Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review

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SUMMARY

Objective This study reviews the evidence for effects of combined intervention programmes for both the informal caregiver and the person with dementia.

Method Systematic review. Electronic databases and key articles were searched for effect studies of combined programmes, published between January 1992 and February 2005. The resulting 52 reports were scored according to set inclusion criteria.

Results Twenty five reports relating to 22 programmes met the inclusion criteria. Various aspects of caregivers’ mental health and burden were studied. Best results were obtained regarding general mental health. Other aspects often showed modest and varying results. Caregivers’ competence was less often addressed. The effects on the cognitive and physical functioning, behavioural problems and survival of the persons with dementia were modest and inconsistent, whereas their mental health is positively affected and admittance to long stay care is often delayed.

Conclusion Combined programmes may improve some, not all, aspects of functioning for caregiver and person with dementia. Care professionals must define their programme goals and target groups before advising their clients on a combined programme. Research may focus on the effects of programmes that were introduced fairly recently and on subgroups of caregivers (female caregivers, depressed caregivers and people with dementia, and minorities). Copyright © 2007 John Wiley & Sons, Ltd.

KEY WORDS — systematic review; caregivers; dementia; combined interventions; effects

INTRODUCTION

Various studies have shown the negative physical and psychological consequences of caring for a person with dementia (Eagles et al., 1987; Pot, 1997; Adkins, 1999; Cooke et al., 2001; Cuijpers, 2005). Several studies reviewed the evidence of the impact of programmes designed to prevent the negative consequences of caring for a person with dementia (Bourgeois and Schulz, 1996; Zarit et al., 1999; Cooke et al., 2001; Schulz et al., 2002; Brodaty et al., 2003; Droes et al., 2004a). The programmes vary in the degree in which the persons with dementia are involved. Interestingly, combined care programmes addressing both the person with dementia and their caregiver have been shown to be most effective with
respect to the caregiver (Acton and Kang, 2001; Brodaty et al., 2003). An overview of the effects of these combined interventions on both caregiver and person with dementia, however, is missing.

The present study reviews the evidence for effects of combined programmes for both the informal caregiver and the person with dementia.

METHOD

Medline and Psychinfo were consulted in two search strategies covering the period January 1992 to February 2005. One search strategy focused on single studies of interventions, using the following key words: dementia, family members, caregivers, caregiver burden, support program, training, counselling, care-giving skills, intervention, combined intervention, integrated intervention, effec*, effic*. It resulted in 268 potentially relevant studies from the Medline database and 115 studies from Psychinfo. A second search strategy focusing on systematic reviews on the effect of programmes aimed at caregivers of persons with dementia or the persons with dementia. This part of the search involved the above databases and the EBM Reviews-Cochrane database of systematic reviews (in English; German; and Dutch) and resulted in 40 abstracts of potentially relevant reviews in Psychinfo and three in Medline. Nineteen reviews discussed one or more studies on the combined interventions for caregivers and persons with dementia living at home (Brodaty and Gresham, 1989; Cuijpers, 1992; Flint, 1995; Bourgeois and Schulz, 1996; Gräsel, 1997; Dunkin and Anderson-Hanley, 1998; Adkins, 1999; Zarit et al., 1999; Gottlieb and Johnson, 2000; Kennet et al., 2000; Roberts et al., 2000; Acton and Kang, 2001; Cooke et al., 2001; Pusey and Richards, 2001; Cummings and Cole, 2002; Flannery, 2002; Schulz et al., 2002; Souder and Beck, 2003; Dröes et al., 2004a).

Secondly, the first two authors scrutinized the resulting studies and any relevant papers from the reference lists. Fifty-two articles or chapters were thus investigated. Inclusion criteria were: intervention aimed at both caregiver and patient (resulting in personal contacts between care professional, caregiver and person with dementia); caregiver and person with dementia living in their own homes; elderly person suffering from dementia; report of effect study. One article, although published before January 1992, was included, as a complementary publication on the same programme that was published between 1992 and 2005 (Brodaty and Gresham, 1989; Brodaty et al., 1997).

Thirdly, both investigators independently rated the methodological quality of the included studies according to criteria based upon Cochrane Collaboration Guidelines (Clarke and Oxman, 2000).

