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Accepted: 9 May 2008

## Befriending carers of people with dementia: randomised controlled trial

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BMJ 2008;336:1295-7  
doi:10.1136/bmj.39549.548831.AE

### ABSTRACT

**Objective** To evaluate the effectiveness of a voluntary sector based befriending scheme in improving psychological wellbeing and quality of life for family carers of people with dementia.

**Design** Single blind randomised controlled trial.

**Setting** Community settings in East Anglia and London.

**Participants** 236 family carers of people with primary progressive dementia.

**Intervention** Contact with a befriender facilitator and offer of match with a trained lay volunteer befriender compared with no befriender facilitator contact; all participants continued to receive "usual care."

**Main outcome measures** Carers' mood (hospital anxiety and depression scale—depression) and health related quality of life (EuroQoL) at 15 months post-randomisation.

**Results** The intention to treat analysis showed no benefit for the intervention "access to a befriender facilitator" on the primary outcome measure or on any of the secondary outcome measures.

**Conclusions** In common with many carers' services, befriending schemes are not taken up by all carers, and providing access to a befriending scheme is not effective in improving wellbeing.

**Trial registration** Current Controlled Trials  
ISRCTN08130075.

### INTRODUCTION

Providing care for a person with dementia is stressful and demanding, and carers of people with dementia have poorer physical and mental health than carers of people with other conditions.<sup>1</sup> A short term (eight week) trial of the provision of a befriending, peer support intervention for family carers of people with dementia found that it had no significant impact.<sup>2</sup> As

friendships take time to evolve, and therefore befriending should be evaluated over the long term, we carried out the befriending and costs of caring (BECCA) randomised controlled trial of a long term voluntary sector based befriending intervention.<sup>3</sup>

### METHODS

#### Design

We used a randomised controlled trial to compare usual care plus a social support intervention (access to a befriender facilitator) with control (usual care) for carers of people with dementia. We collected data at baseline and at 6, 15, and 24 months after randomisation. We identified the 15 month data as the main outcome data at the start of the trial.

#### Participants

Participants were family carers of a community dwelling recipient of care with a primary progressive dementia. We recruited carers between April 2002 and July 2004 in community settings in the counties of Norfolk and Suffolk and in the London Borough of Havering. Carers were eligible to participate if they were spending 20 hours or more a week on care tasks.

#### Baseline assessments and randomisation procedures

Researchers did baseline assessments before randomisation. Interviews generally took place in carers' own homes. Baseline measures included demographics; service use; carers' wellbeing and health related quality of life; and carers' burden, relational deprivation, loneliness, and perceived social support. We block randomised participants and stratified them by kinship of the carer to the person with dementia and by density of population. Trial participants were not blinded to group

This article is an abridged version of a paper that was published on [bmj.com](http://bmj.com). Cite this article as: *BMJ* 2008, doi: 10.1136/bmj.39549.548831.AE

allocation. However, interviewers were independent of the befriending services, and we used well validated self report inventories for measuring outcomes.

#### Intervention and control conditions

All participants and recipients of care received usual care as provided in their area by health, social, or voluntary services. Typical services included community psychiatric services, day hospitals, day centres, home care or personal care, respite care, and carers' information or support groups. We sent all participants information on local services for carers.

We offered carers in the intervention group contact with a local befriending scheme set up specifically for the research trial.<sup>3</sup> BECCA befriending schemes were based in voluntary organisations with experience of supporting befriending volunteers and were organised and administered separately from the research interviews. Each scheme was coordinated by a befriender facilitator, who had responsibility for the recruitment, screening, training, matching, and ongoing support of befriending volunteers. Befriending volunteers had the role of providing emotional support for their matched carers through companionship and conversation and being a "listening ear." We also permitted informational support or "signposting" in limited, appropriate circumstances. We explicitly excluded advice giving and practical caring tasks that would otherwise be carried out by a paid worker. The volunteers followed good practice guidelines for volunteer support. Volunteers participated in 12 hours of training. We expected that befriending contact would be weekly home visits for at least six months.

