s-a făcut pentru 79% din pacienții îngrijiți de persoanele din anturaj, 83% de cei de pe lista de așteptare și 90% din cei care urmau programul de antrenare a memoriei. Evaluarea statistică pe 8 ani a indicat că pacienții ai căror îngrijitori au primit training au putut să rămână acasă semnificativ mai multă vreme ( $p=0.037$ ) și au avut o tendință de a trăi mai mult.

**Concluzii:** Programele de antrenament a persoanelor implicate în îngrijire pot prelungi momentul în care instituționalizarea persoanelor cu demență devine necesară.

**Cuvinte cheie:** demență, persoane implicate în îngrijire, training, intervenție, instituționalizare.

## Abstract:

**Objective.** To describe the theory, elements and practice of a successful caregiver training programme; and report the 8-year outcome.

**Design.** Prospective, randomized control trial and longitudinal follow-up over approximately 8 years.

**Setting.** Psychiatry unit, general teaching hospital, Sydney, Australia.

**Participants.** 96 persons less than 80 years old with mild to moderate dementia and their cohabiting caregivers.

**Interventions.** All patients received a 10-day structured memory retraining and activity programme. Caregivers in the immediate and wait-list caregiver training groups received a structured, residential, intensive 10-day training programme, boosted by follow-ups and telephone conferences over 12 months. Those in the wait-list group entered the programme after waiting 6 months. The third group of caregivers received 10 days' respite (while patients underwent their memory retraining programme) and 12 months booster sessions as for the other groups.

**Main outcome measures.** Nursing home admission; time until patient death.

**Main results.** 64% of patients whose caregivers were in the immediate training group, 53% of wait-list group patients and 70% of memory retraining patients had died. Nursing home admission had occurred in 79% of the immediate training, 83% of the delayed and 90% of the memory retraining group. Eight-year survival analysis indicated that patients whose caregivers received training stayed at home significantly longer ( $p = 0.037$ ) and tended to live longer ( $p = 0.08$ ).

**Conclusions.** Caregiver training programmes demonstrably can delay institutionalization of people with dementia.

**Key words:** dementia; caregiver; training; intervention; institutionalization

## INTRODUCTION

Results of a randomized control trial of an intensive, comprehensive and extensive intervention programme for dementia caregivers (Brodaty and Gresham, 1989) indicated that it was able to reduce psychological morbidity in caregivers, delay institu-

tional placement of persons with dementia (hereafter called patients) and achieve an average saving of A\$8000 (or US\$6000) per couple in its first 3 years of operation even though the programme was residential in a teaching hospital and therefore more costly than necessary (approximate cost of training A\$8850; Brodaty and Peters, 1991). A 5-year follow-up

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confirmed the programme's efficacy for patients in delaying nursing home placement and delaying mortality (Brodaty et al., 1993). Lack of caregiver training was the most significant factor predicting nursing home placement, ahead of dementia severity, rate of dementia deterioration and caregiver psychological morbidity (Brodaty et al., 1993; McGilchrist et al., 1994). We now describe the theoretical underpinnings of the programme, provide a practical outline of its content and procedures, report the 8-year follow-up of programme participants and suggest adaptations for future intervention programmes.

**Theoretical underpinnings of intervention programmes**

High levels of caregiver psychological morbidity have been extensively documented (Brodaty and Hadzi-Pavlovic, 1990; Coope et al., 1995; Gallagher et al., 1989; Gilleard, 1984; Morris et al., 1988; Zarit et al., 1985). A model can be devised, based on that proposed by Poulshock and Deimling (1984), which is helpful heuristically and clinically to explain caregiver strain (Fig. 1). In this model, dementia is associated with behavioural problems, such as aggression and incontinence, which in turn impose a burden on the caregiver. Some caregivers take this behaviour in their stride without untoward stress. Others develop distress or strain which may manifest itself psychologically, physically, socially or in the use of health services. Intervention can be directed at one or several points in this model, for example education - so that greater understanding enhances the caregiver's capacity to cope, skills acquisition - to lessen the impact of problem behaviours, or garnering support to share the load and provide emotional succour.