Finally, we constructed tables describing the outcomes for every programme. In order to facilitate a quick and comprehensive overview the results are described in three columns: significant effects, heterogeneous effects, no significant effects. The heterogeneous effects column includes studies that reported effects that: (a) were significant for some measures of the same outcome category but not for other measures; (b) reached statistical significance at some but not at all measurement points in longitudinal studies (except when later measurement points resulted in significant effects, whereas earlier measurements did not. In the latter case a delayed effect may have occurred); (c) report positive effects for some subgroups but not for the total group that was studied.

RESULTS

Twenty-five reports (relating to 22 programmes) of the 52 studies met the inclusion criteria (Table 1). Some publications described two programmes and some programmes were described in two or more publications. All programmes vary in intensity, duration and the type of client addressed (degree of mental health complaints of person with dementia and carer, severity of dementia).

The quality of the studies according to the Cochrane Collaboration Guidelines ranged from 4 to 9 (Table 1). Eight studies were rated as good quality studies (8 or more). Most studies were not randomised controlled trials and standardised d scores could not be calculated in 12 of the 25 studies, precluding meta-analyses.

Significant effects are defined as significantly stronger ($p < 0.05$) improvement in the programme group than in the control group. For one study this criterion was not applied as a regular control group was not available (Romero and Wenz, 2002).

Effects on caregiver by outcome

The findings on the 25 included studies were classified into three outcome categories with respect to caregivers: mental health (14 studies), burden (13 studies), and competence (7 studies) (Table 2).