#### End points

The primary end point was carers' wellbeing, as measured by the seven item hospital anxiety and depression scale (HADS) depression scale.<sup>4</sup> Secondary end points were health related quality of life (quality adjusted life years and the EuroQol visual analogue scale),<sup>5</sup> wellbeing as measured by the HADS anxiety scale,<sup>4</sup> positive affectivity (positive and negative affectivity scale, PANAS),<sup>6</sup> loneliness,<sup>7</sup> and perceived social support (multidimensional scale of perceived social support, MSPSS).<sup>8,9</sup> We also recorded institutionalisation and death of the person with dementia.

#### Statistical methods

From the sample size calculations and the lower than anticipated dropout rate at six months, our

randomisation target was 235 carers. We assumed that the HADS, PANAS, MSPSS, and loneliness scores followed a normal distribution. We tested for a difference in means between groups and used a general linear model to compare groups while adjusting for baseline scores and by stratification variables. We tested for a difference in median time to institutionalisation between the two groups.

We did accuracy checks and missing data analyses. Psychometric data were generally complete (missing data less than 5%); more data were missing for baseline interviews than for follow-up interviews. We did two pre-planned subgroup analyses on the primary end point: an analysis including those carers who received their group intervention as described in the protocol and an analysis including only carers who were spouses of the people with dementia.

#### RESULTS

We received expressions of interest from 316 potential participants. After exclusions, 236 carers met the study entry criteria and were randomised, 116 to the intervention group and 120 to the control group (see [bmj.com](http://bmj.com)).

Baseline data on demographic, psychometric, and service use variables showed that most participants were white, female, above retirement age, and living with and usually married to the person with dementia. Almost all were providing daily assistance. The mean age of carers was 68 (range 36-91) years, and the mean duration of caring was just under four years. The mean age of the people with dementia was older, at 78 years. One in five (17%) carers reached case levels of depression (HADS depression score  $\geq 11$ ). Baseline comparability between the groups was good.

Overall retention was good. At 24 months, 190 (81%) of the original 236 carers were still participating in the study. The withdrawal rate was almost identical in the two groups. The main reason for loss was carers' health, and six carers died. All carers who were followed up were included in the analysis, with the exception of three intervention carers and two control carers who had missing HADS data at baseline.

We found no evidence for a benefit of intervention over control at any time point, either for the unadjusted analysis or when we repeated analyses by using a general linear model with baseline scores and the stratification variables as covariates (table). Analyses of the secondary end points also showed no evidence of

Primary endpoints at 6, 15, and 24 months post-randomisation (HADS depression scale)

| Time point | Intervention (n=116) |             | Control (n=120) |             | Unadjusted analysis*    |         | Adjusted analysis†                    |         |
|------------|----------------------|-------------|-----------------|-------------|-------------------------|---------|---------------------------------------|---------|
|            | No                   | Mean (SD)   | No              | Mean (SD)   | Mean difference (95%CI) | P value | Least squares mean difference (95%CI) | P value |
| 6 months   | 104                  | 6.03 (3.63) | 113             | 5.84 (3.96) | -0.193 (-1.21 to 0.83)  | 0.709   | -0.485 (-1.23 to 0.26)                | 0.201   |
| 15 months  | 96                   | 6.03 (4.00) | 106             | 6.71 (4.18) | 0.676 (-0.46 to 1.81)   | 0.241   | 0.468 (-0.50 to 1.44)                 | 0.342   |
| 24 months  | 93                   | 6.25 (4.12) | 97              | 6.35 (4.59) | 0.103 (-1.15 to 1.35)   | 0.871   | -0.207 (-1.32 to 0.90)                | 0.713   |

HADS=hospital anxiety and depression scale.

\*Based on two sample *t* test.

