

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

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# BMJ

### RESEARCH

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

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#### **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 do carers of people with other conditions. Carers who find caring a stressful experience are at higher risk of mortality than are non-carers. Social aspects of burden include loss of relationship with the recipient of care and reduced social network owing to stigma or lack of opportunities to socialise. In addition, chronic illness can result in family conflicts that reduce the available emotional support, and family and friends may "distance" themselves physically or psychologically from carers. Carers can feel lonely, and loneliness has

been associated with increased mortality and physical and psychiatric morbidity.

In the United Kingdom, one to one social support is commonly provided through voluntary sector based befriending services. Britain has a long tradition of voluntary action, and the emphasis on partnership in recent government policies has given voluntary, community, and users' organisations a more central role in the delivery of services.<sup>34</sup>

We could identify only one published trial of befriending for family carers of people with dementia; it evaluated the provision of a short term (eight week) peer support intervention that showed no significant impact. We may anticipate that friendships take time to evolve, and therefore befriending should be evaluated over the long term. In this paper, we describe the clinical outcomes of the befriending and costs of caring (BECCA) multi-site randomised controlled trial of a long term voluntary sector based befriending intervention. 6

#### **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, as this time point balanced the aims of maximising the likelihood that intervention carers would have experienced the target duration of at least six months' befriending and minimising the proportion of withdrawals from the research interviews.

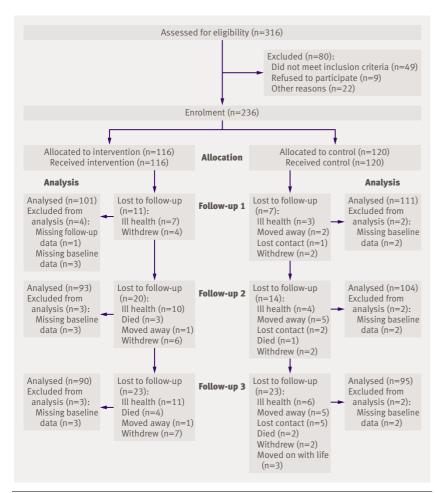
#### **Participants**

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 East Anglian 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. We excluded carers with pronounced congenital or acquired cognitive impairment, as well as those with terminal illness and carers of people in permanent residential, nursing, or long stay hospital accommodation. We obtained informed consent from carers but not from the people with dementia, as the data collection and intervention were carer focused.

#### 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. The trial statistician (LS) drew up randomisation lists before the start of recruitment, and the research administrator (blind to information on participants' characteristics) held these. We block randomised participants by using a concealed block length of six and two stratifications—kinship of the carer to the person with dementia (vertical: daughter, son v horizontal: spouse, sibling) and density of population (urban:  $>10\,000$  people/km<sup>2</sup>v rural:  $<10\,000$  people/ km<sup>2</sup>). Team members involved in carers' consent and interviews were not involved in the randomisation



Flow of participants through study

process. We could not blind trial participants to group allocation because of the nature of the intervention. 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>6</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, including guidelines for those working with potentially vulnerable people.<sup>78</sup> Volunteers participated in 12 hours of training, including boundaries of the role, listening skills, carers' problems, health and safety risk assessment, and confidentiality. The befriender facilitators coordinated befriender-carer matches, supported introductions, and carried out periodic checks. 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. Secondary end points were health related quality of life (quality adjusted life years and the EuroQol visual analogue scale), wellbeing as measured by the HADS anxiety scale, positive affectivity (positive and negative affectivity scale, PANAS), loneliness, and perceived social support (multidimensional scale of perceived social support, MSPSS). We also recorded institutionalisation and death of the person with dementia.

#### Sample size calculation

We based sample size calculations on the HADS and the effect size seen in befriending interventions with different client groups (that is, 0.42 to 0.45), as no directly comparable trials were available at the time of

