

## Brief Report

# Making Memories: pilot evaluation of a new program for people with dementia and their caregivers

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**Objective:** To evaluate the effects of the Alzheimer's Association's (NSW) Making Memories program on people living at home with dementia and their caregivers.

**Methods:** Twenty-four couples participated in the program that included 8 weekly education sessions, individual counselling, occupational therapy, 10 weekly diversional therapy sessions and ongoing monthly support groups. Ratings of psychological distress, quality of life and service use concerning the person with dementia, and depression, psychological distress, quality of life and physical health as regards to the caregiver were completed at baseline, 9 and 24 weeks.

**Results:** Psychological distress decreased significantly over time in persons with dementia. Caregivers were significantly less distressed in relation to behavioural disturbance after controlling for the frequency of the behaviour immediately after the program, but this rose at the 6-month follow-up. For caregivers there was a non-significant trend towards better quality of life but no improvement in psychological distress or depression.

**Conclusions:** The Making Memories program decreased psychological distress in people with dementia. It had a short-term beneficial effect on caregiver reactions to behavioural disturbance that was not maintained at follow-up.

**Key words:** caregiver, dementia, education, stress, support.

### Introduction

Families inevitably shoulder the burden of caring for persons with dementia and, as a result, often experience adverse psychological, physical, social and financial consequences [1]. Caregivers tend to experience higher rates of depression and poorer physical health than non-caregiver controls [2–4], social isolation [5], and direct (e.g. medications) and indirect (e.g. loss of earnings due to relinquishing of paid work) financial costs. Caregivers are crucial for maintaining people affected with dementia in the community. When there is no caregiver, or when the caregiver is stressed, the likelihood of nursing home admission rises sharply [6].

Successful caregiver interventions have been demonstrated to reduce caregiver distress, depression and psychological morbidity; to delay nursing home admission of patients; and to improve patients' psychological well-being [7–10].

The aim of the present study was to determine the effectiveness of the *Making Memories* pilot program run by the Alzheimer's Association (New South Wales). Specifically, we hypothesised that participation in the program would result in lowered overall caregiver psychological distress, caregiver depression, caregiver reaction to problem behaviours and patient psychological distress.

### Methods

#### Sample

Twenty-four persons with early dementia and their caregivers volunteered for and participated in the *Making Memories* program conducted by the NSW Alzheimer's Association. As the Alzheimer's Association decided on ethical grounds against a wait-list control group, no comparison group was used.

#### Intervention

The *Making Memories* program comprised discussion and behavioural modification components and ongoing support. The discussion component consisted of 8 weekly, 2-h sessions during which people with dementia participated in a memory loss group and caregivers concurrently attended an education and support group. Topics discussed included planning for the future, communication, anger and frustration. At approximately 4 weeks, couples had single sessions with both a counsellor and a diversional therapist. The behavioural modification component consisted of 10 weekly leisure activity groups in which a diversional therapist taught participants with dementia, task analysis to simplify and increase pleasure from activities. Caregivers concurrently met in a self-directed group. After completion, participants continued to attend monthly support and discussion groups.

#### Assessment

Assessments were performed before commencing the program (baseline), at the end of the program and 24 weeks after commencing the program.

#### Instruments

##### *Person with dementia and caregiver demographics and physical health (via interview with caregiver)*

These included age, sex, education, occupation, relationship to caregiver, accommodation arrangements, diagnosis, current

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**Table 1: Variable means and standard deviations (SD) at baseline, 9 and 24 weeks**

	Baseline (mean ± SD)	3 months (mean ± SD)	6 months (mean ± SD)	MANOVA
RMPBCL frequency	14.57 ± 12.68	21.61 ± 16.19	19.00 ± 12.84	
RMPBCL caregiver reaction	28.74 ± 13.23	33.71 ± 15.57	33.50 ± 13.97	$F = 16.37$ , d.f. = 39,3, $p = 0.000^{*†}$
BDI	10.13 ± 6.74	10.42 ± 6.79	10.50 ± 6.81	$F = 0.626$ , d.f. = 44,2, $p = 0.539$
% cases (i.e. BDI ≥ 13)	34.7	40.0	29.2	
Patient GHQ	2.38 ± 2.06	2.25 ± 2.19	1.22 ± 1.93	$F = 10.103$ , d.f. = 19,1, $p = 0.005^{*}$
% cases (i.e. GHQ ≥ 5)	14.8	20.8	8.7	
Caregiver GHQ	3.15 ± 2.64	2.17 ± 2.60	3.17 ± 3.17	$F = 1.762$ , d.f. = 38,2, $p = 0.784$
% cases (i.e. GHQ ≥ 5)	30.0	29.2	25.0	
Caregiver QOL	70.83 ± 16.79	70.63 ± 17.28	72.52 ± 12.04	$F = 4.32$ , d.f. = 71,2, $p = 0.042$
Patient QOL	55.63 ± 22.84	62.17 ± 17.47	61.43 ± 17.11	$F = 0.086$ , d.f. = 38,2, $p = 0.918$
Hours per week service use	0.44 ± 0.99	0.69 ± 1.19	1.48 ± 3.94	$F = 1.295$ , d.f. = 44,2, $p = 0.276$

\*Significant at the 0.007 level. BDI, Beck Depression Inventory; GHQ, General Health Questionnaire; QOL, quality of life; RMPBCL, Revised Memory and Behaviour Problems Checklist. †Controlling for RMPBCL frequency.

medications, use of psychotropics, acetylcholinesterase inhibitors and alcohol, incapacitation due to illness and overall physical health.

