

Effectiveness of Nonpharmacological Interventions in Delaying the Institutionalization of Patients with Dementia: A Meta-Analysis

Anouk Spijker, MA,^{*†} Myrra Vernooij-Dassen, PhD,^{*†} Emmelyne Vasse, MSc,^{*†} Eddy Adang, PhD,[‡] Hub Wollersheim, MD, PhD,^{*} Richard Grol, PhD,^{*} and Frans Verhey, MD, PhD[§]

Contemporary healthcare policies are designed to shape the conditions that can help delay the institutionalization of patients with dementia. This can be done by developing support programs that minimize healthcare risks for the patients with dementia and their informal caregivers. Many support programs have been developed, and some of them are effective, but there has been no systematic review with a meta-analysis of all types of nonpharmacological support programs with odds of institutionalization or time to institutionalization as an outcome measure. A systematic review with a meta-analysis was therefore conducted to estimate the overall effectiveness of nonpharmacological support programs for caregivers and patients with dementia that are intended to delay institutionalization. Thirteen support programs with a total of 9,043 patients were included in the meta-analyses. The estimated overall effectiveness suggests that these programs significantly decrease the odds of institutionalization (odds ratio (OR) = 0.66, 95% confidence interval (CI) = 0.43–0.99, $P = .05$) and significantly increase the time to institutionalization (standardized mean difference (SMD) = 1.44, 95% CI = 0.07–2.81, $P = .04$). A meta-analysis of the best-quality studies still showed a positive significant result for the odds of institutionalization (OR = 0.60, 95% CI = 0.43–0.85, $P = .004$), although the time to institutionalization was no longer significant (SMD = 1.55, 95% CI = –0.35– 3.45, $P = .11$). The analysis of the intervention characteristics showed that actively involving caregivers in making choices about treatments distinguishes effective from ineffective support programs. Further investigation should be directed toward calculating the potential efficiency of these support programs by

applying net-benefit or cost-effectiveness analysis. *J Am Geriatr Soc* 56:1116–1128, 2008.

Key words: informal caregivers; dementia; nonpharmacological interventions; institutionalization; meta-analysis

In Western Europe, the rapidly aging population will, according to the estimates, peak in approximately 2040.¹ An aging population demands more health care and puts pressure on the healthcare budget. The institutionalized care of patients with dementia is one of the three most expensive areas of health care.^{2,3} This budgetary constraint necessitates the exploration of temporary alternatives, such as care at home and the postponement of institutionalization. Care at home is often intensive and burdensome. Informal caregivers of patients with dementia reportedly carry a greater burden than informal caregivers of other chronically ill patients,⁴ and they are at greater risk of depression.^{5–7} Support is required to prevent informal caregivers from becoming overburdened and depressed. An informal caregiver's sense of competence (feelings of being capable of giving care) is a strong determinant of delaying institutionalization.⁸ Contemporary policies, therefore, are designed to shape conditions favorable for caring for patients with dementia at home as long as possible and to minimize the risks for informal caregivers. Several support programs for caregivers of patients with dementia have been developed, but the results concerning the effectiveness with regard to same outcome measures are conflicting.^{9,10} This raises the question "What support programs are available, and what is known about their effectiveness?" No systematic review has included a meta-analysis of the data to estimate the effectiveness of all types of nonpharmacological support programs with the odds of institutionalization or time to institutionalization as an outcome measure. Therefore, the literature has been systematically reviewed to estimate the overall effectiveness of nonpharmacological support programs for caregivers and patients with dementia in delaying or preventing institutionalization.

From the ^{*}Centre for Quality of Care Research; [†]Alzheimer Centre, Radboud University, Radboud University Nijmegen Medical Centre, Nijmegen, the Netherlands; [‡]Department of Epidemiology, Biostatistics, and Health Technology Assessment, Radboud University Nijmegen Medical Centre, Nijmegen, the Netherlands; and [§]Department of Psychiatry and Alzheimer Centre Maastricht, University Hospital of Maastricht, Maastricht, the Netherlands.

Address correspondence to Anouk Spijker, MA, Centre for Quality of Care Research (WOK), Radboud University Nijmegen Medical Centre, P.O. Box 9101/KWAZO 114, 6500 HB Nijmegen, the Netherlands.
E-mail: A.Spijker@kwazo.umcn.nl

DOI: 10.1111/j.1532-5415.2008.01705.x

METHODS

Study Design

This study was a systematic review of the literature and a meta-analysis of the data of the relevant publications.

Search Strategy

A multicomponent search strategy was used to optimize the identification of relevant studies. The computerized databases of PubMed (including Medline), Web of Knowledge, and PsycInfo were searched in March 2006. The PICO worksheet¹¹ was used to identify subject-specific keywords to describe the population, comparison, and outcomes of interventions. The search terms referred to six subject-specific keywords: controlled studies, dementia, costs, institutionalization, time spent giving care, and caregivers. Depending on the nature of the selected database sources, medical subheading terms, a thesaurus or a combination of a thesaurus and free text, and words from the selected subject-specific keywords were combined with the Boolean operator “OR.” The three searches referring to the outcome measure were then combined with the Boolean operator “OR.” The results were combined with the Boolean operator “AND” for the subject-specific keywords referring to controlled studies, dementia, and caregivers. Database source-specific filters were used wherever possible to limit the search period to January 1990 to March 2006. In addition, an unindexed search strategy with the same set of six subject-specific keywords was developed to identify studies in PubMed that would not yet have been cited or indexed. The results obtained from both searches were scrutinized for studies that met the inclusion criteria. The snowball method was used to manually check the references of the included studies to identify any relevant studies that had not yet been included.

Inclusion Criteria

Two reviewers (AS, MVD) independently assessed the retrieved studies for inclusion. The initial selection for inclusion was based on the title and abstract of the study. In cases of doubt, a full copy of the study was scanned to determine whether it should be discarded. For the final selection, full-text copies of the candidate studies were scrutinized. Both reviewers used the inclusion criteria that required:

1. a study population of patients with dementia and their informal caregivers
2. community-dwelling patients with dementia and informal caregivers
3. an outcome measure of institutionalization
4. a single-study design (not a review or a meta-analysis)
5. a controlled, clinical study
6. a nonpharmacological study
7. a study written in English

Disagreement between the reviewers about whether to include a particular study was resolved by discussion.

Methodological Quality

The methodological quality of the included studies was assessed and reported in accordance with the guidelines of the Cochrane Consumers and Communication Review

Group,¹² which recommends the evaluation of selection bias, performance bias, detection bias, and attrition bias. Each source of potential bias was assessed with respect to the following quality elements: randomization, allocation concealment, baseline comparability (selection bias), blinding of participants or providers (performance bias), blinding of outcome assessors (detection bias), reporting of attrition rate, and the use of intent-to-treat analyses (attrition bias). Two reviewers (AS, EV) independently assessed the methodological quality of the studies. If assessment was not possible, the quality element under consideration was scored as “unknown.” All positively scored quality elements were counted; the maximum total score was 7. Disagreements between reviewers were resolved by discussion, which led to consensus.