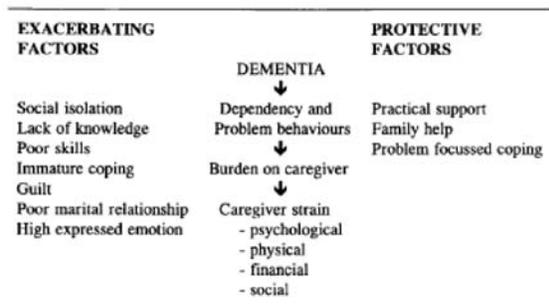


Figure 1. Model of effects of dementia on caregivers

**Caregiver intervention programmes**

Caregiver interventions have used different strategies, the elements of which can be categorized into three broad strands (see Table 1) - psychological, educational and social (see reviews by Brodaty, 1992; Toseland and Rossiter, 1989). The outcomes of these interventions are variable. A meta-analysis of studies

between 1980 and 1990, although omitting at least one (Brodaty and Gresham, 1989), concluded that intervention programmes had weak to moderate effect sizes in reducing psychological morbidity and decreasing burden scores (Knight et al., 1993). Our earlier review (Brodaty, 1992) and subsequent work (eg Mittelman et al., 1993) suggested that caregiver interventions improved caregiver knowledge, decreased family burden, improved coping skills, were rated by participants as helpful, sometimes reduced caregiver psychological morbidity and sometimes delayed institutionalization. On the basis of the theoretical underpinnings described and the empirical data prior to 1985, we designed and piloted a programme which we anticipated would overcome some previous methodological and content limitations.

Table 1. Elements of caregiver interventions. From Brodaty (1992)

<p><b>Psychological</b></p> <p>Support</p> <ul style="list-style-type: none"> <li>- ventilation, group process, sharing, acknowledging,</li> <li>- learning, mutual support, recognition of universality</li> </ul> <p>Counselling, insight therapy, cognitive therapy, relaxation</p> <ul style="list-style-type: none"> <li>- training, stress management</li> </ul> <p>Emotional impact stress, anger, grief, guilt</p> <p>Self-care</p> <p>Interpersonal relations and communication</p> <p><b>Educational</b></p> <p>Information</p> <p>Improving home care skills</p> <p>Developing therapeutic skills, problem-solving, behavioural techniques</p> <p>Planning emergencies, legal, financial</p> <p><b>Developing support system</b></p> <p>Personal, family</p> <p>Community</p> <p>Professional</p>
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**METHOD**

**Trial methodology**

In summary (see Brodaty and Gresham, 1989 for details), 96 couples were randomly allocated to one of three treatment conditions: group I, immediate caregiver training (N = 33); group II, wait-list or (delayed) caregiver training (N = 32); and group III, memory retraining (N = 31). Group I care-givers were admitted with their partners and received the training programme outlined below shortly after application to join the programme, while group II caregivers received training

approximately 6 months after application. There was no drop out, institutionalization or death in the 6 months waiting period. Group III caregivers received 10 days respite and no training while their partners were admitted for the patient part of the programme. Follow-up procedures including telephone conference calls were the same for all three groups.

### Subjects

Participants were people with dementia and their cohabiting supporters, 93% of whom were spouses. Dementia was diagnosed using standard criteria and procedures (Brodaty, 1990) and confirmed by longitudinal follow-up, and was required to be progressive and of mild to moderate severity, defined as the patient still being able to dress. Patient and caregiver variables were similar for the three groups (see Brodaty and Gresham, 1989). One subject who was included in the 1989 report was subsequently excluded when his diagnosis was confirmed as benign senescent forgetfulness, another subject, from the memory retraining programme, was excluded because he and his wife subsequently undertook a caregiver training programme, and a third subject, from the wait-list group, had not provided sufficient data. Of the 93 patients, 65 were diagnosed with probable Alzheimer's disease, 21 had multi-infarct dementia, three had Pick's disease and four had other causes of dementia (two subcortical, one carbon monoxide and one diagnosis deferred)

