

Appendix - Evaluation of Training and Activity Programmes

(Brodaty)

Authors: Title: Journal details:	Brodaty H, Gresham M. Effect of a training programme to reduce stress in carers of patients with dementia BMJ (1989); 299: 1375-79
Study Aim:	To reduce the psychological stress and improve skills in coping of people who care for relatives with dementia
Study Population	A Sydney teaching hospital, Australia
Eligible population	People less than 80 years old, mild to moderate dementia, living at home with carer
Population agreeing to be randomized	101 patients and carers
Gender distribution	Carers 44 men 52 women Patients 50 men 46 women
Age distribution	Patients 49-79 years [70.2 (6.5)]
Degree of cognitive impairment	Clinical dementia rating scale 1.1 (0.5) MMSE 17.1 (6.5)
Residential setting	Living at home with carer
Inclusion criteria	Under 80 Living at home with carer
Exclusion criteria	Over 80 years No carer In institutional care
Extent to which study population can be extrapolated	Could be extrapolated to New Zealand subjects
Study Design/Type: Level of randomisation	Assignment in fours to one of three groups
Method of randomisation	Sequential allocation according to date of postal application
Numbers of groups	3
Numbers allocated into each group	33 carers programme, 31 memory training, 32 wait list

(Brodaty)

Blinding	
Baseline measures	Patients <ul style="list-style-type: none"> • orientation information memory concentration scale • dementia rating scale (blessed) • mini mental state examination (MMSE) • activities of daily living/ADL • Hamilton scale for depression • geriatric depression scale

	<ul style="list-style-type: none"> clinical rating scale for dementia <p>Carers</p> <ul style="list-style-type: none"> general health questionnaire Zung depression scale Hamilton scale health diary
Comparison of baseline measures between groups	Groups were comparable
Intervention Type/description	<p>Group 1 Carers received training in coping with people with dementia and patients had memory retraining</p> <p>Group 2 Patients admitted for 10 days carer respite and had memory retraining</p> <p>Group 3 Carers waited six months before receiving training</p>
Duration of intervention	12 months
Dates of intervention	
Compliance	96 of 101 entrants completed the trial
Co-intervention or contamination	Nil
Outcome: Outcome measures	<ul style="list-style-type: none"> GHQ scores at 12 months Entrance into institutional care Measures of clinical deterioration in patients
Cost measures	Not assessed
Measurement of outcomes	At 12 months and at 30 months
Numbers lost to follow-up	5
Evidence of intervention effects - size of effect - precision of effect	Carers programme resulted in significantly lower psychological stress than memory retraining, 12 months 4.69 (5.58) and 7.4 (9.39); p<0.05. At 30 months, 65% of patients were still living at home compared with 26% in memory retraining group.
Total costs	Not assessed
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes
Appropriate analyses undertaken	Yes
Random Error: Sufficient power to detect an effect	Yes
Sufficient length of follow-up to identify an effect	Yes
Systematic Error: Confounding bias	None apparent

Bias due to misclassification and missing subjects	Nil
Analysis bias	Nil
Summary Assessment: Effectiveness (potential benefit)	The intensive intervention programme described for carers of patients with dementia can reduce the psychological morbidity of the carer and delay placement in an institution without increasing the use of health services by patient or carer
Level of evidence	Reasonably strong
Cost effectiveness	Not assessed
Recommendations:	Evidence in favour of the effectiveness of intensive intervention programme for carers in improving their well-being and delaying placement of persons with dementia in continuing care.
Comments:	

(Rovner)

Authors:	Rovner BW, Steele CD, Shmueli Y, Folstein MF.
Title:	A Randomised Trial of Dementia Care in Nursing Homes.
Journal details:	J American Geriatrics Society (1996); 44: 7-13.
Study Aim:	To evaluate the efficacy of a dementia care programme to reduce behaviour disorders in nursing home patients with dementia.
Study Population	Community nursing home, Maryland, USA.
Eligible population	118
Population agreeing to be randomized	89 81 (91%) completed the trial
Gender distribution	Intervention group N = 42 Control N = 39 % female 86% 67% (p<0.05)
Age distribution	Intervention group Control group Mean age 82.0 (8.0) 81.2 (7.2)
Degree of cognitive impairment	Moderate - severe MMSE 9.1 (7.4) intervention 8.9 (6.1) controls
Residential setting	A community nursing home
Inclusion criteria	Presence of a behaviour disorder determined by research nurse or research psychiatrist and psychogeriatric dependency rating scale
Exclusion criteria	Nil
Extent to which study population can be extrapolated	Extent to which these patients with dementia are similar to populations within New Zealand
Study Design/Type: Level of randomisation	Randomised controlled clinical trial
Method of randomisation	Uniform randomisation by computer algorithm
Numbers of groups	2
Numbers allocated into each group	Intervention group - 42 Control group - 39
Blinding	Psychiatrist - blinded. Nurses - unblinded.
Baseline measures	<ul style="list-style-type: none"> • Behaviour rating scales • Psychogeriatric Dependency Rating Scale (PGDRS) • MMSE