Data Extraction

Data extracted from the studies comprised a description of the methods used, the participants, the intervention and its characteristics, the measured outcomes and their effect or effect size, and the methodological quality. To ensure standardized scoring, the Cochrane Group’s predesigned table¹³ was used and modified until a tailor-made, workable format evolved. Because the studies were expected to be heterogeneous with respect to methods, participants, and interventions, they were described qualitatively in detail. The results are summarized alphabetically according to author in Table 1.

Meta-Analysis

The Cochrane Collaboration Group’s Review Manager 4.2 (the Cochrane Collaboration, Copenhagen, Denmark) was used to present the overall estimate of the differences between the experimental group and the control group in the odds of institutionalization and time to institutionalization. The odds ratio (OR) and its 95% confidence interval (CI) were calculated as the effect size for the dichotomous outcome measure odds of institutionalization. The OR is a relative measure of risk indicating how much more likely it was that a patient whose caregiver had received the support program would be institutionalized than a patient whose caregiver had not. The standardized mean difference (SMD) and its 95% CI were calculated for the continuous outcome measure time to institutionalization. The SMD compares the time to institutionalization in the experimental and control groups in terms of a uniform standardized score. The SMD was calculated as the difference between the mean change in time to institutionalization (number of days from baseline to institutionalization) in the experimental group and the control group divided by the standard deviation of the difference. By convention, an SMD of 0.8 indicates large intervention effects, 0.5 a moderate effect, and 0.2 a small effect.¹⁴ For both effect sizes, the OR and the SMD, a $P \leq .05$ (two-tailed) or a 95% CI not including the null point was regarded as statistically significant. Separate analyses using a fixed-effects model were undertaken for both measurements of institutionalization. The fixed-effects model assumes that all studies consider a common homogeneous population and that the effect size (OR or SMD) is not significantly different between the various trials. This assumption was tested using the test for heterogeneity that uses the I^2 statistic. The I^2 value provides

Table 1. Characteristics of the 13 Included Studies

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes		
					NI/TTIM	P < .05	Methodological Quality
Brodady et al. 1991	RCT Follow-up 7 and 48 months (median 34.6 months) Two experimental groups	Country: Australia Setting: inpatient, psychiatry unit, general teaching hospital Number: 96 PWD-CG dyads Mean age PWD 70.2 ± 6.5 with mild-to-moderate AD; mean duration of dementia 3.9 ± 2.4 years (range 0.5–10 years), 47.9% women Mean age CG 67.7 ± 8.2, 54.17% women Living arrangement: cohabiting Dropout: 4% Attrition rate: 2.1% Referral: U	E1: Immediate CG training E2: Delayed CG training, approximately 6 months after application C: PWD group memory training, 10 days respite for CG	Multicomponent: Yes Content: A, B, E, G, H Tailor-made: No Professionals: Case manager: No Counselor: No Training: U Caregivers: Intensity: High Involvement: Active Choice: No	E1: 14.6% E2: 18.8% C: 26.0%	Comparing E1 and E2 with C: +	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: + Performance bias Blinded providers/participants: – Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analysis: + Total: 6
Brodady et al. 1997	RCT Follow-up between 6.5 and 8.5 years (mean 7.7 ± 0.5) Two experimental groups	Country: Australia; Setting: inpatient; psychiatry unit, general teaching hospital Number: 93 PWD-CG dyads Mean age PWD 70.1 ± 6.6 with mild-to-moderate AD (average CDRS = 1.1 ± 0.6), 48.4% women Mean age CG 67.5 ± 8.0, 53.8% women, 93% spouses Living arrangement: cohabiting Dropout: 3.1% Attrition rate: 0% Referral through self-referral (41.7%), local doctors (16.7%), Alzheimer Disease and Related Disorders Society (15.6%), media publicity (8.3%), and other sources (17.7%)	Same	Same	E1: 79% E2: 83% C: 90% E1: 47.5 M E2: 35.7 M C: 27.6 M	Comparing E1 and E2: NS Comparing E1 and E2 with C: +	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: + Performance bias Blinded providers/participants: – Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analyses: – Total: 5
Droës et al. 2004	Pretest/posttest control group design; Follow-up at 3 and 7 months, 18-month end point	Country: The Netherlands Setting: outpatient Number: 73 PWD-CG dyads EGr (n = 36); CG mean age 63.6 ± 13.3, 72.2% women, 77.8% partner, 22.2% daughter/son/in-law, 72.2% shared household, PWD mean severity of dementia (BCRSO-56) 31.1 ± 7.5; CG (n = 19): CG mean age 60.9 ± 12.7, 68.4% women, 36.8% partner, 47.4% daughter/son/	E: Meeting Centres Support Program C: Psychogeriatric day care	Multicomponent: Yes Content: B, C, F, G, H Tailor-made: Partly Professionals: Case manager: No Counselor: No Training: Yes Caregivers: Intensity: High Involvement: Passive Choice: Yes	After 3 months E: 5% C: 18.2% After 7 months E: 7.5% C: 39.3% 18 months +	After 3 months: + After 7 months: + 18 months +	Selection bias Randomized: Allocation concealed: – Comparable baseline characteristics: – Performance bias Blinded providers/participants: – Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: +

(Continued)

Table 1. (Contd.)

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes			
					NI/TTIM	P < .05	Methodological Quality	
Dröes et al. 2006	Pre-/posttest control group design; Follow-up at 7 months, 18-month end point	in-law, 52.6% shared household, PWD mean severity of dementia (BCRS) 35.2 ± 7.2; Dropout: 8.8%; Attrition rate: 24.7%; Recruitment through health services or self-referral Country: The Netherlands; Setting: outpatient Number: 128 PWD-CG dyads; EGr (n = 71): CG mean age 64.5 ± 12.4, 83.1% women, 64.8% partner, 26.8% daughter/son (in law), 67.6% shared household, PWD severity of dementia: slight to moderate; CGr (n = 13): CG mean age 60.8 ± 13.6, 76.9% women, 38.5% partner, 53.8% daughter/son (in law), 61.6% shared household, PWD severity of dementia: moderate to moderately severe; Drop out: 11.7%; Attrition rate: 16.0%; Recruitment through health services or self-referral	Same	Same	After 7 months E: 4% C: 25% 18 months E: 9.61 M C: 5.81 M	After 7 months + 18 months +	Same	Intention-to-treat analysis: — Total: 2 —
Eloniemi-Sulkava et al. 2001	RCT; Follow-up at 1 and 2 years	Country: Finland; Setting: combination outpatient and in-home care; Number: 100 PWD-CG dyads; EGr PWD (n = 53): mean age 78.8 (range 65–97), 49% women, mean MMSE score 14.4 ± 6.2; EGr CG (n = 53): mean age 64.8 years (range 34–83), 75% women, 60% spouse; CGr PWD (n = 47): mean age 80.1 (range 67–91), 57% women, mean MMSE score 15.3 ± 5.5; CGr CG (n = 47): mean age 63.3 (range 40–86), 62% women, 51% spouse; Living arrangement: 91% cohabiting; Drop out: 41%; Attrition rate: 0%; Recruitment through 5 Social Insurance Institutions	E: Nurse case management C: Usual services provided for geriatric patients in community care by the municipal social and healthcare system or the private sector	Multicomponent: Yes Content: A, H, F Tailor-made: Yes Professionals: Case manager: No Counselor: Yes Training: Yes Caregivers: Intensity: High Involvement: Passive Choice: Partly	1st year E: 8% C: 19% 2nd year E: 32% C: 30% Subgroup with severe dementia	1st year: + 2nd year: - Subgroup with severe dementia: +	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: — Performance bias Blinded providers/participants: — Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analysis: + Total: 5	
Miller et al. 1999	RCT; Follow-up at 3 years Two experimental groups	Country: USA; Setting: outpatient; Number: 8,095 PWD-CG dyads; EGr (n = 4,151): PWD age range 65–90 90.6%, 61.3% women, MMSE 0–10	E1: Model A, expanded community-based services and case	Multicomponent: Yes Content: F Tailor-made: Yes Professionals:	E: 44.1% C: 42.9% E: 33.7 M C: 34.1 M	All sites combined: NS Model A and model B	Selection bias Randomized: + Allocation concealed: + Comparable baseline	(Continued)