Table 1 | Baseline characteristics of 236 carers randomised to intervention and control. Values are numbers (percentages) unless stated otherwise

| Mean (SD) age (years)         116         68.4 (11.3)         120         67.6 (11.6)           Female         116         76 (66)         120         76 (63)           Ethnicity: white         116         116 (100)         118         116 (98)           Kinship: spouse         116         76 (66)         120         83 (69)           Urban location         116         71 (61)         120         75 (63)           Cohabiting         116         99 (85)         120         105 (88)           Daily assistance         114         110 (97)         120         116 (97)           24 hours/day "on duty"         105         67 (64)         111         72 (65)           Retired         115         78 (68)         120         80 (67)           Mean (SD) years caring         114         3.9 (7.7)         118         3.7 (3.5)           Mean (SD) EuroQoL VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) EuroQul VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) positive affect (PANAS) score*         108         31.03 (7.5)         118         7.9 (4.6)           Mean (SD) loneliness score*         112   |  | Intervention (n=116) |             | Control (n=120) |             |  |
|---|--|----------------------|-------------|-----------------|-------------|--|
| Mean (SD) age (years)         116         68.4 (11.3)         120         67.6 (11.6)           Female         116         76 (66)         120         76 (63)           Ethnicity: white         116         116 (100)         118         116 (98)           Kinship: spouse         116         76 (66)         120         83 (69)           Urban location         116         71 (61)         120         75 (63)           Cohabiting         116         99 (85)         120         105 (88)           Daily assistance         114         110 (97)         120         116 (97)           24 hours/day "on duty"         105         67 (64)         111         72 (65)           Retired         115         78 (68)         120         80 (67)           Mean (SD) years caring         114         3.9 (7.7)         118         3.7 (3.5)           Mean (SD) EuroQoL VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) EuroQul VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) positive affect (PANAS) score*         108         31.03 (7.5)         118         7.9 (4.6)           Mean (SD) loneliness score*         112   | _  | No                   | Value       | No              | Value       |  |
| Female         116         76 (66)         120         76 (63)           Ethnicity: white         116         116 (100)         118         116 (98)           Kinship: spouse         116         76 (66)         120         83 (69)           Urban location         116         71 (61)         120         75 (63)           Cohabiting         116         99 (85)         120         105 (88)           Daily assistance         114         110 (97)         120         116 (97)           24 hours/day"on duty"         105         67 (64)         111         72 (65)           Retired         115         78 (68)         120         80 (67)           Mean (SD) years caring         114         3.9 (7.7)         118         3.7 (3.5)           Mean (SD) HADS depression score*         113         6.7 (3.6)         118         6.9 (3.9)           Mean (SD) EuroQol VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) positive affect (PANAS) score*         108         31.03 (7.5)         111         31.7 (7.7)           Mean (SD) positive affect (PANAS) score*         112         2.00 (2.2)         115         2.2 (2.2)           Mean (SD) perceived social support (MSPSS) sc   | Carers' characteristics                                |                      |             |                 |             |  |
| Ethnicity: white         116         116 (100)         118         116 (98)           Kinship: spouse         116         76 (66)         120         83 (69)           Urban location         116         76 (66)         120         83 (69)           Urban location         116         71 (61)         120         75 (63)           Cohabiting         116         99 (85)         120         105 (88)           Daily assistance         114         110 (97)         120         116 (97)           24 hours/day "on duty"         105         67 (64)         111         72 (65)           Retired         115         78 (68)         120         80 (67)           Mean (SD) years caring         114         3.9 (7.7)         118         3.7 (3.5)           Mean (SD) HADS depression score*         113         6.7 (3.6)         118         6.9 (3.9)           Mean (SD) EuroQoL VAS score*         112         74.0 (16.8)         114         73.1 (18.1)           Mean (SD) Demoque VAS score*         113         7.5 (4.5)         118         7.9 (4.6)           Mean (SD) Doselive affect (PANAS) score*         113         7.5 (4.5)         111         31.7 (7.7)           Mean (SD) perceived social support (MSPSS) score* </td <td>Mean (SD) age (years)</td> <td>116</td> <td>68.4 (11.3)</td> <td>120</td> <td>67.6 (11.6)</td> | Mean (SD) age (years)                                  | 116                  | 68.4 (11.3) | 120             | 67.6 (11.6) |  |
