# REVIEW

# Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review

Netta Van't Leven,<sup>1</sup> Anna-Eva J. C. Prick,<sup>2</sup> Johanna G. Groenewoud,<sup>1</sup> Pepijn D. D. M. Roelofs,<sup>1</sup> Jacomine de Lange<sup>1,3</sup> and Anne Margriet Pot<sup>2,3</sup>

<sup>1</sup> Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rotterdam, The Netherlands <sup>2</sup>Department of Clinical Psychology, VU University of Amsterdam, and EMGO Institute for Health and Care Research (EMGO+), Amsterdam, The Netherlands

<sup>3</sup> Program on Aging, Netherlands Institute on Mental Health and Addiction, Utrecht, The Netherlands

#### ABSTRACT

**Background:** In this review, we study the effects of dyadic psychosocial interventions focused on communitydwelling people with dementia and their family caregivers, and the relationship of the effects with intervention components of programs.

**Methods:** A search from January 2005 to January 2012 led to 613 hits, which we reviewed against our inclusion criteria. We added studies from 1992 to 2005 reviewed by Smits *et al.* (Smits, C. H. M., De Lange, J., Droes, R.-M., Meiland, F., Vernooij-Dassen, M. and Pot, A. M. (2007). Effects of combined intervention programs for people with dementia living at home and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry*, 22, 1181–1193). We assessed the methodological quality of 41 programs with the Cochrane criteria and two items of the Oxford Centre of Evidence-based Medicine guidelines.

**Results:** Studies of moderate to high quality concerning 20 different dyadic psychosocial programs for people with dementia and caregivers were included. Nineteen of these programs show significant effects on the patient with dementia, the caregiver, or both. Due to differences in the programs and the studies, this study does not provide an unequivocal answer about which programs are most effective. Programs with intervention components that actively train one or more specific functional domains for the person with dementia and/or the caregiver seem to have a beneficial impact on that domain, although there are exceptions. Reasons can be found in the program itself, the implementation of the program, and the study design.

**Conclusions:** Dyadic psychosocial programs are effective, but the outcomes for the person with dementia and the caregiver vary. More attention is needed for matching the targeted functional domains, intervention components, and delivery characteristics of a program with the needs of the person with dementia and the family caregiver.

Key words: Alzheimer, dementia, informal caregivers, psychosocial treatment, intervention, burden, mood, quality of life

## Introduction

Most people with dementia live in their own homes in the community. They need support and care in everyday life, and they are dependent on informal care, mainly provided by spouses and adult children, but also by neighbors or friends. Although caregiving is satisfying for most informal caregivers because they care about their loved ones, it is also very burdensome (Cuijpers, 2005; Pinquart and Sorensen, 2007; Peeters *et al.*, 2010). People with dementia and their caregivers have to cope with impaired daily functioning and changing roles, often with a negative impact on their health condition (Lyketsos *et al.*, 2002; Aalten, 2004; Pinquart and Sorensen, 2007). Many psychosocial supporting interventions for people with dementia and their caregivers have been developed in the last decades (Dröes, 2010; Moniz-Cook *et al.*, 2011). Evidence for the effectiveness of these interventions, being even more effective than pharmacological therapies, has been published (Acton and Kang, 2001; Brodaty and Arasaratnam, 2012; Brodaty *et al.*, 2003). In recent years, psychosocial

*Correspondence should be addressed to*: Netta van't Leven, MSc, Centre of Expertise Innovations in Care, Rotterdam University of Applied Sciences, Rochussenstraat 198 3015 EK Rotterdam, The Netherlands. Phone: +31-10-794-51-85; Fax: +31-10-794-51-59. Email: m.a.van.t.leven@hr.nl. Received 16 Jan 2013; revision requested 3 Mar 2013; revised version received 12 May 2013; accepted 21 May 2013.

interventions have focused on both the person with dementia and the informal caregiver (also referred to as the "dyad" in this paper). Directing the dyad is seen as most effective because of the mutual influence between the person with dementia and the informal caregiver. For instance, behavioral symptoms of dementia may increase the caregiver burden; caregiver management strategies will influence both the behavior of the person with dementia and the feelings of competence and mood of the caregiver (De Vugt et al., 2004). The effects of psychosocial intervention programs have been studied in a previous review that included publications up to 2005 (Smits et al., 2007). The authors found that psychosocial intervention programs may contribute to the quality of life of both members of the dyad, and may decrease caregivers' mental health problems. The effects on most other functional and behavioral domains, however, are moderate or inconsistent. Some interventions led to statistically significant effects in subgroups only. Currently, a wide range of psychosocial programs are offered to people with dementia and their caregivers. Some of these have been evaluated in randomized controlled trials (RCTs). The purpose of our current study was to update Smits et al.'s (2007) systematic review, and to provide the current best evidence about psychosocial programs for the dyads that involve face-to-face contact between professional caregivers and both the patient and the caregiver. We describe the program characteristics and the measured effects on both members of the dyads. These outcomes are related to the intervention components of the programs.