Table 1. (Contd.)

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes	
					N/TTIM	P < .05
		27.7%; 11-15 15.8%; 16-20 21.4%; 21-25 19.9%; 26-30 9.2%; missing 6%; CG aged < 70 58.1%, (range 70-84) 33.5%, at least 68.3% women, CG relationship to PWD: 46.9% partners, 28.8% daughter, 8.1% son; Living arrangement: 70.2% cohabiting with relative; CG (n = 3,944): PWD age range 65-90 90.4%, 59.2% women, MMSE 0-10, 28.1%; 11-15, 16.3%; 16-20, 21.1%; 21-25, 18.6%; 26-30, 10%; missing, 6%; CG, 59.4% aged < 70, 32.5% aged 70-84, at least 69.1% women, CG relationship to PWD: 46.4% partners, 27.6% daughter, 8.4% son; Living arrangement: 70.2%; cohabiting with relative; Dropout: 3.5%; Attrition rate: 10.0%; Recruitment through physician and self-referral	management. Target case manager-to-client ratio of 1:100 with a monthly community services reimbursement cap of \$290-\$489 per month per client E2: Model B, target case manager-to-client ratio of 1:30 with a reimbursement cap of \$430-\$699 per month per client C: Usual care	Case manager: Yes Counselor: No Training: U Caregivers: Intensity: U Involvement: U Choice: U	separately: NS Each site separately: NS, except for Rochester, New York - Subgroups: NS	characteristics: + Performance bias Blinded providers/participants: - Detection bias Blinded outcome assessors: U Attrition bias Intention rate reported: + Intention-to-treat analysis: - Total: 4
Mittelman et al. 1993	RCT, no pre-defined end point of treatment; Follow-up at 1 year	Country: USA; Setting: outpatient; Number: 206 PWD-CG dyads PWD (n = 206): < 60 years of age 8.3%, 60-69 21.8%, 70-79 49%, 80-89 20.9%, 31.5% moderate, 40.3% moderately severe, 28.2% severe impairment; CG (n = 206): aged < 60 13.1%, 60-69 28.2%, 70-79 43.7%, 80-89 15.0%, 58.3% women; Living arrangement: cohabiting; Spouse 100%; Dropout: 11.4%; Attrition rate: 0%; Recruitment through Aging and Development Research Centre, Alzheimer associations and other agencies that provide social services	E: Formal family and individual counseling; participation in AD caregiver support group that met weekly C: Informal support upon request	Multicomponent: Yes Content: A, H, F Tailor-made: Yes Professionals: Case manager: No Counselor: Yes Training: Yes Caregivers: Intensity: High Involvement: Active Choice: Yes	E: 10.7% C: 23.3%	+ Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: + Performance bias Blinded providers/participants: - Detection bias Blinded outcome assessors: + Attrition bias Intention rate reported: + Intention-to-treat analysis: + Total: 5
Mittelman et al. 1996	RCT, no pre-defined end point of treatment, and stratified by CG sex; Follow-up	Country: USA; Setting: outpatient; Number: 206 PWD-CG dyads Age of male PWD with women CG aged < 60 (3.3%), 60-69 (18.3%), 70-79 (50.8%), 80-89 (27.5%), 32.5% moderate, 40.8% moderately	Same	Same	Adjusted for CG sex E: 40.1 ± 3.6 M C: 29.13 ± 3.2 M Women CG E: 34.0 ± 3.8 M	+ Same Subgroup CG: u

(Continued)

Table 1. (Contd.)

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes		
					NI/TTIM	P < .05	
	point at 3 1/2 year study period	severe, 26.7% severe impairment. Age of women PWD with male CG aged < 60 (15.2%), 60-69 (27.9%), 70-79 (46.5%), 80-89 (10.5%), 30.2% moderate, 39.5% moderately severe, 30.2% severe impairment. Age of women CG < 60 (15.0%), 60-69 (30.0%), 70-79 (42.5%), 80-89 (12.5%). Age of male CG < 60 (10.5%), 60-69 (25.6%), 70-79 (45.3%), 80-89 (18.6%), CG 58.3% women; E: 50.5% women CG; C: 66% women CG; Living arrangement: cohabiting; Spouse 100%; Dropout: U; Attrition rate: 7.28%; Recruitment through Aging and Development Research Centre, Alzheimer associations, and other agencies that provide social services	E: Caregiver Support Program (CSP) C: Conventional (existing) community nursing	Multicomponent: Yes Content: A, B, C, E, H Tailor-made: Yes Professionals: Case manager: No Counselor: Yes Training: Yes Caregivers: Intensity: High Involvement: Active Choice: Party	E: 36.66% C: 36.66%	NS	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: - Performance bias Blinded providers/participants: - Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analysis: + Total: 5
Mohide et al. 1990	RCT, stratified by CG gender and PWD attending day care Follow-up at 3 and 6 months	Country: Canada; Setting: in-home care; Number: 60 PWD-CG dyads; EGr (n = 30); PWD mean age 77.8 ± 9.2, 50% women, mean MMSE score 13.2 ± 6.8. CG mean age 66.1 ± 13.5, 70% women, mean months of caregiving 39.8 ± 30.2, wife 47%; CGr (n = 30): PWD mean age 75.9 ± 7.7, 47% women, mean MMSE score 11.0 ± 6.2. CG mean age 69.4 ± 8.6, 73% women, mean months of care giving 72.4 ± 61.9, wife 57%; Living arrangement: cohabiting; Dropout: 58.9%; Attrition rate: 13.3%; Referral through physicians, community health services, social services, and self-referral	E: Home-based visits by a psychologist and an occupational therapist to prevent	Multicomponent: Yes Content: A, D Tailor-made: Yes Professionals:	E: 11.4% C: 11.8%	u; small numbers of institutionalization did not	Selection bias Randomized: + Allocation concealed: + Comparable baseline
Nobili et al. 2004	RCT Follow-up at 1 year	Country: Italy; Setting: in-home care; Number: 69 PWD-CG dyads; EGr (n = 35 PWD); mean age 74 ± 9.0, 60% women, mean MMSE score					

(Continued)

Table 1. (Contd.)