#### *Memory and behaviour (via interview with caregiver)*

The Revised Memory and Behaviour Problems Checklist (RMPBCL [11]) is a 24-item caregiver-complete checklist of frequency of behaviours and whether the caregiver was bothered by them. Both are rated on 5-point scales (from 0, never occurred to 4, daily or more often; and from 0, not at all to 4, extremely distressed, respectively).

#### *Cognitive functioning of person with dementia (by interview at baseline only)*

The Mini-Mental State Examination (MMSE [12]) is the most widely used measure of cognitive function.

#### *Person with dementia and caregiver's quality of life (QOL) (both caregiver rated)*

Using the European Quality of Life [13] visual analogue thermometer, caregivers rated their quality of life on a visual scale ranging from 1 to 100.

#### *Current psychological status (caregiver and person with dementia self-complete)*

The General Health Questionnaire (GHQ-12 [14]) is a 12-item, four choice scale widely used for the detection of psychological morbidity with a sensitivity of 89% and specificity of 80%. The GHQ-12 is has been shown to be valid for use in subjects with MMSE scores > 24 [15]. A 28-item version of the GHQ was found to be valid for subjects with MMSE scores between 4 and 21 [16].

#### *Depression (caregiver self-complete)*

The Beck Depression Inventory (BDI [17]) is self-rated: maximum score = 63; ≥ 13 indicates depression.

#### *Service use (caregiver self-complete)*

Caregivers indicated from a list (including day care, house-keeping and counselling) the frequency and duration of the services they were currently using, allowing calculation of total service hours received.

#### **Statistical analyses**

Repeated measures analysis of variance (MANOVA) was used to determine differences between preprogram, postprogram and follow-up assessments of outcome variables. For caregiver QOL, caregiver self-rated health was controlled. For caregiver reaction on the RMPBCL, frequency of problem behaviours on the RMPBCL was controlled. After Bonferroni corrections for seven multiple comparisons, the *P*-value for significance was set at 0.007.

#### **Results**

Twenty-four married couples began and completed the *Making Memories* program. Caregivers were predominantly female (18/24, 75.0%), had an average age of 67.0 (SD ± 8.96; range 45–80) years and had received an average of 11.9 (± 2.56; range 8–16) years of education. Persons with dementia were on average 70.9 (± 9.2; range 49–90) years old with 13.0 (± 2.6; range 8–18) years of education. Their mean MMSE score at baseline was 25.8 (± 3.7; range 18–30). Couples had an average of 2.9 (± 1.1; range 0–5) children and had been living together an average of 40.6 (± 12.0; range 12–55) years. Ten of the 24 (41.7%) persons with dementia were taking acetylcholinesterase inhibitors at baseline, five were on antidepressants and none was taking an antipsychotic.

Mean scores over three time-points for outcome variables and MANOVA results are presented in Table 1. Data were missing on some variables for three subjects. The GHQ scores of persons with dementia decreased linearly significantly over time. After controlling for RMBPCL frequency scores, there was a significant quadratic change on RMBPCL caregiver reaction scores over time with reaction decreasing at 9 weeks then increasing at 6 months. There was no significant change in caregivers' depression or psychological morbidity scores.

#### **Discussion**

The key findings of interest were decreased psychological morbidity in persons with dementia, a short-term decrease in caregiver reactions to behavioural disturbance that was not maintained at follow-up and a trend towards increased caregiver quality of

life after participating in the *Making Memories* program. The main limitations of this paper were the lack of a control group, small subject numbers and limited power.

This quasi-experimental study provides some evidence that the NSW Alzheimer's Association's *Making Memories* program benefits both people with dementia and caregivers. Further research may include a larger sample to enable identification of which program components are most helpful for which caregivers and persons with dementia.

### Acknowledgements

*This study was supported by the Alzheimer's Association of NSW. We are grateful to the study participants, Alzheimer Association staff and Dusan Hadzi-Pavlovic.*

### Key Points

- The *Making Memories* program consisted of individual and group counselling, education, and occupational and diversional therapy and ongoing support groups.
- The program decreased psychological distress in persons with dementia.
- Caregiver depression and psychological well-being did not improve, although there was a trend towards improved caregiver quality of life.

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