Fifteen aspects of Mental health of the caregiver were distinguished. Two of the seven studies reporting on depressive symptoms showed significant improvement. Heterogeneous results were described in three
<table>
<thead>
<tr>
<th>Description of programme</th>
<th>Authors of study</th>
<th>Cochrane Quality rating</th>
<th>Measured interval after pretest</th>
<th>Group size</th>
<th>Caregiver Measurement instruments</th>
<th>Person with dementia Measurement instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Weekly groups during 2 years</td>
<td>Berger et al., 2004</td>
<td>5–6</td>
<td>6, 12, 24 months after start programme</td>
<td>P = 18 C = 18</td>
<td>Mental health: GDS, in course of study replaced by BDI Burden: Zarit Burden Inventory</td>
<td>Cognitive functioning: MMSE GDS and BCKS Physical functioning: NOSGER, Physical Self Maintenance Scale</td>
</tr>
<tr>
<td>2. 10 days-training in hospital</td>
<td>Brodaty and Gershon, 1989</td>
<td>9</td>
<td>3, 6, 12 months</td>
<td>P = 33 C = 32 (waiting list) C = 31 (control)</td>
<td>Mental health: GHQ, Zung</td>
<td>Time to admission: Placement in institution</td>
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<tr>
<td>3. Meeting centres support programme for people with dementia and caregivers; Continuous program.</td>
<td>Droes et al., 2000</td>
<td>5–6</td>
<td>3, 7 months</td>
<td>P = 33 C = 19</td>
<td>Mental health: Philadelphia Geriatric Centre Morale Scale (PGCMS), Cornell Depression Scale</td>
<td>Behavioural problems: Interview for deterioration in daily life in dementia, Assessment Scale Elderly Patients subscales inactivity and aggressive behaviour, Behaviour Observation Scale for Intramural Psychogeriatrics subscale non-social behaviour, Composite measure behaviour problems Time to admission: Institutionalisation/ nursing home admission</td>
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<td>4.</td>
<td>Droes et al., 2004b</td>
<td>6</td>
<td>3, 7 months</td>
<td>P = 36 C = 19</td>
<td>Mental health: Carer Strain Questionnaire, PGCMS GHQ Burden: Social support list, loneliness scale Competence: Jalowiec Coping Scale, Feeling of Competence Scale</td>
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<td>5.</td>
<td>Droes et al., 2004c</td>
<td>6</td>
<td>7 months</td>
<td>P = 89 C = 23</td>
<td>Mental health: PGCMS Dementia Quality of Life</td>
<td>Behavioural problems: Assessment Scale for Elderly Patients and Behaviour Observation Scale for Intramural Psychogeriatrics: subscales non-social behaviour, Composite Measure for behavioural problems Mental health: PGCMS Cornell Scale for Depression in Dementia Dementia Quality of Life</td>
</tr>
<tr>
<td>Description of programme</td>
<td>Authors of study</td>
<td>Cochrane Quality rating</td>
<td>Measured interval after pretest</td>
<td>Group size(^1)</td>
<td>Caregiver Measurement instruments</td>
<td>Person with dementia Measurement instruments</td>
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<tr>
<td>4. Interdisciplinary family group intervention, multi-media training sessions during seven weekly meetings CR: activities and skills training; CG: education, support, skills training</td>
<td>Ostwald et al., 1999</td>
<td>6</td>
<td>3, 5 months</td>
<td>P = 45–53 C = 30</td>
<td>Mental health: CES-D Burden: Zarit Burden Inventory Competence: Revised Memory and Behavioral Problems Checklist (reaction of caregiver)</td>
<td>Behavioural Problems: RMBPC</td>
</tr>
<tr>
<td>5. Multimodal four week treatment programme, four hours a day. CR: memory training, psychotherapy, art therapy, psychomotor therapy; CG: psycho education, psychotherapy, art therapy; Both: therapeutic sessions.</td>
<td>Romero and Wenz, 2002</td>
<td>4</td>
<td>Post</td>
<td>P = 31(^2) No control group, but Alzheimer group and Frontotemporal groups</td>
<td>Mental health: Allgemeine Depression Skala, Mood part of Mehrdimensionaler Befindlichkeitsfragebogen</td>
<td>Mental health: Cornell Depression Scale Behavioural problems: CERAD behaviour rating scale</td>
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<tr>
<td>8. Extensive case management: case load 100 client pairs</td>
<td>Miller et al., 1999</td>
<td>9</td>
<td>Every 6 months to 3 years</td>
<td>P (Programme A) 3965</td>
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<tr>
<td>9. Intensive case management: case load 30 client pairs</td>
<td>Newcomer et al., 1999</td>
<td>9</td>
<td>Every 6 months to 3 years</td>
<td>P (Programme A) and P2 (Programme B) Summed: C = 2.731 C = 2.576</td>
<td>Mental health: Geriatric Depression Scale Burden: Zarit Burden Interview</td>
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<td></td>
<td>Yordi et al., 1997</td>
<td>6</td>
<td>Every 6 months to 3 years</td>
<td>P1 (Programme A) and P2 (Programme B) Summed: 2707 C = 2547</td>
<td>Burden: Constructed. Number of caring hours. Importance of CG in (i)adl support of person with dementia; Total help from third person in adl tasks, Formal help in adl tasks, Unfulfilled needs in adl tasks</td>
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<td>Table 1. (Continued)</td>
<td>Description of programme</td>
<td>Authors of study</td>
<td>Cochrane Quality rating</td>
<td>Measured interval after pretest</td>
<td>Group size</td>
<td>Authors of study</td>
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<td>10. Expanded case management: 2 year support programme</td>
<td>Both: nurse management, systematic and comprehensive support, psychosocial intervention</td>
<td>Eloniemi-Sulkava et al., 2001</td>
<td>9</td>
<td>12, 24 months</td>
<td>P=53</td>
<td>C=47</td>
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</tbody>
</table>
| 11. Different cognitive domains (12 weeks) | Two home based cognitive training programmes for caregiver (as mediator) and person with dementia | Quayhagen and Quayhagen, 2001 | 7 | Post test | Programme 1: P=20, Placebo=19, C=17 | Programme 2: P=18, C=12 | Cognitive functioning: 25-point logical memory Wechsler: WMS-R DRSThis is a specific assessment tool used for evaluating cognitive function.

12. Adapted version (8 weeks) | Two home based cognitive training programmes for caregiver (as mediator) and person with dementia | Quayhagen and Quayhagen, 2001 | 7 | Post test | Programme 1: P=20, Placebo=19, C=17 | Programme 2: P=18, C=12 | Physical functioning: SF36, SIPMobility Restricted activityTime to admission: time to institutionalisation due to behavioural problems |

13. Behaviour therapy and pleasant events | Two interventions for caregiver (as mediator) and person with dementia: | Teri et al., 1997 | 8–9 | Post test, 6 months | P1 = 23 | P2 = 19 | C1 = 10 (typical care) C2 = 20 (waiting list) | Mental health: HDRS | Mental health: HDRS, CSDD, BDI |