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes	
					N/TTIM	P < .05
						Methodological Quality
						allow statistical comparison
				Case manager: No Counselor: No Training: U Caregivers: Intensity: Low Involvement: Passive Choice: No		characteristics: + Performance bias Blinded providers/participants: U Detection bias Blinded outcome assessors: U Attrition bias Attrition rate reported: + Intention-to-treat analysis: — Total: 4
Teri et al. 2003	RCT Follow-up at 2 years	11.1 ± 7.0; CGr (n = 34 PWD): mean age 75 ± 10.0, 59% women, mean MMSE score 12.0 ± 7.4; E (n = 35 CG): mean age 53 ± 16.0, 89% women, length of care 33 ± 25 months, h/d time spent caring 4.9 ± 3.9; CGr (n = 34 CG): mean age 59 ± 12.0, 74% women, months of care 34 ± 24, time spent caring 2.5 ± 2.3 h/d; Living arrangement: >80% cohabiting; Spouse 46.5%; Dropout: 33%; Attrition rate: 20.3%; Recruitment through Alzheimer Italia	E: Home-based exercise program combined with CG training in behavioral management techniques C: Routine medical care, including acute medical or crises intervention, provided at community healthcare centers	Multicomponent: Yes Content: A, E, G Tailor-made: U Professionals: Case manager: No Counselor: No Training: U Caregivers: Intensity: High Involvement: Passive Choice: No	E: 68% C: 67%	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: + Performance bias Blinded providers/participants: — Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analysis: + Total: 6
Vernooij-Dassen, 1993	RCT, stratified by PWD gender and availability of regular home help; Follow-up at 10 months	Country: The Netherlands; Setting: in-home care; Number: 126 PWD-CG dyads; PWD: mean age 78, 69% women, light dementia 12.8%, moderate dementia 58.2%, and severe dementia 29.1%. CG: mean age 63, 67.3% women, mean duration of care 48.8 months; 49% spouses, 36% children, and 15% friends and neighbors; Living arrangement: respectively 63% and 87% of the women and male CG shared a household; Dropout: 10.6%; Attrition rate: 5.6%; Referral through GP	E: Home-based support program consisting of guidelines for emotional and practical support carried out by home helps C: Usual care	Multicomponent: Yes Content: E, H Tailor-made: Yes Professionals: Case manager: No Counselor: Yes Training: Yes Caregivers: Intensity: High Involvement: Active Choice: Yes	E: 14% C: 28%	Selection bias Randomized: + Allocation concealed: + Comparable baseline characteristics: — Performance bias Blinded providers/participants: — Detection bias Blinded outcome assessors: + Attrition bias Attrition rate reported: + Intention-to-treat analysis: + Total: 5
						NS

(Continued)

Table 1. (Contd.)

Study	Method	Participants	Intervention	Intervention Characteristics	Outcomes	
					NI/TTIM	P < .05
Woods et al. 2003	Comparison group quasi-experimental design; Follow-up at 8 months	Country: United Kingdom; Setting: combination in-home care and outpatient care; Number: 104 PWD-CG dyads; EGr (n = 43); PWD mean age 80.9 ± 7.80, 48.8% women, mean CDR score 1.4 ± 0.6. CG: mean age 62.4 ± 15.9, 74.4% women, duration of care 3.7 ± 3.8 years, 76.7% co-residing, 44.2% spouse, 44.2% child; CGr (n = 61); PWD mean age 79.7 ± 7.2, 67.2% women, mean CDR score 1.3 ± 0.7; CG: mean age 58.8 ± 13.2, 70.5% women, duration of care 2.7 ± 2.6 years, 55.7% co-residing, 34.4% spouse, 50.8% children; Living arrangement: 64.4% co-residing; Spouse: 38.5%; Dropout: 18.8; Attrition rate: 18.8%; Referral through GPs and memory clinics	E: Admiral Nurse Services C: Conventional Services	Multicomponent: Yes Content: F Tailor-made: Yes Professionals: Case manager: No Counselor: Yes Training: U Caregivers: Intensity: U Involvement: U Choice: U	E: 12% C: 11%	Selection bias Randomized: — Allocation concealed: — Comparable baseline characteristics: — Performance bias Blinded providers/participants: U Detection bias Blinded outcome assessors: U Attrition bias Attrition rate reported: + Intention-to-treat analysis: — Total: 1

Method: CG = caregiver, PWD = person with dementia, RCT = randomized, controlled trial.

Participants: in-home care setting = intervention took place at home, outpatient care setting = subjects went to an organization for the intervention and returned home after each session, inpatient care setting = subjects were hospitalized during the intervention and returned home after completion of this part of the intervention. AD = Alzheimer's disease; EGr = experimental group; CDR = Clinical Dementia Rating Scale; CGr = control group; MMSE = Mini-Mental State Examination; BCRS = Brief Cognitive Rating Scale; SD = standard deviation; U = unknown; Duration of caregiving = mean duration of caregiving or mean duration of caregiving since diagnosis of dementia; Dropout = number of participants invited to participate minus number of participants eligible at baseline; Attrition rate = number of participants eligible at baseline minus participants who dropped out during the study period for reasons other than institutionalization.

Intervention characteristics: A = psychoeducation; B = cognitive behavioral therapy; C = respite care; D = environmental modification; E = skills training/problem solving; F = case management; G = person with dementia focused memory training; H = general support; U = unknown; Case manager = person who facilitated access and coordinated and obtained appropriate formal healthcare services for caregivers and people with dementia. The case manager provides continuity and advocacy over time; Counselor = person who helped caregivers and people with dementia cope with mental or emotional distress; understanding and resolving problems that came up. Sometimes counselors also acted as case managers. Intensity: high = support program consisted of at least 10 professional-caregiver contacts or sessions. Involvement: passive = no active collaboration from the caregiver required.

Outcomes: NI = outcome measure: number of institutionalizations in percentages; TTIM = outcome measure: time to institutionalization in months; P < .05 (+ = statistically significant in favor of the experimental group; NS = not significant; — = statistically significant in favor of the control group; u = unknown).

an estimate of the amount of variance across studies due to heterogeneity rather than chance. If the test for heterogeneity is significant ($P < .05$), the fixed-effects model may be invalid.¹⁵ In this case, the analysis was repeated using the random-effects model, in which the random variation within each study and the variation between the various studies are both incorporated. This tends to give a more conservative estimate (broader CI), but the results from the two models usually agree when there is no heterogeneity.¹⁶ It occurred that more than one study by the same authors, with the same study population but different follow-up periods, were included in this systematic review. Because only one of these same population studies could be included in the meta-analysis, studies with follow-up periods closest to

the mean follow-up periods of the other studies included were selected in the interests of the potential homogeneity across studies.