†Based on general linear model adjusting for baseline difference, kinship, and area (that is, stratification variables).

**WHAT IS ALREADY KNOWN ON THIS TOPIC**

Social support is related to mental and physical health  
 Caring for people with dementia adversely affects social support  
 Short term peer support for carers of people with dementia is not effective

**WHAT THIS STUDY ADDS**

Long term befriending was taken up by a minority of carers  
 Access to a befriending service did not improve carers' wellbeing

any significant differences between groups for any of the variables considered at any time point (see [bmj.com](http://bmj.com)).

In the pre-planned subgroup analyses, the per protocol analysis indicated a between group difference of borderline significance at the 15 month time point. The spouses-only subgroup analysis resulted in no statistically significant difference between intervention and control. When we looked at time to institutionalisation with death or end of study as a censor when these occurred before institutionalisation, we found no difference between groups (intervention median 728 days, control median 707 days;  $P=0.673$ , log rank test).

**DISCUSSION**

The BECCA trial evaluated the impact of access to a voluntary sector based befriender facilitator for family carers of people with dementia. We found no evidence for a benefit of "access to a befriender facilitator" on primary or secondary outcome measures. This negative finding may be due to the limited uptake of the befriending intervention and to the higher than anticipated levels of family support and contact with carers' support services. Where carers of spouses have local family, interventions to mobilise family resources are known both to reduce the carer's depression and to delay institutionalisation of the person with dementia.<sup>10</sup> In the BECCA trial, befriending was more likely to be used by carers with no local family and little contact with family, friends, or neighbours.<sup>11</sup>

**Generalisability of results**

The external validity of this pragmatic trial is high, and the level of psychological morbidity in carers is in keeping with other studies of carers of people with dementia.<sup>12,13</sup> Two aspects limit its generalisability: lack of ethnic mix and wide geographical spread. The challenge of travel in rural areas led to decisions to alternate face to face meetings with telephone befriending or to meet fortnightly rather than weekly.

**Limitations of the study**

At 48%, the proportion of carers requesting a match with a befriender is similar to the level of participation in other trials of psychosocial interventions involving carers. However, only 37 (32%) intervention carers received the intended minimum duration of match (six months) before the 15 month follow-up, of whom five

withdrew from the follow-up and one died. Furthermore, the intended "dose" of befriending (one hour a week) was rarely achieved. The difference between intervention and control conditions was narrow, given that the research interviewers were frequently experienced as "a good person to talk to" and befriending support was at a low level.

**Conclusion**

Access to a befriender facilitator is not effective in improving carers' wellbeing or health related quality of life. Future studies may benefit from selection criteria that maximise the likelihood of uptake of the intervention, although this would reduce the external validity.

We thank Norwich and Norfolk Voluntary Services, Age Concern Suffolk, and Age Concern Havering for hosting the befriending schemes and all the participating carers for their time and support. We also thank Tom Arie for the initial suggestion of evaluating voluntary sector support for carers.

**Contributors:** See [bmj.com](http://bmj.com).

**Funding:** The BECCA trial was commissioned by the NHS R&D Health Technology Assessment (HTA) Programme (project no 99/34/07) after a call for primary research into "support for carers" and the associated peer review process. Volunteers' out of pocket expenses were provided by Norfolk and Suffolk Social Services and the King's Lynn and West Norfolk Branch of the Alzheimer's Society. GC's time was funded through a Department of Health ad hoc grant to North East London Mental Health Trust. The authors' work is independent of the funders. Views and opinions expressed in this paper are not necessarily those of the Department of Health.

**Competing interests:** None declared.

**Ethical approval:** Eastern Multi Regional Ethics Committee (01/5/48), the five local ethical research committees in Norfolk and Suffolk, and Barking and Havering local ethical research committee.

**Provenance and peer review:** Not commissioned; externally peer reviewed.

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**Accepted:** 3 April 2008