Average age at baseline of patients was 70.1 years (SD 6.6) and of carers 67.5 years (SD 8.0), with no significant differences between groups ( $F(2, 90) = 1.52$ , NS;  $F(2, 90) = 0.92$ ; NS; respectively). Approximately half the patients (51.6%) and half the carers (46.2%) were male and there were no significant differences between the groups. ( $\chi^2 = 0.07$ ;  $df = 2$ , NS;  $\chi^2 = 0.84$ ;  $df = 2$ , NS; respectively). The average patient MMSE (Mini-Mental Status Examination; Folstein et al., 1975) score at baseline was 17.0 (SD 6.5) and the average patient CDRS (Clinical Dementia Rating Scale; Hughes et al., 1982) score was 1.1 (SD 0.6); similarly, these did not differ between groups ( $F(2, 90) = 0.19$ ; NS;  $F(2, 90) = 0.02$ , NS; respectively). Rates of cognitive, IADL (Instrumental Activities of Daily Living; Lawton and Brody, 1969) and ADL (Activities of Daily Living; Katz and Apkom, 1976) decline, assessed at 3, 6 and 12 months after intervention, were similar for the three groups (Brodaty and Gresham, 1989).

Measures of formal and (indirectly) informal or social support were recorded over the first 12 months of follow-up by caregivers keeping a health diary of all health care visits and medication use for both themselves and the care receiver, as well as rating both frequency of and satisfaction with personal and telephone contacts. There were no differences at baseline assessment between the groups on any measure (Brodaty and Gresham, 1989), and the only difference between the groups over time was a significant increase ( $p < 0.01$ )

in non-medical health professional consultations in the 7±12-month follow-up period (compared to the first 6 months) for patients in the wait-list group (Brodaty and Peters, 1991).

The dementia caregivers' programme Programme content. The content of the 10-day intensive programme can now be conceptualized under 10 rubrics. (Discipline of professional/s conducting the session, number of sessions and duration of sessions are indicated in parentheses). 1. Reducing caregiver distress (social worker/ occupational therapist (OT); 2 \_ 2 hours . 1 \_ 1. hours). In our pilot programme caregivers were unable to acquire new knowledge until their psychological distress had been dealt with. Sessions were informal, supportive and expressive in nature, with caregivers encouraged to unburden themselves. Discussion in the first session included topics such as care-givers' stories, the stresses of caring, associated feelings, setting limits for the person with dementia and caregiver, coping with caring and role changes. The second session explored the additional themes of acceptance of the disease and how dementia affects relationships with family, friends and community. The third session focused on caregiver burnout and how to look after one's individual needs. 2. Combating isolation (psychiatrist; 1 \_ 1 hour.: We aimed to reduce caregivers' social isolation by the group interaction, residential setting and bringing together of four caregivers for 10 days. This often led to mini-support groups forming and was a rehearsal for participation in other support groups. After the intensive residential programme, telephone conference calls and hospital follow-up visits strengthened bonds between groups of four caregivers. Extended formal family sessions brought together an expanded network of potential caregivers. For many families it was the first time they had all gathered to discuss ways of assisting with care. Sometimes geographically distant families participated using speaker telephones. 3. Guilt and separation. Caregivers trapped by their role, guilt, or their partner's insecurity or suspiciousness were separated from their charges for most sessions, and encouraged to enjoy a number of activities, such as excursions to the local shopping centre or co-ee shop. This provided a rehearsal for the separation process when at home. 4. New ways of thinking (a) Assertiveness training (psychologist or OT; 2 \_ 1. hours). Participants were provided with a working knowledge of assertive, non-assertive and aggressive behaviours, with their own 'Bill of Rights' and with strategies for coping with criticism. Sessions were concrete and used role play extensively. (b) Role playing (psychologist; 1 \_ 2 hours.: This focused on roles concept, definition (mainly by gender), expectations and responsibilities and how these were affected by dementia. Many caregivers had considerable difficulty taking over roles relinquished by the dementing person such as driving, organizing the family and dealing with bureaucracy. Required skills were identified and their

development promoted (c) Relaxation and stress management (OT; 8\_ hour, daily). Techniques for relaxation, meditation, use of physical imagery and progressive muscular relaxation, complemented by two half-hour discussions on the theory of relaxation and stress response, were very popular. Caregivers obtained audio tapes to practise techniques themselves and with their partners.