RESULTS

Study Selection

The computerized, indexed search resulted in 241 references; PubMed retrieved 106 references, Web of Science 73, and PsychInfo 62 (Figure 1). The computerized, unindexed search in PubMed resulted in 41 references. The main reasons for the exclusion of studies from the computerized searches on the basis of the algorithm of inclusion were that care was given in hospitals or nursing homes; neither odds

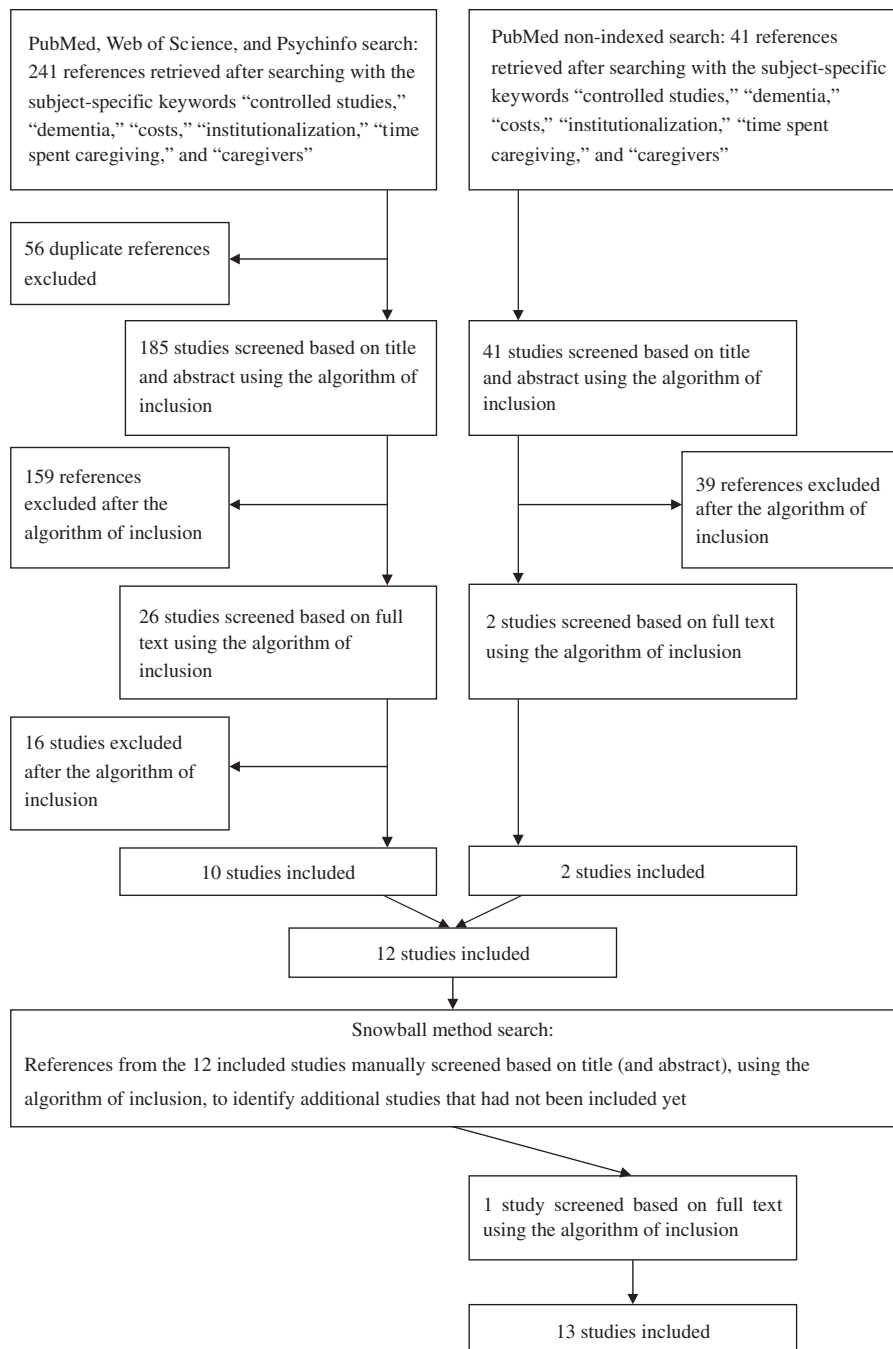


Figure 1. Flowchart of the search strategy.

of institutionalization nor time to institutionalization was an outcome measure in at least one arm of the study; the study was designed as a review; and the study was predictive, modeling, or noninterventional. There were no non-English-language European studies that met all inclusion criteria other than that of English language. After exclusion of the irrelevant studies, 12 studies remained. The snowball search of these studies yielded one additional study for inclusion, so that 13 studies were included for further systematic review.

Study Characteristics

Of the 13 studies, 10 used a randomization procedure to allocate the interventions (Table 1). The follow-up periods ranged from 3 to 102 months. The studies were predominantly conducted in Europe (n = 6) and the United States (n = 4). Although the populations of all the studies consisted of community-dwelling subjects, the interventions of five studies took place in outpatient settings (e.g., day care, a university, or a mental health service), and they returned home after each session. In four studies, subjects were treated in their own home-care setting. In two studies, subjects were hospitalized (inpatient setting) for the duration of the treatment. Two interventions were conducted in a combined outpatient and home-care setting. The sample size (the number of caregiver-patient dyads eligible to participate in the study) ranged from 60 to 8,095. With the exception of the 8,095 caregiver-patient dyads from one study,¹⁷ the mean sample size of the studies ± standard deviation was 120.9 ± 49.1. The proportion of female patients varied from 41% to 67.2%. The proportion of female caregivers varied from 50.5% to 89%. Because the authors used diverse methods to chart the ages of patients and their caregivers, it was not possible to quote a reliable range or average of ages for the participants. In all the studies, most patients with dementia shared a household with the partic-

ipating caregiver; in five studies, each dyad lived together. The mean length of caregiving since the diagnosis of dementia or the commencement of the study was reported in six studies and varied from 32.0 to 72.4 months. In most studies, the severity of dementia at baseline varied from mild to severe.

Methodological Quality

The overall score for the methodological quality of the studies ranged from 1 to 6 (maximum 7), with a mean overall score of 4.2 ± 1.6 (Table 1). Two studies¹⁸⁻²⁰ with low methodological quality, basically due to their unrandomized design, accounted for most of the variance. The authors of three studies^{17,20,21} did not report whether the outcomes were assessed blindly, and the author of one study^{9,22} reported that outcomes were not assessed blindly, which may be a source of bias.