| Kinship: spouse 116 76 (66) 120 83 (69) Urban location 116 71 (61) 120 75 (63) Cohabiting 116 99 (85) 120 105 (88) Daily assistance 114 110 (97) 120 116 (97) 24 hours/day "on duty" 105 67 (64) 111 72 (65) Retired 115 78 (68) 120 80 (67) Mean (SD) years caring 114 3.9 (7.7) 118 3.7 (3.5) Mean (SD) HADS depression score* 113 6.7 (3.6) 118 6.9 (3.9) Mean (SD) EuroQoL VAS score* 112 74.0 (16.8) 114 73.1 (18.1) Mean (SD) Bands anxiety score* 113 7.5 (4.5) 118 7.9 (4.6) Mean (SD) positive affect (PANAS) score* 112 2.00 (2.2) 115 2.2 (2.2) Mean (SD) perceived social support (MSPSS) score* 113 44.0 (9.9) 116 44.4 (9.1)  Support  Regular family/friend support 109 39 (36) 117 30 (26) Carers' services 113 71 (63) 118 67 (57)  People with dementia's characteristics and service use  Mean (SD) age (years) 116 78.6 (8.9) 120 77.8 (8.5) Day care 114 58 (51) 120 59 (49) Home care   | Female   | 116                  | 76 (66)     | 120             | 76 (63)     |  |
| Urban location       116       71 (61)       120       75 (63)         Cohabiting       116       99 (85)       120       105 (88)         Daily assistance       114       110 (97)       120       116 (97)         24 hours/day "on duty"       105       67 (64)       111       72 (65)         Retired       115       78 (68)       120       80 (67)         Mean (SD) years caring       114       3.9 (7.7)       118       3.7 (3.5)         Mean (SD) HADS depression score*       113       6.7 (3.6)       118       6.9 (3.9)         Mean (SD) EuroQoL VAS score*       112       74.0 (16.8)       114       73.1 (18.1)         Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       39 (36)       117       30 (26)         Carers' services       113 <th< td=""><td>Ethnicity: white</td><td>116</td><td>116 (100)</td><td>118</td><td>116 (98)</td></th<>   | Ethnicity: white                                       | 116                  | 116 (100)   | 118             | 116 (98)    |  |
| Cohabiting 116 99 (85) 120 105 (88)  Daily assistance 114 110 (97) 120 116 (97)  24 hours/day "on duty" 105 67 (64) 111 72 (65)  Retired 115 78 (68) 120 80 (67)  Mean (SD) years caring 114 3.9 (7.7) 118 3.7 (3.5)  Mean (SD) HADS depression score* 113 6.7 (3.6) 118 6.9 (3.9)  Mean (SD) EuroQoL VAS score* 112 74.0 (16.8) 114 73.1 (18.1)  Mean SD HADS anxiety score* 113 7.5 (4.5) 118 7.9 (4.6)  Mean (SD) positive affect (PANAS) score* 108 31.03 (7.5) 111 31.7 (7.7)  Mean (SD) perceived social support (MSPSS) score* 113 44.0 (9.9) 116 44.4 (9.1)  Support  Regular family/friend support 109 39 (36) 117 30 (26)  Carers' services 113 71.63 118 67 (57)  People with dementia's characteristics and service use  Mean (SD) age (years) 116 78.6 (8.9) 120 77.8 (8.5)  Day care 114 58 (51) 120 59 (49)  Home care   | Kinship: spouse  | 116                  | 76 (66)     | 120             | 83 (69)     |  |
| Daily assistance 114 110 (97) 120 116 (97) 24 hours/day "on duty" 105 67 (64) 111 72 (65) Retired 115 78 (68) 120 80 (67) Mean (SD) years caring 114 3.9 (7.7) 118 3.7 (3.5) Mean (SD) HADS depression score* 113 6.7 (3.6) 118 6.9 (3.9) Mean (SD) EuroQoL VAS score* 112 74.0 (16.8) 114 73.1 (18.1) Mean SD HADS anxiety score* 113 7.5 (4.5) 118 7.9 (4.6) Mean (SD) positive affect (PANAS) score* 108 31.03 (7.5) 111 31.7 (7.7) Mean (SD) loneliness score* 112 2.00 (2.2) 115 2.2 (2.2) Mean (SD) perceived social support (MSPSS) score* 113 44.0 (9.9) 116 44.4 (9.1)  Support Regular family/friend support 109 44 (40) 117 54 (46) No family/friend support 109 39 (36) 117 30 (26) Carers' services 113 71 (63) 118 67 (57)  People with dementia's characteristics and service use  Mean (SD) age (years) 116 78.6 (8.9) 120 77.8 (8.5) Day care 114 58 (51) 120 59 (49) Home care  | Urban location   | 116                  | 71 (61)     | 120             | 75 (63)     |  |
| 24 hours/day "on duty"     105     67 (64)     111     72 (65)       Retired     115     78 (68)     120     80 (67)       Mean (SD) years caring     114     3.9 (7.7)     118     3.7 (3.5)       Mean (SD) HADS depression score*     113     6.7 (3.6)     118     6.9 (3.9)       Mean (SD) EuroQoL VAS score*     112     74.0 (16.8)     114     73.1 (18.1)       Mean SD HADS anxiety score*     113     7.5 (4.5)     118     7.9 (4.6)       Mean (SD) positive affect (PANAS) score*     108     31.03 (7.5)     111     31.7 (7.7)       Mean (SD) loneliness score*     112     2.00 (2.2)     115     2.2 (2.2)       Mean (SD) perceived social support (MSPSS) score*     113     44.0 (9.9)     116     44.4 (9.1)       Support       Regular family/friend support     109     39 (36)     117     30 (26)       Carers' services       113     71 (63)     118     67 (57)       People with dementia's characteristics and service use       Mean (SD) age (years)     116     78.6 (8.9)     120     77.8 (8.5)       Day care     114     58 (51)     120     32 (27)   | Cohabiting   | 116                  | 99 (85)     | 120             | 105 (88)    |  |
| Retired       115       78 (68)       120       80 (67)         Mean (SD) years caring       114       3.9 (7.7)       118       3.7 (3.5)         Mean (SD) HADS depression score*       113       6.7 (3.6)       118       6.9 (3.9)         Mean (SD) EuroQoL VAS score*       112       74.0 (16.8)       114       73.1 (18.1)         Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120  | Daily assistance                                       | 114                  | 110 (97)    | 120             | 116 (97)    |  |
| Mean (SD) years caring       114       3.9 (7.7)       118       3.7 (3.5)         Mean (SD) HADS depression score*       113       6.7 (3.6)       118       6.9 (3.9)         Mean (SD) EuroQoL VAS score*       112       74.0 (16.8)       114       73.1 (18.1)         Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25) </td <td>24 hours/day "on duty"</td> <td>105</td> <td>67 (64)</td> <td>111</td> <td>72 (65)</td>  | 24 hours/day "on duty"                                 | 105                  | 67 (64)     | 111             | 72 (65)     |  |
| Mean (SD) HADS depression score*       113       6.7 (3.6)       118       6.9 (3.9)         Mean (SD) EuroQoL VAS score*       112       74.0 (16.8)       114       73.1 (18.1)         Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)  | Retired  | 115                  | 78 (68)     | 120             | 80 (67)     |  |