14. Behaviour therapy and problem solving | Mental health: HDRS | Teri et al., 1997 | 8–9 | Post test, 6 months | P1 = 23 | P2 = 19 | C1 = 10 (typical care) C2 = 20 (waiting list) | Mental health: HDRS | Mental health: HDRS, CSDD, BDI |

15. Home exercise training programme for person with dementia and caregiver (as mediator) and training of caregiver in behavioural management | Teri et al., 2003 | 9 | 3, 6, 9, 12, 18, 24 months | P=76 | C=77 | | Physical functioning: Functional Independence Measure |


17. Ibidem, but more intensive program. | Gitlin et al., 2003 | 8 | 6 months | P=89 | C=101 | Mental health: Perceived Change Index Burden: RMBCP: upset, memory related problems; upset, disruptive behaviour; Upset with IADL assistance, upset IADL vigilance, hours IADL help, hours ADL help, total days receiving ADL help Competence: Perceived change in ability to manage, Caregiving Mastery Index, Task Management Strategy Index |

18. Individualized intervention package for behaviour manifestations of dementia; | Hinchliffe et al., 1995 | 7 | Post test, 16 months | P=22 | C=18 | Mental health: GHQ, GMS/ICD 10 case numbers | Behavioural Problems: Present Behavioural Examination Cognitive functioning: Memory Test Time to admission: time to institutionalisation/ permanent residential care |

(Continues)
Table 1. (Continued)

<table>
<thead>
<tr>
<th>Description of programme</th>
<th>Authors of study</th>
<th>Cochrane Quality rating</th>
<th>Measured interval after pretest</th>
<th>Group size</th>
<th>Caregiver Measurement instruments</th>
<th>Person with dementia Measurement instruments</th>
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<tbody>
<tr>
<td>19. Two memory clinic visits</td>
<td>Logiudice et al., 1999</td>
<td>7</td>
<td>6, 12 months</td>
<td>P = 25</td>
<td>C = 25</td>
<td>Mental health: GHQ, FLP: Alertness behaviour, emotional behaviour, recreation/pastime, social interaction, sleep/rest, total behavioural problems. Burden: Zarit Burden Inventory. Competence: Dementia Knowledge Test</td>
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<td>CG: interview and advice</td>
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<td>Time to admission: time to institutionalisation permanent residential care.</td>
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<td>Both: family counselling, care plan.</td>
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<td>CR: memory rehabilitation</td>
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<td>Both: counselling in early stage of dementia</td>
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<tr>
<td>CR: nursing care, activities, social care</td>
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<td>(post test, 18 months)</td>
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<td>CG: respite care</td>
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<td>Both: practical and emotional support after comprehensive assessment for both.</td>
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<tr>
<td>CR: nursing care</td>
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<tr>
<td>CG: counselling and support groups</td>
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$^1$P = Programme group; C = control group.

$^2$CR = care recipient (person with dementia); CG = caregiver.
Table 2. Effects of combined programmes by outcome category: caregiver mental health, burden and competence (improvement in comparison to control)