5. New coping skills (a) Communication (psychologist; 1\_2 hours.: The first half was theoretical and focused on how to communicate with a dementing person, the functions and expectations of communication and how communication processes can be disrupted. Information was provided on receptive and expressive dysphasia, and on techniques for clear communication, eg the four Ss, keep it Simple, Slow, Short and Specific (Ball, 1987). In the second half, techniques were practised by each patient/caregiver dyad while being videotaped and observed by the group through a one-way mirror. Caregivers were able to review the videotape and analyse their performance and communication techniques. (b) Reality orientation .OT; 1 \_ 1 hour.: This was based on a 24-hour environmental reality orientation model with use of verbal techniques, signs, pictures, clocks, diaries and other strategies. (c) The therapeutic use of activities (OT; 1 \_ 1 hour.: This introduced the concepts of activity as being goal-directed use of time, energy and attention. 'Activity analysis' was explained as breaking tasks into small steps, then modifying, eliminating or replacing steps which prevented the dementing person from completing the task (eg having a bath, playing golf, cooking) There was also much discussion on appropriate leisure pursuits. (d) Reminiscence .OT; 1 \_ 1 hour.: Caregivers were taught how to compile a 'This Is Your Life' book, comprising mementos and photographs which described the past life of the patient. This proved to be a positive experience and subsequently provided a good stimulus for conversation and reminiscing. (e) Coping with physical frailty (various; 3 \_ 1 hour.: First, a physiotherapist discussed back care, walking and mobility aids. Secondly, an OT discussed the use and abuse of aids to daily living; caregivers tried out many of these aids in a modified kitchen, bathroom and bedroom in the occupational therapy department. Thirdly, a registered nurse outlined the care of bed-bound, chair-bound and incontinent persons.

6. Fitness, diet, organizing the day and home .various; 3 \_ 1 hour. (a) A physiotherapist encouraged fitness and flexibility in caregivers as well as patients. For example, a daily routine of walking after lunch was established. (b) A dietitian outlined the principles of a healthy, balanced diet and discussed time-saving kitchen techniques as well as food fads and eating problems associated with dementia. (c) In a session on work simplification, and organization and safety in the home, techniques of prioritizing, simplifying and using outside assistance were explored by the OT to help

caregivers achieve a balance between work, leisure and rest in their life. Safety issues pertinent to the older person and the dementing process were discussed and a safety checklist for the home and garden provided.

7. Medical aspects of dementia (psychiatrist; 2 \_ 1 hour.: These sessions provided information on dementia, different types of dementia, principles of management, psychiatric complications and behavioural changes, use and abuse of medication, the interaction of dementia and other illnesses, and prognosis. As with all of these sessions, much time was given to answering individual concerns.

8. Using community services (welfare officer; 1 \_ 1. hours). This very practical session included procedures and eligibility for obtaining social services, provision of useful contact persons and access to and availability of services. For some caregivers it was a novelty to adopt the role of care manager, eg organizing other people such as domiciliary nurses to help with provision of care, rather than that of care provider, where the caregiver undertook tasks personally. Reinforcement was given that use of services did not represent failure or dereliction of duty. Numerous pamphlets on domiciliary nursing care benefits, pensions, methods of assessing nursing homes and hostels and mechanisms for complaints about services were provided.

9. Planning for the future (psychiatrist; 1 \_ 1 hour). The last formal session was fairly open and considered how to plan for emergencies, eg should something happen to the caregiver. Other issues such as driving, medications, safe use of alcohol, smoking, legal, medical and financial matters and other emergency contingencies were discussed.