Meta-Analysis

Odds of Institutionalization

Three pairs of studies used the same study population. Only the first study of each pair was included in the meta-analysis so that the mean follow-up periods of the 10 studies in the meta-analysis would be as similar as possible.^{9,19,23} A total of 9,043 patients (4,622 in experimental groups and 4,421 in control groups) participating in the 10 studies were included in the meta-analysis. Given the evidence of the heterogeneity of the treatment effect of the studies (chi-square (χ^2) = 24.90, degrees of freedom (df) = 9, P = .003, I² = 63.9%), studies were entered into the meta-analysis using a random-effects model. The analyses show that, overall, patients involved in experimental interventions were significantly less likely to be institutionalized than patients in control groups (OR = 0.66, 95% CI = 0.43-0.99, P = .05; Figure 2). Because the methodological quality of

Review: Effectiveness of non-pharmacological interventions in delaying the institutionalization of people with dementia (OR)
 Comparison: 01 Institutionalization (Number)
 Outcome: 01 Odds of Institutionalization

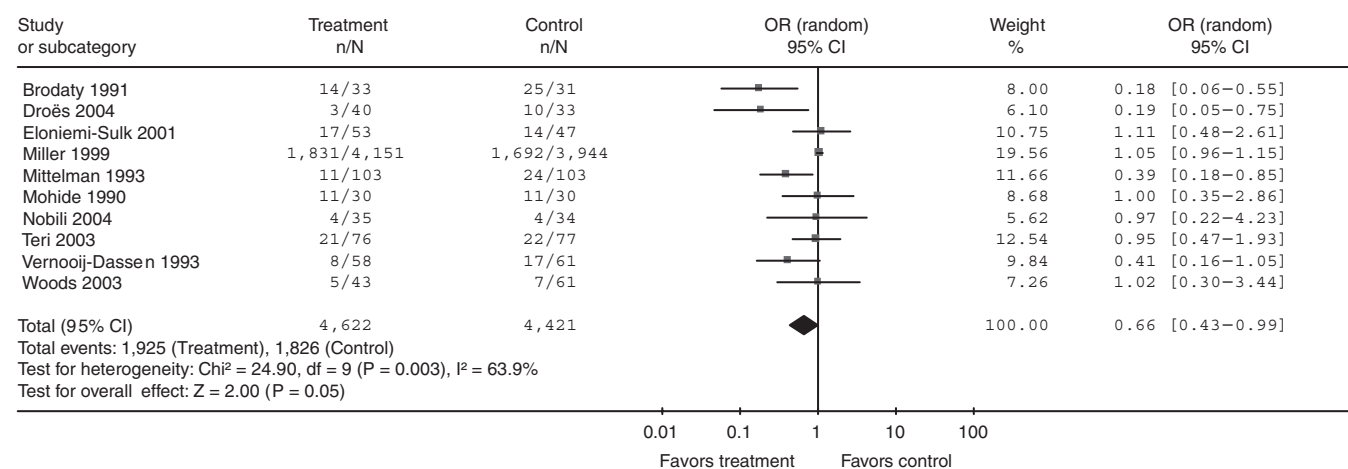


Figure 2. Forest plot of odds of institutionalization. Each study is represented by a black square (■) and a horizontal line, which correspond to the point estimate and the 95% confidence intervals (CIs) of the odds ratios (OR). The solid vertical line corresponds to no effect of treatment (OR = 1.0). The area of the black squares reflects the weight of the study in the meta-analysis. The diamond (◆) represents the combined OR, calculated in a random-effects model, with its 95% CI. df = degrees of freedom; n = number of patients institutionalized at follow-up; N = number of patients at baseline.

the studies might influence the effects, and some studies might put a disproportionate weight on the results, additional analyses were performed. Of the high-quality studies^{9,10,23-26} (score 5-7) using a fixed-effects model ($\chi^2 = 10.86$, $df = 5$, $P = .05$, $I^2 = 53.9\%$), similar significant estimated overall effects were found in which patients involved in experimental interventions were less likely to be institutionalized than patients in control groups (OR = 0.60, 95% CI = 0.43-0.85, $P = .004$). One study¹⁷ disproportionately influenced the overall effect, with a sample size much larger than the sample sizes of the other studies (difference > 7,500 patients). Eliminating this study from the original analysis using a fixed-effects model ($\chi^2 = 14.70$, $df = 8$, $P = .07$, $I^2 = 45.6\%$) resulted in an estimated overall effect that was significantly larger in favor of patients involved in the experimental interventions (OR = 0.59, 95% CI = 0.43-0.81, $P = .001$).

Time to Institutionalization

Of the 13 included studies, five were suitable for the meta-analysis, although two of these five studies used the same study population. Again, only one of these overlapping population studies¹⁹ was included in the meta-analysis. The remaining eight studies were excluded, because the authors did not report any tests (six studies) or they did not report the means and standard deviations for the test scores before and after the intervention (two studies). The four studies entered in the meta-analyses yielded a total of 498 patients (277 in experimental groups and 221 in the control groups). Use of a fixed-effects model provided evidence of heterogeneity of the treatment effects across the studies ($\chi^2 = 89.28$, $df = 3$, $P < .001$, $I^2 = 96.6\%$). The SMD, calculated in a random-effects model, showed a significant estimated overall effect in favor of the experimental interventions (SMD = 1.44, 95% CI = 0.07-2.81, $P = .04$; Figure 3). The mean change in mean time to institutionalization from baseline to follow-up was significantly greater in patients involved in the experimental interventions than in the control groups. Furthermore, because the four studies included in the meta-analyses each contributed 25% to the overall effect, a SMD of 1.44 reflects a mean difference of 4.9 months in time to institutionalization in favor of patients involved in the experimental groups over controls.

Concentrating on high-quality studies^{22,25,27} (score 5-7) and using random-effects models ($\chi^2 = 83.00$, $df = 2$, $P < .001$, $I^2 = 97.6\%$), no change was found in mean time to institutionalization from baseline to follow-up between the experimental group and the control group (SMD 1.55, 95% CI = -0.35-3.45, $P = .11$).

Characteristics of Effective Interventions

Significant positive effects were found in seven of the 13 studies after the experimental intervention at the last follow-up.^{9,18,19,22,23,26,27} One study²⁴ had not produced any significant positive effects at the last follow-up, but subgroup analyses revealed a significant positive effect in favor of patients with severe dementia involved in the experimental intervention (Table 1). All support programs were multicomponent in offering a comprehensive program with a range of specific, supportive care-giving interventions. Furthermore, most interventions were individualized, intensive, individualized interventions designed to meet the unique needs of patients and their caregivers at the appropriate time. The function of professionals (e.g., a case manager or counselor) who received intervention-specific training varied with each study, and no distinctive intervention seemed to be characteristic of the estimated effectiveness in the odds of being institutionalized and the delay of institutionalization. Conversely, a combination of involvement and choice seemed to be the main intervention characteristic that distinguished effective support programs from ineffective ones.