| Mean (SD) EuroQoL VAS score*       112       74.0 (16.8)       114       73.1 (18.1)         Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)   | Mean (SD) years caring                                 | 114                  | 3.9 (7.7)   | 118             | 3.7 (3.5)   |  |
| Mean SD HADS anxiety score*       113       7.5 (4.5)       118       7.9 (4.6)         Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)  | Mean (SD) HADS depression score*                       | 113                  | 6.7 (3.6)   | 118             | 6.9 (3.9)   |  |
| Mean (SD) positive affect (PANAS) score*       108       31.03 (7.5)       111       31.7 (7.7)         Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)  | Mean (SD) EuroQoL VAS score*                           | 112                  | 74.0 (16.8) | 114             | 73.1 (18.1) |  |
| Mean (SD) loneliness score*       112       2.00 (2.2)       115       2.2 (2.2)         Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)  | Mean SD HADS anxiety score*                            | 113                  | 7.5 (4.5)   | 118             | 7.9 (4.6)   |  |
| Mean (SD) perceived social support (MSPSS) score*       113       44.0 (9.9)       116       44.4 (9.1)         Support         Regular family/friend support       109       44 (40)       117       54 (46)         No family/friend support       109       39 (36)       117       30 (26)         Carers' services       113       71 (63)       118       67 (57)         People with dementia's characteristics and service use         Mean (SD) age (years)       116       78.6 (8.9)       120       77.8 (8.5)         Day care       114       58 (51)       120       59 (49)         Home care       115       29 (25)       120       32 (27)   | Mean (SD) positive affect (PANAS) score*               | 108                  | 31.03 (7.5) | 111             | 31.7 (7.7)  |  |
| Support       Regular family/friend support     109     44 (40)     117     54 (46)       No family/friend support     109     39 (36)     117     30 (26)       Carers' services     113     71 (63)     118     67 (57)       People with dementia's characteristics and service use       Mean (SD) age (years)     116     78.6 (8.9)     120     77.8 (8.5)       Day care     114     58 (51)     120     59 (49)       Home care     115     29 (25)     120     32 (27)   | Mean (SD) loneliness score*                            | 112                  | 2.00 (2.2)  | 115             | 2.2 (2.2)   |  |
| Regular family/friend support     109     44 (40)     117     54 (46)       No family/friend support     109     39 (36)     117     30 (26)       Carers' services     113     71 (63)     118     67 (57)       People with dementia's characteristics and service use       Mean (SD) age (years)     116     78.6 (8.9)     120     77.8 (8.5)       Day care     114     58 (51)     120     59 (49)       Home care     115     29 (25)     120     32 (27)   | Mean (SD) perceived social support (MSPSS) score*      | 113                  | 44.0 (9.9)  | 116             | 44.4 (9.1)  |  |
| No family/friend support         109         39 (36)         117         30 (26)           Carers' services         113         71 (63)         118         67 (57)           People with dementia's characteristics and service use           Mean (SD) age (years)         116         78.6 (8.9)         120         77.8 (8.5)           Day care         114         58 (51)         120         59 (49)           Home care         115         29 (25)         120         32 (27)   | Support  |                      |             |                 |             |  |
| Carers' services         113         71 (63)         118         67 (57)           People with dementia's characteristics and service use           Mean (SD) age (years)         116         78.6 (8.9)         120         77.8 (8.5)           Day care         114         58 (51)         120         59 (49)           Home care         115         29 (25)         120         32 (27)  | Regular family/friend support                          | 109                  | 44 (40)     | 117             | 54 (46)     |  |
| People with dementia's characteristics and service use           Mean (SD) age (years)         116         78.6 (8.9)         120         77.8 (8.5)           Day care         114         58 (51)         120         59 (49)           Home care         115         29 (25)         120         32 (27)   | No family/friend support                               | 109                  | 39 (36)     | 117             | 30 (26)     |  |
| Mean (SD) age (years)     116     78.6 (8.9)     120     77.8 (8.5)       Day care     114     58 (51)     120     59 (49)       Home care     115     29 (25)     120     32 (27)  | Carers' services                                       | 113                  | 71 (63)     | 118             | 67 (57)     |  |
| Day care         114         58 (51)         120         59 (49)           Home care         115         29 (25)         120         32 (27)  | People with dementia's characteristics and service use |                      |             |                 |             |  |
| Home care 115 29 (25) 120 32 (27)   | Mean (SD) age (years)                                  | 116                  | 78.6 (8.9)  | 120             | 77.8 (8.5)  |  |
|   | Day care   | 114                  | 58 (51)     | 120             | 59 (49)     |  |
| Respite stays 115 27 (23) 117 29 (25)   | Home care  | 115                  | 29 (25)     | 120             | 32 (27)     |  |
|   | Respite stays  | 115                  | 27 (23)     | 117             | 29 (25)     |  |