# Method

# Search strategy

We searched the databases Psychinfo, Embase, Medline, and Cinahl for single studies and reviews, and the Cochrane Library for systematic reviews. Since we built on the review of Smits et al. (2007), our search covered publications from January 2005 to January 2012. We used the same search string with the following keywords: (Alzheimer<sup>\*</sup> OR dementia) AND (caregiv<sup>\*</sup> OR family members) AND (support program OR training OR counselling OR intervention) AND (effec\* OR effic\*) as well as Mesh or Emtree terms to ensure that the search was as complete as possible (Thompson et al., 2007; Furlan et al., 2009; Higgins and Green, 2011). Any systematic reviews that we found were searched for mention of additional single RCTs involving psychosocial interventions (Figure 1).

# **Inclusion criteria**

We included effect studies evaluating dyadic psychosocial interventions for both older people with dementia living in the community and their caregivers. A broad definition of psychosocial interventions was used. Interventions that encompass other treatment components than psychosocial ones - such as environmental modifications and exercise - were also included. The interventions had to involve face-to-face contact between a care professional and the person with dementia as well as the informal caregiver and the same care professional. In addition, the interventions had to target psychosocial outcomes, improving mental health or well-being. In contrast with Smits et al. (2007), we included only RCTs in our current review. We excluded RCTs involving respite interventions, and technological devices, as well as cost-effectiveness studies, studies among nursing home residents, and integrated studies where results could not be related to a specific intervention or program (Table 1).

# Selection of studies

First, one reviewer (NL) screened the titles against the inclusion criteria and discarded obviously irrelevant publications. Second, two pairs of reviewers (NL/AEP and NL/JG) independently assessed the abstracts of the remaining publications and the additional studies found in the reviews. Any discrepancies were resolved by consensus of all three reviewers. Finally, NL/AEP and NL/JG examined potentially relevant articles in full text.

# Quality assessment

The two pairs of reviewers (NL/AEP and NL/JG) independently assessed all publications (that is, those resulting from the current search and any additional ones included in Smits et al.'s (2007) review) for methodological quality by using the Cochrane rating criteria for RCTs (Higgins and Green, 2011). The items "blinding of participants" and "blinding of therapists" were not scored because blinding is not feasible for the type of intervention studied. We added the following two items from the Oxford Centre of Evidence-based Medicine guidelines to the Cochrane criteria: the specific components of the intervention should be described, and the experimental and control groups must each have a minimum of 30 participants (www.cebm.net; Olazarán et al., 2010; Table 2). If information was missing, we contacted the corresponding authors of the publication for such information.

# Data analysis

We used several strategies for data analysis to do justice to the variety of programs and studies. First,





we described the intervention programs by delivery characteristics (e.g. dose, mode of delivery, group vs. individual, adaptability/control), intervention components, and targeted functional domains (Czaja *et al.*, 2003). The intensity of contact in the program was rated on a scale ranging from 1 to 4, with 1 representing "1–2 sessions" and 4 representing "more than 10 sessions" (Brodaty *et al.*, 2003). Second, for all outcomes of interest, we assessed the strength of the body of evidence using the Grades of Recommendation, Assessment, Development and Evaluation Working Group (GRADE) approach, as recommended in the Cochrane Handbook 5.1 (Higgins and Green, 2011). The strongest evidence comes from one or more good-quality RCTs. Limitations in the design suggesting bias may warrant downgrading the quality of the evidence of the RCT to moderate or even lower. We assessed the quality of the body of evidence as "low," "moderate," or "high" for each outcome category.

	INCLUSION CRITERIA
Study participants	People with dementia 65 years old or more.
	People with dementia and their informal caregivers living in the community, not a nursing home.
Study design	Effect study: randomized controlled trial.
Psychosocial intervention	Intervention aimed at reducing or preventing the mental health decline of one or both members of the dyad, including the areas of cognition, activities, daily living skills, competence, and interpersonal relationships.
	Face-to-face contact between care professional and person with dementia, and between the same care professional and the caregiver.
Language	English, Dutch, German, and French.
	EXCLUSION CRITERIA
Study aim	Cost-effectiveness.
Pooled data	Combination of intervention studies.