10. Coping with problem behaviours. There was no time set to discuss these specifically, though each session was structured to allow discussion of current or potential problems such as aggression or wandering. The aim was to give caregivers a broad education on the possible reasons for the emergence of problems and a repertoire of skills to prevent their occurrence or to deal with them if they occurred. The patient programme For caregivers to be able to learn in a relaxed setting they needed to know that their partners were receiving satisfactory care. Patients had their own programme which consisted of (i) general ward activities such as occupational therapy, outings and relaxation classes, and (ii) specific programmes group discussion of their frustrations with their memory loss, reminiscence therapy and a memory retraining programme. Given a forum for honest and open discussion, patients established strong bonds with each other, were able to discuss their feelings surprisingly frankly and often became protective of each other. Memory techniques included use of visualization and one-tracking (focusing on one task to be remembered at a time). While we were unable to demonstrate any improvement in cognitive function (H. Christensen, unpublished), our impression was that patient morale improved.

Table 2. Timetable of dementia caregivers' training programme

	am	pm	Evenin
Day 1	Admission procedures	Getting to know you'	<i>Socializing</i>
	Welcome and orientation	Reducing carer distress 1	
Day 2	Stress management and relaxation	Healthy eating for older people'	<i>Film night</i>
	Telling your story'		
	Reducing carer distress 2		
Day 3	Relaxation	Reminiscence	<i>Carer outing</i>
	Reroling	Keeping fit and healthy	
Day 4	Relaxation	Therapeutic use of activities and activity analysis	<i>Socializing</i>
	Assertiveness training 1	Medical aspects of dementia 1	
Day 5	Relaxation practice with tape		<i>Socializing</i>
	<i>Picnic outing</i>		
Day 6	Relaxation practice with tape	<i>Sunday drive</i>	<i>Socializing</i>
	<i>Church</i>		
Day 7	Relaxation	Assertiveness training 2	Extended family sessions
	Communication	Medical aspects of dementia 2	
Day 8	Stress management and relaxation	Work simplification and organization	Extended family sessions
	Reality orientation in the home	Combating burnout	
Day 9	Relaxation	Coping with physical frailty	<i>Socializing</i>
	Use of community services		
Day 10	Relaxation	Farewell afternoon tea and presentation	
	What if 'Dplanning for the future of diplomas		

### **Process**

The course was residential and for a variety of (non-essential) reasons took place in the psychiatric ward of a general teaching hospital, caregiver-patient dyads living in the same room. Advantages of the hospital setting were the availability of facilities and sta.; disadvantages were the inappropriateness of some interactions with psychiatric patients, yet there was no attrition among the 96 participants who attended the programme. The 10-day programme began on a Tuesday and finished on the Thursday of the following week (Table 2). Previously, our 5-day, Monday to Friday, pilot programmes proved too congested and caregivers requested that a weekend be included. This allowed caregivers time to spend talking together, having fun such as a picnic and consolidating some of the knowledge previously presented.

A major aim of the course was for participants to enjoy themselves. Sadly, fun and spontaneity are often lacking from caregivers' lives. Leisure pursuits such as walks, table games like Trivial Pursuit, carpet bowls, singalongs, dances and going out for a drink were included as part of the evening and weekend programme. During these activities caregivers would practise their skills of communication, activity analysis, reality orientation and reminiscence.

Patients and caregivers were given name tags and briefed daily after breakfast in order to review the previous night and to confirm each day's arrangements. Less threatening sessions were scheduled for the first week of the programme; those that required more self-examination or were more confronting about the realities of the dementia were left until the second week. At the end of the programme there was an afternoon tea graduation ceremony and presentation of a diploma.