Comparison of baseline measures between groups	All characteristics similar except for greater numbers of females in intervention group
Intervention Type/description	<ul style="list-style-type: none"> • Regular activity programme • Psychotropic prescribing carried out by psychiatrists according to a protocol • Education of staff by study psychiatrist
Duration of intervention	6 months
Dates of intervention	1989-1991
Compliance	Full compliance
Co-intervention or contamination	Nil
Outcome: Outcome measures	<p>Primary</p> <ul style="list-style-type: none"> • composite behaviour disorder "present" or "absent" at 6 months <p>Secondary</p> <ul style="list-style-type: none"> • patients requiring antipsychotic medication • restraint use • participation in activities • patient care reimbursement costs
Cost measures	<ul style="list-style-type: none"> • Monthly billing records at baseline and six months
Measurement of outcomes	2, 3, 5 and 6 months after baseline
Numbers lost to follow-up	1 control and 1 intervention patient died during the trial (3 month data used)
Evidence of intervention effects - size of effect - precision of effect	<ul style="list-style-type: none"> • At 6 months 12/42 (28.6%) intervention patients exhibited behaviour disorders cf 20/39 (57.3% controls) OR = 0.38; 95% CI (0.15-0.95) p = 0.037. • Controls more likely to be restrained during activities OR = 2.98; 95% CI (1.1-8.04) p<0.03 or on nursing units OR = 2.14; 95% CI (0.9-5.3) p<0.1 • Controls were more than twice as likely to receive antipsychotics OR = 2.55, 95% CI (0.96-6.76) p<0.06 • Intervention patients activity participation OR = 13.71; 95% CI (4.51-41.73) p = 0.001
Total costs	No significant differences between treatment and controls - Treatment \$US2290.6/month Controls \$US2336.6/month
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes - also active treatment
Appropriate analyses undertaken	Yes
Random Error: Sufficient power to detect an effect	Yes
Sufficient length of	Yes

follow-up to identify an effect	
Systematic Error: Confounding bias	Although the assessing psychiatrist was blinded s/he would need to talk to unblinded nursing staff in order to assess behavioural problems.
Bias due to misclassification and missing subjects	Nil
Analysis bias	Nil
Summary Assessment: Effectiveness (potential benefit)	An activity programme, structured prescribing and staff education appear to improve behaviour in patients with dementia and results in lessened use of psychotropic drugs and restraints
Level of evidence	Reasonably strong
Cost effectiveness	Not shown (neutral)
Recommendations:	Further studies to determine whether these findings can be replicated and longer duration studies should be undertaken
Comments:	

(Mittelman)

Authors:	Mittelman MS, Ferris SH, Shulman E, et al.
Title:	A family intervention to delay nursing home placement of patients with Alzheimer's disease: a randomized controlled trial.
Journal details:	JAMA (1996); 276: 1725-1731.
Study Aim:	To determine the long term effectiveness of comprehensive support and counselling for spouse caregivers and families in postponing or preventing nursing home placement of patients with Alzheimer's disease.
Study Population Country	New York City Metropolitan Area, United States of America
Eligible population	Volunteer sample of 206 spouse caregivers
Population agreeing to be randomized	206 of an eligible 208
Gender distribution	Caregivers No (% female) Treatment 52 (50.5) Control 68 (66)
Age distribution	Age of female caregivers % < 60y/60-69/70-79/80-89 (15/30/42.5/12.5) Age of male caregivers % <60y/60-69/70-79/80-89 (10.5/25.6/45.3/18.6) No differences between treatment and control groups
Degree of cognitive impairment	With female caregiver % mild/moderate/severe (32.5/40.8/26.7). With male caregiver % mild/moderate/severe (30.2/39.5/30.2)
Residential setting	Patients with Alzheimer's dementia living with spouse in community
Inclusion criteria	Living with spouse caregiver and one other relative living in the area
Exclusion criteria	Those without spouse caregivers
Extent to which study population can be extrapolated	<ul style="list-style-type: none"> those persons with dementia with spouse caregivers domiciliary supports available would differ in other societies
Study Design/Type: Level of randomisation	Randomized controlled trial
Method of randomisation	By lottery to treatment or control group