HADS=hospital anxiety and depression scale; MSPSS=multidimensional scale of perceived social support; PANAS=positive and negative affectivity scale; VAS=visual analogue scale.

planning.  $^{15\,16}$  Using Nquery,  $^{17}$  and assuming a normal distribution, we calculated that we needed 150 carers in each group to achieve 90% power at the 5% significance level (two tailed), assuming a post-randomisation dropout rate of 20%. As the dropout rate at six months was lower than anticipated, we were able to reduce our randomisation target to 235 carers while maintaining adequate precision and power.

#### Statistical methods

We assumed that the HADS, PANAS, MSPSS, and loneliness scores followed a normal distribution, on the

basis of summary statistics and plots. We initially used a two sample t test with pooled variance to test for a difference in means between groups. We used a general linear model to compare groups while adjusting for baseline scores and by stratification variables (that is, kinship and population density). We constructed confidence intervals for unadjusted and adjusted (least squares) mean differences. We used the logrank test to test 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

Table 2 | Primary endpoints at 6, 15, and 24 months post-randomisation (HADS depression scale)

|            | Intervention (n=116) |             | Control (n=120) |             | Unadjusted analy           | Unadjusted analysis* |                                       | Adjusted analysis† |  |
|------------|----------------------|-------------|-----------------|-------------|----------------------------|----------------------|---------------------------------------|--------------------|--|
| Time point | No                   | Mean (SD)   | No              | Mean (SD)   | Mean difference<br>(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.

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<sup>\*</sup>Higher scores indicate greater depression, perceived good health, anxiety, positive affect, loneliness, and perceived social support.