### **Follow-through**

Follow-through was an essential part of the programme. While the 10-day programme was both intensive and comprehensive and supplemented by take-home written materials and audio tapes, it was felt that the lessons would be lost without reinforcement. Telephone conferences were arranged with the coordinator at decreasing time intervals over 12 months, starting at second weekly and finishing at six weekly. The coordinator's input was gradually diminished on these telelinks. Towards the end of the year, the coordinator would absent herself from teleconference calls. Cohorts of caregivers attended the hospital for follow-up assessments at 3, 6 and 12 months after the completion of the programme, thus providing opportunities for

reunions. Relationships among cohorts of caregivers varied, with some establishing quite close friendships and continuing to meet informally at each other's houses. After the first year, annual telephone follow-ups were conducted. Two outcomes were monitored, nursing home admission and death. Data on these endpoints were obtained for all patients.

### Statistical analyses

Kaplan-Meier survival analysis (22) was used to construct estimated survival curves for the three groups and for an amalgamated immediate and wait-list caregiver training group, and the log rank test was used to compare outcomes between the groups. Time until outcome (death or nursing home admission) was measured from recruitment for all groups. Analysis of variance was used to compare index age, index dementia severity (CDRS) and cognitive impairment (MMSE) and length of follow-up between the groups. The distribution of categorical variables, such as death or institutionalization, between the groups was analysed using the chi-square test.

### RESULTS

Patients were followed up for between 6.5 and 8.5 years (mean = 7.7, SD = 0.50). Length of follow-up differed significantly between the groups, with both the immediate training and the memory retraining groups being followed for on average 7.8 years (immediate SD = 0.56, memory retraining SD = 0.53) and the wait-list group for 7.4 years (SD = 0.37;  $F(2,90) = 6.46, p < 0.01$ ). Of the 33 patients in the immediate caregiver training programme, 21 (64%) had died, four in their own home and 17 in a nursing home. Of the 30 patients in the wait-list caregiver training programme, 16 (53%) had died, three in their own home and 13 in a nursing home. Of the 30 patients in the memory retraining programme, 21 (70%) had died, two in their own home and 19 in a nursing home. Mean time until death was 62.2 months (by group: immediate = 65.0; wait-list = 68.4; memory retraining = 53.0 months). The numbers of patients admitted to nursing homes for each group were 26 (79%), 25 (83%) and 27 (90%) for the immediate, delayed and memory retraining groups respectively ( $\chi^2 = 1.47, df = 2, NS$ ). Mean time until institutionalization was 37.2 months (by group: immediate = 47.5; wait-list = 35.7; memory retraining = 27.6).

Kaplan-Meier survival analysis comparing the two training groups (immediate and delayed) showed no differences for either time to nursing home admission or time to death (log rank test = 0.94,  $df = 1, NS$ ; and log rank test = 0.76,  $df = 1, NS$  respectively). Thus we combined the two training groups for subsequent analyses. When the training groups were compared with the memory retraining group, caregiver training had a significant effect in delaying nursing home admission (log rank test statistic = 4.35,  $df = 1, p < 0.05$ ) and there was a trend towards training delaying patient death (log rank test statistic = 3.03,  $df = 1, p = 0.08$ ) (Figs 2 and 3).

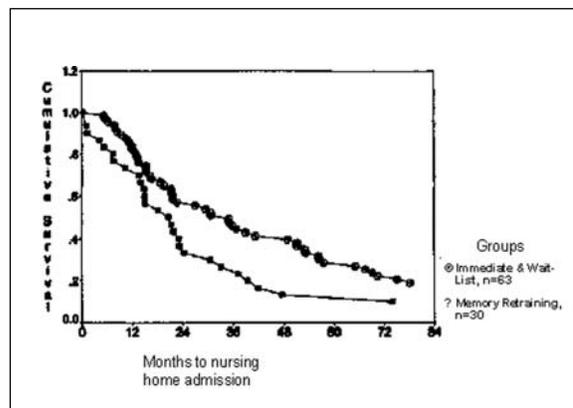


Figure 2. Kaplan-Meier survival functions for nursing home admission comparing the combined training groups with the memory retraining group