Numbers of groups	Two
Numbers allocated into each group	Treatment 103 / Control 103
Blinding	No
Baseline measures	Global Deterioration Scale (GDS) for subjects. Caregiver assessment of own and patient's physical health. Caregiver satisfaction scale of support.
Comparison of baseline measures between groups	Comparable in all respects except that despite randomisation 50.5% of the caregivers in the treatment group were female compared to 66% in control group (P<0.02). Sex of caregiver was therefore used as a covariant in all subsequent statistical analyses.
Intervention Type/description	Two individual and four family counselling sessions in four months. Treatment group spouses were required to join support groups that met weekly. Thereafter counsellors were continuously available to the treatment group. Control group had normally available services.
Duration of intervention	Four months for counselling, then ongoing
Dates of intervention	Enrolment over a 3½ year period
Compliance	High - outcome of only one case unknown
Co-intervention or contamination	Control group were given counselling and advice on request. It is possible that the control group received more support than usual thus reducing the intervention effect.
Outcome: Outcome measures	<ul style="list-style-type: none"> • Median time from baseline to nursing home placement in days • Geriatric depression scale in carers • Caregiver satisfaction scale • Proportional hazards regression to test risk factors associated with nursing home placement
Cost measures	Not determined
Measurement of outcomes	Every 4 months during first year and every 6 months thereafter up to 8 years
Numbers lost to follow-up	One
Evidence of intervention effects - size of effect - precision of effect	Median time to placement in nursing home was 329 days longer in the treatment than in control group p=0.02. Intervention effective in delaying nursing home placement in early/middle stages of dementia (RR, 0.67; 95% CI 0.47-0.96) p=0.02. Mild dementia (RR 0.38; 95% CI 0.17-0.82). Moderate dementia (RR 0.38; 95% CI 0.17-0.82).
Total costs	Not assessed
Adverse effects	Nil
Analyses: Intention to treat analyses undertaken	Yes
Appropriate analyses undertaken	Yes
Random Error: Sufficient power to detect	Yes

an effect	
Sufficient length of follow-up to identify an effect	Yes
Systematic Error: Confounding bias	No assessment of co-morbidity which is an important factor in determining a move to care
Bias due to misclassification and missing subjects	Nil
Analysis bias	
Summary Assessment: Effectiveness (potential benefit)	A programme of counselling and support can substantially increase the time spouse caregivers are able to care for Alzheimer's disease patients at home, particularly during the middle stages of dementia when nursing home placement is generally least appropriate
Level of evidence	Grade 1
Cost effectiveness	Not available
Recommendations:	Strong evidence for benefits of the intervention in delaying nursing home placement for those with moderate dementia
Comments:	

(Weinberger)

Authors:	Weinberger M, Gold DT, Divine GW et al.
Title:	Expenditures in caring for patients with dementia who live at home.
Journal details:	American Journal of Public Health (1993); 83:3, 338-41.
Study Aim:	To estimate the estimated expenditures incurred in caring for dementia patients who live at home
Study Population Country	Subjects attending a University based memory disorders clinic, USA
Eligible population	Primary caregivers of 264 patients with dementia
Gender distribution	67.4% female 32.6% male
Age distribution	Mean age 59.3 11.9 years
Degree of cognitive impairment	Moderate to severe
Residential setting	Living at home with carers
Extent to which study population can be extrapolated	Probably limited extrapolation to other societies
Numbers of groups	One
Numbers allocated into each group	141
Baseline measures	Primary caregivers were asked to produce service diaries in an attempt to

	identify costs of formal and informal services in home dementia care
Duration of intervention	Six months
Outcome: Outcome measures	Costs of formal and informal services for people with dementia in the community
Cost measures	Expenditures incurred over six months
Numbers lost to follow-up	264 primary care givers - 141 returned diaries and these are analysed
Total costs	Expenditures for formal services \$US6986 for six months Expenditures for informal services \$US786 for six months
Analysis bias	The costs in this study are based on conservative estimates. The subjects were those attending a University-based neurology clinic
Level of evidence	Grade 4
Comments:	The expense of caring for people with progressive dementia living at home may be higher than previously estimated and frequently involves expenses paid directly by patients and their families