<sup>\*</sup>Based on two sample t test.

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

data less than 5%); more data were missing for baseline interviews than for follow-up interviews (excluding withdrawals). Where individual data points were missing within a scale, we imputed data by using scale/subscale means.

We did primary and secondary analyses on a modified intention to treat basis, analysing carers according to the group to which they were randomised. We did two preplanned subgroup analyses on the primary endpoint. We did a per protocol analysis including those carers who received their group intervention as described in the protocol—that is, at least six months of befriending

contact in the intervention group and no befriending contact in the control group. We also did a subgroup analysis including only carers who were spouses of the people with dementia. We used SPSS version 12.0.2 and SAS version 8.2 to analyse data.

#### RESULTS

The figure shows the flow of participants through the study. We received expressions of interest from 316 potential participants, of whom 49 did not meet the eligibility criteria. The most common reasons for exclusion were that the person with dementia lived in

Table 3 | Secondary endpoints at 6, 15 and 24 months post-randomisation

|                    | Interv           | ention (n=116)           | Contr  | ol (n=120)     | Unadjusted analysis*        |         | Adjusted analysis†                           |         |
|--------------------|------------------|--------------------------|--------|----------------|-----------------------------|---------|--|---------|
|                    | No               | Mean (SD)                | No     | Mean (SD)      | Mean difference<br>(95% CI) | P value | Least squares<br>mean difference<br>(95% CI) | P value |
| EQ5D—visual an     | alogue scale     |                          |        |                |                             |         |  |         |
| 6 months           | 101              | 75.7 (17.0)              | 112    | 72.9 (17.7)    | -2.81 (-7.51 to<br>1.89)    | 0.240   | -2.06 (-5.51 to<br>1.38)                     | 0.239   |
| 15 months          | 95               | 73.8 (18.3)              | 106    | 69.9 (18.1)    | -3.87 (-8.94 to<br>1.19)    | 0.133   | -2.33 (-6.88 to 2.23)                        | 0.315   |
| 24 months          | 92               | 72.5 (19.7)              | 96     | 68.1 (18.2)    | -4.35 (-9.82 to<br>1.11)    | 0.119   | -3.03 (-8.42 to<br>2.35)                     | 0.268   |
| Carers' quality ac | ljusted life yea | ars (QALYs) gained (cumu | ative) |                |                             |         |  |         |
| 6 months           | 98               | 0.45 (0.14)              | 109    | 0.46 (0.15)    | 0.00 (-0.035 to<br>0.043)   | 0.83    | 0.00 (-0.01 to<br>0.01)                      | 0.69    |
| 15 months          | 88               | 1.00 (0.29)              | 99     | 0.99 (0.28)    | -0.02 (-0.10 to<br>0.06)    | 0.68    | -0.01 (-0.06 to 0.04)                        | 0.74    |
| 24 months          | 84               | 1.55 (0.45)              | 90     | 1.52 (0.45)    | -0.03 (-0.17 to<br>0.11)    | 0.64    | -0.015 (-0.13 to 0.10)                       | 0.79    |
| HADS anxiety sca   | ale              |                          |        |                |                             |         |  |         |
| 6 months           | 104              | 6.35 (4.46)              | 113    | 6.96 (4.37)    | 0.610 (-0.57 to<br>1.79)    | 0.311   | 0.218 (-0.43 to<br>0.97)                     | 0.568   |
| 15 months          | 96               | 6.55 (4.54)              | 106    | 7.55 (4.47)    | 1.005 (-0.25 to<br>2.26)    | 0.115   | 0.610 (-0.33 to<br>1.55)                     | 0.200   |
| 24 months          | 93               | 6.55 (4.49)              | 97     | 6.97 (4.50)    | 0.419 (-0.87 to<br>1.71)    | 0.521   | -0.037 (-1.10 to<br>1.03)                    | 0.946   |
| PANAS—positive     | affect           |                          |        |                |                             |         |  |         |
| 6 months           | 103              | 30.1 (8.13)              | 111    | 31.5 (8.31)    | 1.40 (-0.82 to<br>3.62)     | 0.214   | 0.922 (-0.98 to<br>2.83)                     | 0.341   |
| 15 months          | 96               | 30.5 (8.22)              | 106    | 30.5 (8.02)    | 0.03 (-2.22 to<br>2.29)     | 0.976   | -0.079 (-2.13 to<br>1.97)                    | 0.940   |
| 24 months          | 92               | 30.1 (8.73)              | 95     | 31.2 (8.34)    | 1.10 (-1.36 to<br>3.57)     | 0.378   | 1.17 (-1.26 to<br>3.59)                      | 0.344   |
| Loneliness         |                  |                          |        |                |                             |         |  |         |
| 6 months           | 104              | 2.06 (2.04)              | 112    | 2.21<br>(2.21) | 0.148 (-0.42 to<br>0.72)    | 0.611   | 0.016 (-0.41 to<br>0.45)                     | 0.945   |
| 15 months          | 96               | 2.21 (2.27)              | 106    | 2.57<br>(2.23) | 0.358 (-0.27 to<br>0.98)    | 0.260   | 0.320 (-0.20 to<br>0.84)                     | 0.230   |
| 24 months          | 93               | 2.24 (2.39)              | 97     | 2.63<br>(2.30) | 0.392 (-0.28 to<br>1.06)    | 0.251   | 0.173 (-0.37 to<br>0.72)                     | 0.529   |
| Perceived suppo    | rt (MSPSS)       |                          |        |                |                             |         |  |         |
| 6 months           | 102              | 45.0 (9.02)              | 113    | 45.3<br>(9.16) | 0.351 (-2.10 to<br>2.80)    | 0.778   | 0.044 (-1.93 to<br>2.02)                     | 0.965   |
| 15 months          | 95               | 44.0 (10.19)             | 106    | 44.6<br>(9.88) | 0.606 (-2.19 to<br>3.40)    | 0.669   | -0.756 (-2.89 to<br>1.38)                    | 0.486   |
| 24 months          | 92               | 44.5 (10.29)             | 97     | 45.4<br>(9.17) | 0.894 (-1.9 to<br>3.69)     | 0.529   | -0.460 (-2.76 to<br>1.84)                    | 0.693   |