<table>
<thead>
<tr>
<th>Outcome category and outcome measures</th>
<th>Studies reporting significant effects</th>
<th>Studies reporting heterogeneous effects</th>
<th>Studies reporting no significant effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver mental health: Depressive symptoms</td>
<td>1. Romero and Wenz, 2002 2. Teri et al., 1997</td>
<td>1. Ostwald et al., 1999 ns total sample, trend in depressed subgroup 2. Moniz-Cook et al., 1998 trend, more depressed at 6 months, less depressed at 18 months 3. Newcomer et al., 1999 sign but small reduction in three of eight sites, ns over total sample</td>
<td>1. Chu et al., 2000 2. Berger et al., 2004 ns, after 24 months trend: P group more depressed</td>
</tr>
<tr>
<td>Caregiver mental health: General mental health/Psychological and psychosomatic complaints</td>
<td>1. Hinchliffe et al., 1995 2. Moniz-Cook et al., 1998 trend 3. Brodaty and Gresham, 1989 sign after 12 months, trend at other measurement points</td>
<td></td>
<td>1. Droes et al., 2004b</td>
</tr>
<tr>
<td>Caregiver mental health: Well-being</td>
<td>1. Anxiety (Moniz-Cook et al., 1998) 2. Psychiatric caseness (Hinchliffe et al., 1995) 3. Perceived change in affect (Gitlin et al., 2003) 4. Social interaction (after 6 and 12 months, Logiudice et al., 1999)</td>
<td>1. Alertness Behavior (sign after 6 months, ns after 12 months Logiudice et al., 1999)</td>
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<td>Caregiver mental health: Other aspects of mental health</td>
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</table>
| Caregiver Burden: Other aspects | 1. Fatigue (Romero et al., 2002: Alzheimer group) 2. Internal restlessness (Romero et al., 2002: Alzheimer group) 3. Satisfaction with marital relationship (Quayhagen and Quayhagen, 2001: Intervention 1, 12 weeks) 4. Upset with memory problems of person with dementia (Gitlin et al., 2003) 5. Number of unfulfilled needs adl tasks (Yordi et al., 1997) 6. Total days adl help (Gitlin et al., 2003). | 1. Experienced support of Services (Droes et al., 2004b: Sign. after 3 months, ns after 7 months) 2. Total help from third person in adl tasks ns. Trend: Better match formal care and (i)adl tasks (Yordi et al., 1997) | 1. Positive Aspects of burden (Teri et al., 1997) 2. Experienced social support (Droes et al., 2004b) 3. Loneliness (Droes et al., 2004b) 4. Fatigue (Romero et al., 2002: frontotemporal group) 5. Internal restlessness (Romero et al., 2002: frontotemporal group) 6. Satisfaction with marital relationship (Quayhagen and Quayhagen, 2001: Intervention 2: 8 weeks) 7. Upset with disruptive behaviour and (i)adl-problems of person with dementia (Gitlin et al., 2003) 8. Experienced problems (Riordan and Bennett, 1998) 9. Hours (i)adl help needed (Gitlin et al., 2003) 10. Primary caregiver tasks: significantly slower in programme groups (Yordi et al., 1997) 11. Level of secondary caregiver assistance 12. Number of care giving hours (Yordi et al., 1997) | (Continues)
publications. One study showed no significant effects. Finally, one study reported increased depression in the carers participating in a program offering support groups for caregivers and memory/music groups for the persons with dementia.

Of the four studies focusing on General mental health/psychological and psychosomatic complaints three studies found significant improvement (or a trend) due to the programme studied; one study found no significant effects. Overall well-being was focused on in three studies, one reporting significant effects (trend), the other two not.

Of the remaining twelve outcome variables that were described in single studies four studies reported significant effects. One study reported heterogeneous results, seven reported no significant effects.

Thirteen studies focussed on the impact of the intervention on fifteen aspects of the burden of the caregiver.

One of the seven studies reporting on subjective burden showed a positive effect. Heterogeneous results were described in two studies. Three other studies showed no significant effect. In one study subjective burden had increased after 24 months.

The number of studies on the remaining 14 aspects of burden (e.g. upset with memory problems, hours of help needed, unfulfilled needs) was too small to allow for conclusions.

Seven studies provided information on the changes of the programmes on the competence of the caregiver (Table 2). One study resulted in positive findings of support programmes on the caregiver’s competence to provide an adequate response to disruptive behaviour of the person with dementia. Another study reported a significant positive effect on feeling of competence after seven months. Five studies reported heterogeneous results of the four programmes studied: One study reported a significant effect on the coping subscale avoidance after three months, but no effect after seven months. Two studies showed significant improvement in subgroups (women, spouses, minorities) rather than in the total group. Another two studies reported only significant improvement in the subgroup of female household members. Finally, one study reported no significant effect on the competence of the caregiver.

We conclude that clear positive effects of combined programmes on the mental health, burden and competence of the caregiver are difficult to establish. Only a few outcome measures were reported on by an adequate number of studies: caregiver mental health (depressive symptoms, general mental health and well-being) and caregiver burden (subjective burden). General mental health appears to be the most
promising target for combined programmes. The effects of the programmes on other aspects of caregiver mental health, burden and competence are less conclusive.

Effects on people with dementia by outcome

Studies focused on the mental health, cognitive functioning, behavioural problems, physical functioning, delayed admission to long-stay care and mortality of the person with dementia (Table 3).