DISCUSSION

To the authors' knowledge, this is the first systematic review applying a meta-analysis to estimate the overall effectiveness of all types of nonpharmacological support programs for caregivers and patients with dementia about odds of institutionalization and time to institutionalization. The meta-analysis of 13 support programs showed that these programs can significantly decrease the odds of institutionalization and significantly increase the time to institutionalization. This is a promising result in view of contemporary policies designed to allow caregivers to care for people with dementia at home for as long as possible. Analyses of the intervention characteristics show that a

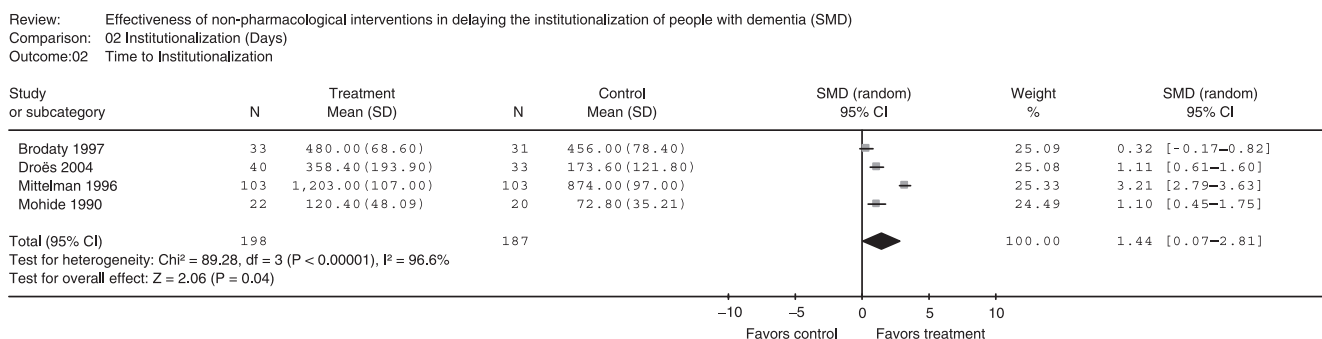


Figure 3. Forest plot of time to institutionalization. A black square (■) and a horizontal line, which correspond to the point estimate and the 95% confidence intervals (CIs) of the standardized mean difference (SMD), represent each study. The *solid vertical line* corresponds to no effect of treatment (SMD = 0). The area of the black squares reflects the weight of the study in the meta-analysis. The *diamond* (◆) represents the combined SMD, calculated in a random-effects model with its 95% CI. df = degrees of freedom; N = number of patients at baseline, followed by the mean number of days of time to institutionalization and corresponding standard deviations for patients in the experimental and control groups, respectively.

combination of involvement and choice seems to be the main intervention characteristic that distinguishes effective support programs from ineffective ones. Effective support programs include counseling and personal assistance with problem solving, and they offer caregivers a choice of various support strategies and support services. This is consistent with previous findings.²⁸ One intervention^{23,27} that offered a wide range of support strategies and services but gave no choice as to which parts of the support program to follow was an exception.

Having so many choices or being able to choose one of several interventions might lead to satisfactory involvement. Such choices offer caregivers and patients a sense of freedom that might result in a greater sense of personal control, more satisfaction with treatment, better adherence and transition to the daily routine, and consequently better outcomes.

This meta-analysis had some limitations. Cultural differences between and within countries in the presence, types, and preferences of institutional care, heterogeneity in the duration and severity of dementia, the follow-up periods, and the numbers of participants might have affected the treatment effects.

Concerning cultural differences, a common trend toward deinstitutionalization, less inpatient treatment, and improvement of community services characterizes the development of systems of mental health care in Western Europe and North America,^{29,30} although within and between countries, there are substantial differences in the design of organization and financing of health care (including long-term care), the provision of informal and formal care (e.g., various types of residential accommodation), and cultural preferences concerning institutionalization.^{29–31} Italy, for example, continues to rely on the traditional provision of informal care by the family, a situation that not only economic factors, but also sociocultural factors, determines. National surveys show that families with some economic means who are caring for an elderly relative employ foreign migrant workers who assume the main burden of care for modest payment.^{31,32} The number of people aged 65 and older in residential homes in Italy is one of the lowest in Europe.³¹ To what extent this fact has affected the results about odds of institutionalization and time to institutionalization across countries is unclear. In general, the effects of these differences on patient outcomes are not reflected in outcome differences in a coherent way, the empirical evidence is limited, and further studies are required.³⁰

In six studies, there was heterogeneity in the mean time of care giving since the diagnosis of dementia or the commencement of the study; most studies did not report the duration of dementia. This might have affected the treatment effects. The same is true for the severity of dementia, which varied in most studies from mild to severe at baseline, and the heterogeneity in follow-up periods across studies. In all these cases, the odds of institutionalization were larger, and the time to institutionalization shorter, with cognitive decline over time. A combination of a population that is more homogenous with respect to duration and severity of dementia at baseline and standardized follow-up periods might have limited the supposed heterogeneity and thereby the probable influence on treatment effects. By using the random-effects model, the statistical heterogeneity that is mainly caused by the different sample sizes of the studies

was taken into account. Finally, it is unlikely that the different interventions contributed to the heterogeneity across studies. One study³³ distinguished different types of interventions beforehand and consequently pooled homogeneous interventions in its meta-analysis. The current meta-analysis had no such a priori subdivision, mainly because careful analysis of monocomponent support programs (psychoeducational interventions, case management, and general support) reveals that such programs have a multicomponent composition. It is unlikely that pooling homogenous interventions adjusted for other causes of possible heterogeneity across studies, for example, cultural differences in the presence, types, and preferences of institutional care; differences in the duration or severity of dementia; the follow-up periods; and the sample size. Nevertheless, it is still unknown which components of the support programs contributed to the treatment effects.

Owing to the lack of data in the studies analyzed, an estimation of the overall treatment effect on certain high-risk groups, such as women and spouse caregivers, could not be made, although in the present study, the most caregivers in the various support programs shared a household with the patient. The conclusions of this systematic review should be seen in the context of the methodological quality of the studies. In general, the methodological quality of most of the studies was good. Because of the nature of nonpharmacological intervention studies, it was not always possible to use a randomized, controlled trial design and to blind providers of the various support programs as to who was receiving the support program and who was not. Analysis of studies with the best methodological quality showed similar odds, so the analysis in the best methodological quality studies and the analysis in all 10 of the studies included in the meta-analysis showed that the odds of being institutionalized were lower for patients involved in experimental interventions than patients in control groups. However, for mean time to institutionalization, concentrating on the best-quality studies resulted in no difference between the experimental and control groups.