HADS=hospital anxiety and depression scale; MSPSS=multidimensional scale of perceived social support; PANAS=positive and negative affectivity scale.

<sup>\*</sup>Based on two sample t test.

<sup>†</sup>Based on general linear model adjusting for baseline difference, kinship, and area (that is, stratification variables); in addition, QALYs adjusted for follow-up length.

permanent care or had already died. Other reasons were ill health of the carer and the care recipient having an illness other than a primary progressive dementia. Overall, 236 carers met the study entry criteria and were randomised into the trial, 116 to the intervention group and 120 to the control group. Administrative error led to three control carers being put in contact with a befriender facilitator. They were offered the intervention but under the intention to treat strategy were analysed as control.

Table 1 presents baseline data on demographic, psychometric, and service use variables. 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  $\geq 11$ ). As can be seen from table 1, 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.

Table 2 shows the analysis of the primary end point. 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 3 shows the analyses of the secondary end points. Again, we found no evidence of any significant differences between groups for any of the variables considered at any time point.

Table 4 shows the pre-planned subgroup analyses. The per protocol analysis (intervention group carers receiving at least six months' befriending compared with controls with no contact with a befriender facilitator) 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>18</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>19</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. Two aspects limit its generalisability: lack of ethnic mix and wide geographical spread. Participants were almost exclusively white British, and we can therefore draw no conclusions on the

Table 4 | Subgroup analyses of primary endpoint (HADS depression scale) at 6, 15, and 24 months post-randomisation