Three of the five studies focussing on various aspects of mental health of the person with dementia resulted in significant improvements in depression scores in the programme versus a control group. One study showed improvement for some aspects of mental health, but not for others. Another study did not show any improvement in those elderly included in the programme group.

Two of the five studies addressing cognitive functioning, reported significantly less cognitive decline in the programme group than in the control group, one study described heterogeneous results, and in two studies no (significant) difference was established.

One of the nine studies focussing on behavioural problems described positive effects on all behavioural problems measured. Three studies found heterogeneous results and five found no significant effects.

One of the four studies on the physical functioning of the person with dementia resulted in positive findings. One study described heterogeneous results. Two studies showed no significant results.

Eight of the 12 studies reporting on admission into a long-stay facility (usually a nursing home) described positive findings, indicating a longer time period until admission in the programme groups than in the control groups. Three studies reported heterogeneous results. One study found no significant delay of admission.

One study reported a significantly longer survival in the support group than in the control group. Another study did not find a significant effect on mortality.

Combined programmes appear to be effective on the mental health (depressive symptoms) of persons with dementia. The programmes also delay the admission of the person with dementia to long-stay care. The effects on cognitive and physical functioning, behavioural problems and survival of the person with dementia vary.

Combined effects of programmes

Although all 22 programmes aimed to affect both caregiver and the person afflicted with dementia, for only 18 programmes data for the effects on both caregiver and the person with dementia were available.

Four of the 22 programmes resulted in consistent positive results for both caregiver and patient (Teri et al., 1997; Brodaty and Gresham, 1989; Brodaty et al., 1997; Moniz-Cook et al., 1998; Romero and Wenz, 2002). Another six studies reported partly positive results for both caregiver and patient (Vernooij-Dassen, 1993; Vernooij-Dassen et al., 1995; Hinchliffe et al., 1995; Chu et al., 2000; Gitlin et al., 2001; Dröes et al., 2000, 2004b, 2004c). Five studies reported positive results only for the caregiver and seven had only positive results for the person with dementia. One programme had no positive effects at all.

CONCLUSION

We studied the research literature on combined programmes for the effects on the care receiver and the caregiver. 25 of the evaluated 52 studies (22 programmes) were analysed in detail.

Caregiver general mental health is positively affected by combined programmes. The findings for other mental health outcomes, such as depressive symptoms, well-being and for burden are not conclusive. Competence has been addressed in more recent years than aspects of mental health and burden. The combined programmes may be promising for the competence of some subgroups, in particular women and minority caregivers.

For the persons with dementia mental health is often improved and admission to long-stay care is delayed by the programmes.

For 18 of the programmes data are available for both caregiver and person with dementia. Four of the combined programmes resulted in consistent positive results for both caregiver and patient. Another six showed some positive effects for both groups. The remaining studies describe positive results for either group. We conclude that almost half of the combined programmes benefit both caregiver and person with dementia.

DISCUSSION

Our results are hampered by the limited number and varying quality of the available studies. The number of studies using identical instruments and follow-up measurement points in similar target groups is limited. The aims of an intervention, and subsequently the primary outcome measures of its effect studies are often not clearly stated. The use of multiple measurement instruments for the same or similar outcomes increases the risk of chance capitalization.
Table 3. Effects of combined programmes on persons with dementia by outcome category (improvement in comparison to control)