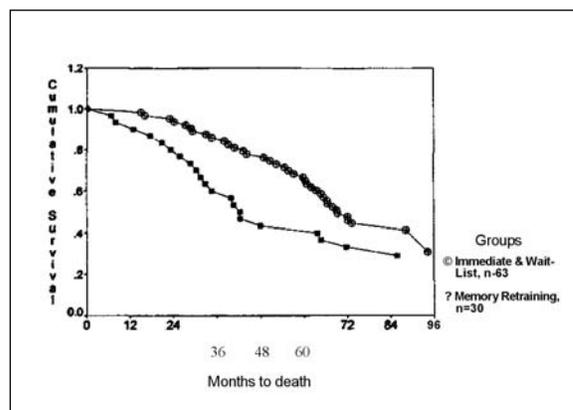


Figure 3. Kaplan-Meier survival functions for death comparing the combined training groups with the memory retraining group

### DISCUSSION

Caregiver intervention programmes have considerable potential. They can improve the quality of life of caregivers and, probably, that of patients. The meta-analysis by Knight (14) and the results from Mittelman (15) confirm the effectiveness of such interventions. Our programme, which was comprehensive, involving many different strands, intensive in that it was highly structured and residential over 10 days in a group of four couples and extensive in that regular telephone conferences with cohorts of caregivers continued over 12 months and was supplemented by written and other materials, was demonstrably effective. The results of the 8-year follow-up were very similar to those of the 5-year follow-up (delaying nursing home admission and delaying mortality) except now the survival curves are converging.

One difficulty in devising such interventions is that of targeting—which intervention for which caregiver with what person with dementia at what stage of the disease? While our empirical study of a package of interventions is unable to evaluate which of its components was effective, we have some qualitative data. At

the 12 months' follow-up when caregivers were asked which part of the programme had been most useful for them, there was marked variety in the answers, suggesting that different components were helpful for different caregivers. Another programme, which focused more narrowly on education and skills training for participants utilizing the support groups of the Alzheimer's Association, was not demonstrably effective although there were a number of logistical and methodological difficulties that may have militated against positive results (23).

A residential setting may be an advantage, and could also be conducted in a holiday resort, a hotel or in a residential facility. The advantage of a residential programme is that it promotes more cohesive bonding and allows for observation of behaviours not easily accessible with a day programme. Others have since conducted programmes as 10 single days at weekly intervals run in conjunction with a day care centre or more intensive 10-day workshops on a daily but non-residential basis. We set a maximum of four caregivers but others have included more caregivers, which clearly has economies of scale. We feel that numbers greater than 8-10 would impede the group process. Also, although there is no empirical support, our experience suggests that the earlier the intervention, the better. Matching of caregiver cohorts would profit from more study. Our impressions are that it may be advantageous to aim for heterogeneity in caregiver gender and generation (spouse and child principally), but for homogeneity as regards dementia severity, geographical area of residence (in order to facilitate post-intervention mutual support building) and possibly ethnic and educational backgrounds.

While the study was not blind, the intervention team was not involved in further management of participants after the first year and had no influence on end-point, nursing home admission or death. We concede that our recruitment procedures may have introduced a sampling bias towards caregivers more receptive to training and more eager to avoid institutionalization, thereby limiting generalizability of the results. However subjects agreed to participate in the study prior to randomisation.

Future research might benefit from a careful comparison of the comprehensive programme that we have described and a targeted, more selective approach. With the latter, the particular needs of individual caregivers would need to be carefully analysed and a tailored package of interventions offered accordingly, eg psychological therapy, education, skills training, practical help. The challenge is to develop specific indications and contraindications for psychosocial interventions so that these can be prescribed accurately (24). Our impression from our pilot groups was that once the dementia has progressed to the later stages, the benefits of training, education and other approaches diminish for both caregiver and patient. However, early in the course of the dementia, training may have a preventa-

tive aspect and may be cost-effective in delaying the need for residential care (2). If confirmed, this has important implications for policy. For example, it may be effective to divert funds from residential care budgets to caregiver training programmes. The arrival of drugs which may prolong the life and cognitive functioning in persons with dementia increases the need for effective caregiver interventions for reasons that are both humanitarian and economic.

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