|                  | Intervention (n=37) |             | Con | itrol (n=117) | Unadjusted and                | Unadjusted analysis* |   | Adjusted analysis† |  |
|------------------|---------------------|-------------|-----|---------------|-------------------------------|----------------------|---|--------------------|--|
|                  | No                  | Mean (SD)   | No  | Mean (SD)     | Mean<br>difference<br>(95%CI) | P value              | Least squares<br>mean difference<br>(95%CI) | P value            |  |
| Per protocol and | alysis              |             |     |               |                               |                      |   |                    |  |
| 6 months         | 34                  | 5.47 (3.37) | 111 | 5.86 (3.97)   | 0.383 (-1.11 to 1.87)         | 0.612                | 0.107 (-1.00 to<br>1.21)                    | 0.848              |  |
| 15 months        | 31                  | 5.06 (3.45) | 104 | 6.75 (4.21)   | 1.684 (0.04 to 3.32)          | 0.044                | 1.377 (-0.09 to<br>2.84)                    | 0.066              |  |
| 24 months        | 30                  | 4.97 (4.11) | 95  | 6.37 (4.63)   | 1.402 (-0.47 to 3.27)         | 0.140                | 1.038 (-0.63 to<br>2.71)                    | 0.220              |  |
| Spouse carers of | nly                 |             |     |               |                               |                      |   |                    |  |
| 6 months         | 68                  | 6.36 (4.46) | 78  | 6.50 (4.38)   | 0.143 (-1.31 to 1.59)         | 0.846                | -0.332 (-1.24 to 0.57)                      | 0.469              |  |
| 15 months        | 60                  | 6.78 (4.48) | 73  | 7.01 (4.39)   | 0.233 (-1.29 to 1.76)         | 0.764                | -0.110 (-1.24 to 1.02)                      | 0.848              |  |
| 24 months        | 57                  | 6.56 (4.46) | 69  | 7.09 (4.72)   | 0.523 (-1.11 to 2.15)         | 0.527                | 0.146 (-1.15 to<br>1.47)                    | 0.824              |  |

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#### 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

applicability or effectiveness of the befriending intervention for other ethnic or cultural groups. The befriending schemes were set up specifically for the trial and, although local, covered a wider geographical area than would be typical for the host organisations. 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, as many carers were too busy to set aside that amount of time on such a regular and long term basis. 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.

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- Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and non-dementia caregivers. *Gerontologist* 1999;39:177-85.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality—the caregiver health effects study. JAMA 1999;282:2215-9.
- 3 HM Treasury. The role of the voluntary and community sector in service delivery: a cross cutting review. London: Stationary Office, 2002 (available at www.hm-treasury.gov.uk/media/8/4/ CCRVolSec02.pdf).
- 4 Hawkins S, Restall M. Volunteers across the NHS: improving the patient experience and creating a patient-led service. London: Volunteering England,
  - 2006 (available from www.volunteering.org.uk).
- 5 Pillemer K, Suitor JJ. Peer support for Alzheimer's caregivers: is it enough to make a difference? *Res Aging* 2002;24:171-92.
- 6 Charlesworth G, Shepstone L, Wilson E, Thalanany M, Mugford M, Poland F. Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia (PwD), and at what cost? A randomised controlled trial. Health Technol Assess 2008;12(4):1-78.
- 7 National Centre for Volunteering. Safe and alert: good practice advice on volunteers working with vulnerable clients. London: National Centre for Volunteering, 2000.
- 8 Scottish Befriending Development Forum. Code of practice: working together to promote good practice in befriending. Falkirk: Scottish Befriending Development Forum, 1997.
- 9 Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361-70.
- Brooks R. EuroQol: the current state of play. Health Policy 1996;37:53.
- 11 Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: the PANAS scales. J Pers Soc Psychol 1988;54:1063.
- 12 Stroebe W, Stroebe M, Abakoumkin G, Schut H. The role of loneliness and social support in adjustment to loss: a test of attachment versus stress theory. J Pers Soc Psychol 1996;70:1241-9.
- 13 Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *J Pers Assess* 1988;52:30-41.
- 14 Stanley MA, Beck JG, Zebb BJ. Psychometric properties of the MSPSS in older adults. Aging Ment Health 1998;2:186-93.
- 15 Lipsey MW, Wilson DB. The efficacy of psychological, educational, and behavioral treatment: confirmation from meta-analysis. Am Psychol 1993;48:1181-209.
- 16 Harris T, Brown GW, Robinson R. Befriending as an intervention for chronic depression among women in an inner city. I: randomised controlled trial. *Br J Psychiatry* 1999;174:219-24.
- 17 Elashoff JD. nQuery advisor version 5.0 user's guide. Cork, Ireland: Statistical Solutions, 2002.
- Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social support: five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. Soc Sci Med 2006:63:957-67.
- 19 Charlesworth G, Tzimoula X, Higgs P, Poland F. Social networks, befriending and support for family carers of people with dementia. Quality Ageing 2007;8:37-44.
- 20 Cuijpers P. Depressive disorders in caregivers of dementia patients: a systematic review. Aging Ment Health 2005;9:325-30.
- 21 Richards K, Moniz-Cook E, Duggan P, Carr I, Wang M. Defining 'early dementia' and monitoring intervention: what measures are useful in family caregiving? Aging Ment Health 2003;7:7-14.

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