With respect to the recommendations, this systematic review shows that, if a support program is to be capable of delaying institutionalization, it must be intensive. The caregiver and the patient with dementia are then actively involved in seeking solutions together and can try out and choose the support strategies or services that are best individualized to their needs. In addition, to meet future policies concerning efficiency, authors should evaluate their support programs on the net benefit or cost effectiveness. In this manner, the caregiver and patient with dementia can be offered an efficient support program that will improve the quality of life of both parties and, most importantly, meet the wishes of both parties for the patient with dementia to stay at home for as long as possible.

ACKNOWLEDGMENTS

This study was funded by a grant from the Dutch Organization of Health Research and Development. The views are those of the authors and not necessarily of the funding body. We are grateful to Dr. Irena Draskovic, Senior Researcher, who used her technical and statistical skills to help us use Review Manager 4.2.

REFERENCES

1. van Ewijk C, Kuipers B, ter Rele H et al. Ageing in the Netherlands. CPB Special Publication, Sdu, The Hague, the Netherlands: 2000.
2. Meerding WJ, Bonneux L, Polder JJ et al. Demographic and epidemiological determinants of healthcare costs in Netherlands: Cost of illness study. *BMJ* 1998;317:111–115.
3. Slobbe LCJ, Kommer GJ, Smit JM et al. Kosten van ziekten in Nederland 2003. Zorg voor euro's. [Costs of illness in the Netherlands in 2003. Concern for euros]. Bilthoven: National Institute for Public Health and the Environment; 2006. RIVM Report No: 270751010.
4. Draper BM, Poulos CJ, Cole AMD et al. A comparison of caregivers for elderly stroke and dementia victims. *J Am Geriatr Soc* 1992;40:896–901.
5. Burns A, Rabins P. Carer burden in dementia. *Int J Geriatr Psychiatry* 2000; 15:9–13.
6. Clyburn LD, Stones MJ, Hadjistavropoulos T et al. Predicting caregiver burden and depression in Alzheimer's disease. *J Gerontol B-Psychol Sci Soc Sci* 2000; 55B:S2–S13.
7. Sherwood PR, Given CW, Given BA et al. Caregiver burden and depressive symptoms: Analysis of common outcomes in caregivers of elderly patients. *J Aging Health* 2005;17:125–147.
8. Gaugler JE, Kane RL, Kane RA et al. Caregiving and institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *Gerontologist* 2003;43:219–229.
9. Mittelman MS, Ferris SH, Steinberg G et al. An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *Gerontologist* 1993;33:730–740.
10. Teri L, Gibbons LE, McCurry SM et al. Exercise plus behavioral management in patients with Alzheimer disease: A randomized controlled trial. *JAMA* 2003;290:2015–2022.
11. PICO and Search Query Strategy Worksheet, 2001. Ebling Library, University of Wisconsin, Madison [on-line]. Available at http://ebling.library.wisc.edu/portals/ebhc/PICO_worksheet.pdf Accessed January 5, 2005.
12. Study quality guide. Guide for review authors on assessing study quality. Last updated: March 2007. Cochrane Consumers & Communication Review Group 2007 Available at <http://www.latrobe.edu.au/cochrane/assets/downloads/StudyQualityGuide050307.pdf> Accessed January 5, 2005.
13. Higgins J, Green S. *Cochrane Handbook for Systematic Reviews of Interventions* 4.2.6; Section 3.6. The Cochrane Library, Issue 4, 2006. Chichester, UK: John Wiley & Sons, Ltd, 2006.
14. Qualitative research methods in health technology assessment: A review of the literature. *Health Technol Assess* 1998;2:71.
15. Ioannidis JP, Patsopoulos NA, Evangelou E. Uncertainty in heterogeneity estimates in meta-analyses. *BMJ* 2007;335:914–916.
16. Egger M, Smith GD, Phillips AN. Meta-analysis: Principles and procedures. *BMJ* 1997;315:1533–1537.
17. Miller R, Newcomer R, Fox P. Effects of the Medicare Alzheimer's disease demonstration on nursing home entry. *Health Serv Res* 1999;34:691–714.
18. Dröes RM, Meiland FJ, Schmitz MJ et al. Effect of the meeting centres support program on informal carers of people with dementia: Results from a multi-centre study. *Aging Mental Health* 2006;10:112–124.
19. Dröes RM, Breebaart E, Meiland FJ et al. Effect of meeting centres support program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging Mental Health* 2004;8:201–211.
20. Woods RT, Wills W, Higginson IJ et al. Support in the community for people with dementia and their carers: A comparative outcome study of specialist mental health service intervention. *Int J Geriatr Psychiatry* 2003;18: 298–307.
21. Nobili A, Riva E, Tettamanti M et al. The effect of a structured intervention on caregivers of patients with dementia and problem behaviors—a randomized controlled pilot study. *Alz Dis Assoc Disorders* 2004;18:75–82.
22. Mittelman MS, Ferris SH, Shulman E et al. A family intervention to delay nursing home placement of patients with Alzheimer disease—a randomized controlled trial. *JAMA* 1996;276:1725–1731.
23. Brodaty H, Peters KE. Cost effectiveness of a training program for dementia carers. *Int Psychogeriatr* 1991;3:11–22.
24. Eloniemi-Sulkava U, Notkola IL, Hentinen M et al. Effects of supporting community-living demented patients and their caregivers: A randomized trial. *J Am Geriatr Soc* 2001;49:1282–1287.
25. Mohide EA, Pringle DM, Streiner DL et al. A randomized trial of family caregiver support in the home management of dementia. *J Am Geriatr Soc* 1990;38:446–454.
26. Vernooij-Dassen MJFJ. *Dementia and Homecare: Determinants of the Sense of Competence of Primary Caregivers and the Effect of Professionally Guided Caregiver Support*. Lisse: Swets & Zeitlinger, 1993.
27. Brodaty H, Gresham M, Luscombe G. The Prince Henry Hospital dementia caregivers' training programme. *Int J Geriatr Psychiatry* 1997;12:183–192.
28. Vernooij-Dassen MJFJ, Lamers C, Bor H et al. Prognostic factors of effectiveness of a support program for caregivers of dementia patients. *Int J Aging Hum Dev* 2000;51:259–274.
29. Kodner DL. Whole-system approaches to health and social care partnerships for the frail elderly: An exploration of North American models and lessons. *Health Soc Care Commun* 2006;14:384–390.
30. Becker T, Kilian R. Psychiatric services for people with severe mental illness across Western Europe: What can be generalized from current knowledge about differences in provision, costs and outcomes of mental health care? *Acta Psychiatr Scand Suppl* 2006, 9–16.
31. Lamura G. Supporting carers of older people in Europe: a comparative report on six European countries. Paper (updated version) presented at the 11th European Social Services conference, Venice, July 2–4, 2003. <http://www.socialeurope.com/pdfs/Venice/presentations/lamura1.pdf> 2003.
32. *Dementia in Europe Yearbook 2006, including the Alzheimer Europe Annual Report 2005*. Luxembourg: Alzheimer Europe, 2006.
33. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *Int Psychogeriatr* 2006;18:577–595.