<table>
<thead>
<tr>
<th>Outcome category and outcome measures</th>
<th>Studies reporting significant effects</th>
<th>Studies reporting heterogeneous effects</th>
<th>Studies reporting no significant effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with dementia: cognitive functioning: various cognitive functions</td>
<td>1. Aupperle and Coyne, 2000 2. Moniz-Cook et al., 1998</td>
<td>1. Quayhagen et al., 2001: Programme 1: Improvement in all cognitive functions; decline in all functions in placebo and control group. Significant in some functions, not all. Programme 2: Improvement in all cognitive functions in experimental group; decline in control group. Significant in some functions</td>
<td>1. Berger et al., 2004 2. Riordan and Bennett, 1998</td>
</tr>
<tr>
<td>Person with dementia: behavioural problems: in general, memory related problems and disruption related problems, behavioural disorder</td>
<td>1. Romero and Wenz, 2002</td>
<td>1. Droes et al., 2000: Significant effect problem behaviour, Inactivity (3 and 7 months) and non-social behaviour (7 months) and total score behavioural problems (7 months). Otherwise ns. 2. Hinchliffe et al., 1985: Significant difference after phase 1 (1/5 vs 2/13) and improvement remains; no improvement for waiting list condition after intervention 3. Droes et al., 2004c: Significant effect Inactivity, Non-social behaviour and Behavioural Problems total; ns for Aggressive behaviour.</td>
<td>1. Gitlin et al., 2001 2. Gitlin et al., 2003 3. Ostwald et al., 1999 4. Riordan and Bennett, 1998 5. Berger et al., 2004</td>
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<tr>
<td>Person with dementia: survival</td>
<td>1. Brodaty et al., 1997</td>
<td>1.</td>
<td>1. Miller et al., 1999</td>
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</table>
and complicates interpretation of the results. Many studies lack sufficient power. Regrettably, the included reports did not allow for a meta-analysis.

The modest effects on caregivers’ burden and depression of interventions aimed at caregivers of persons with dementia have been noted before and must be seen in the context of a progressive degenerative condition (Cooke et al., 2001; Zarit and Leitsch, 2001; Schulz et al., 2002; Brodaty et al., 2003; Droes et al., 2004a). Thus, the delay of admission to long-stay care is a major success of combined programmes.

It has been argued that many programmes do not show optimal effects because of their low intensity or dosage (Adkins, 1999; Zarit and Leitsch, 2001). Although some studies show more effects after a long period of support (e.g. Moniz-Cook et al., 1998; Quayhagen and Quayhagen, 2001; Droes et al., 2004c), others find no or modest differences between programmes that vary in intensity or duration (Yordi et al., 1997; Moniz-Cook et al., 1998; Logiudice et al., 1999; Gitlin et al., 2001, 2003). Thus, our results do not suggest that intensive and long programmes are more effective than brief programmes.

In order to explain the relationship between intervention dosage and outcome more information on the effects of different programme components or programme types is needed (Bourgeois and Schulz, 1996; Brodaty et al., 2003; Meiland et al., submitted). The results suggest that attention needs to be paid to the different needs of subgroups. Gitlin et al. (2001, 2003) described relatively better outcomes in female caregivers, in minority caregivers and spouse caregivers. One study showed a greater improvement in mental health in caregivers and persons with dementia with depressive symptoms than in those without these symptoms (Ostwald et al., 1999). Hinchliffe et al. (1995) showed significant improvement in the mental health of depressed caregivers. Recently, lonely caregivers were seen to benefit from the support programme that was included in the present review (Droes et al., 2006). A programme targeting depressed persons with dementia improved their mental health (Teri et al., 1997). Gitlin et al. (2001, 2003) and Chu et al. (2000) showed that it may be worthwhile to target a sample with mild dementia.

Just as combined programmes may improve by addressing specific subgroups, a focus on specific rather than a multitude of needs, may be productive, as Teri et al. show (1997, 2003).

The large number of inconclusive effects precludes recommendations of immediate large scale implementation of evidence based combined programmes.

**KEY POINTS**

- Combined intervention programmes are often effective in delaying admittance to long stay care and to a lesser extent in improving the general mental health of the caregiver and mental health of the person with dementia. Effects on other mental health aspects, burden and competence of the caregiver, and on survival, physical health, cognitive functioning and behavioural problems of the person with dementia are less conclusive.

- Research and practice should focus on the diversity of needs of different target groups for whom programmes may be most effective.

- Care professionals must define their programme goals and target groups well.

In the area of clinical decision making the results regarding institutionalization, caregiver general mental health and the mental health of people with dementia are promising. The meaning of various other outcomes such as caregiver depression, burden and competence is still debatable. Care professionals and policy makers may address those for whom positive effects may be expected, such as female and minority caregivers and depressed persons with dementia.

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**REFERENCES**


Dro¨es RM, Meiland FJ, van Tilburg W. 2006. Effect of meeting centres support programme on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging Mental Health* 8: 201–211.


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Soudier E, Beck C. 2003. Nursing care for persons with cognitive impairment. In *The Dementias. Diagnosis, Treatment and...