#### Table 1. Inclusion and exclusion criteria

If the data warranted it, we quantitatively compared studies for the same targeted psychosocial outcome with the Review Manager (software version 5.1) (Higgins and Green, 2011). The standardized mean difference was used to compare effect sizes if the studies used different instruments to measure the outcome of interest. A random effects model analysis was applied for the statistical heterogeneity of the studies. Data obtained after intervention (or at 12 months for the programs that lasted one year or more) were used for this analysis. Pooled estimates were not calculated because of the clinical and statistical heterogeneity between the studies.

## Results

#### Literature search and quality assessment

For the period 2005–2012, the search strategy led to 608 single studies and five additional studies in the reviews. After the inclusion and exclusion criteria were applied, 25 publications remained. Smits *et al.* (2007) included 25 publications from the period 1992 to 2005. Therefore, in total 50 publications were judged on methodological quality (Figure 1). These 50 publications concerned 41 intervention programs. Table 2 shows the outcomes for the methodological quality criteria per study and the final judgment for inclusion. Finally, 20 dyadic psychosocial programs studied in 23 RCTs were included in this review. Thus, three RCTs were replication studies of intervention programs that were already studied in an earlier RCT.

#### **Program characteristics**

Table 3 shows the characteristics of each program (the numbers in square brackets in the text below correspond with the program numbers in Table 3). On the basis of delivery characteristics, programs can be classified in the following three categories:

- Short-period, intensive programs, consisting of six to ten home visits [six programs: 2, 4a, 4b, 5, 6a, 6b, 8, 9] or group sessions [four programs: 1, 3, 7, 10] during a period of five weeks to six months with scheduled topics. All these programs explicitly target both members of the dyad.
- 2. Long-lasting programs, that is, case management up to 2 years, with home visits and telephone contact [six programs: 11, 13, 14, 15, 16, 17] or in combination with a group session [one program: 12]. The intervention components of these programs primarily target the caregiver, and to a lesser extent the person with dementia.
- 3. Other programs with temporary hospitalization [three programs: <u>18</u>, <u>19</u>, <u>20</u>]. The Integrative Reactivation and Rehabilitation (IRR) program involves hospitalization of the person with dementia for at least 13 weeks and limited supervision or training of the caregiver [<u>18</u>]. The supporting program and the training program include residence for both members of the dyad for ten days, with focus on both [<u>19</u>, <u>20</u>]. (Numbers of short-period programs are written in standard font, long-lasting programs in *italics*, and other programs are <u>underlined</u>.)

Most programs consist of multiple treatment components, including information, training for activities of daily life (ADL), walking or exercise, and environmental adaptations for the person with dementia; and information, psycho-education, skills training, and coping strategies for the caregiver. Targeted functional domains include behavioral problems, cognitive functioning, mood, independence in daily activities, sleep, and quality of life of the person with dementia; and mood, burden, competence, and quality of life of the caregiver. The intervention targets of two programs, the Reality Orientation Program [15] and the Sleep-Supporting Intervention [2], involve one single functional domain. The other programs target two or more functional domains for change. Some programs aim at

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	1	2	3	4	5	6	7	Ι	II		
COLUMNS 1-7: COCHRANE CRITERIA, AND COLUMNS I, II: OXFORD CENTRE OF EVIDENCE-BASED MEDICINE GUIDELINES FOR ASSESSING METHODOLOGICAL QUALITY	WAS ALLOCATION RANDOMIZED?	WAS RANDOMIZATION PROCEDURE ADEQUATE AND TRANSPARENT?	WAS DATA COLLECTION BLINDED (INDEPENDENT ASSESSOR)?	WERE BASELINE CHARACTERISTICS OF STUDY GROUPS COMPARABLE?	WERE FOLLOW-UP DATA AVAILABLE, AND WERE DROPOUTS DESCRIBED? <sup>a</sup>	WERE DATA FOR ALL RESPONDENTS ANALYZED IN THE GROUP OF RANDOMIZATION? WAS INTENTION- TO-TREAT DATA ANALYZED?	WERE EXPERIMENTAL AND CONTROL GROUPS TREATED THE SAME WAY EXCEPT FOR THE INTERVENTION?	WAS A DETAILED DESCRIPTION OF THE INTERVENTION GIVEN?	WERE THE EFFECTS ON AT LEAST 30 PATIENTS ASSESSED?	INCLUSION	PROGRAM
2012-2005											
Iansen et al. (2011)	+	+	+	+	+	+	+	+	+	+	1
Clare <i>et al.</i> $(2010)$	+	+	+	+	+	5	+	+	_	_	1
Chien and Lee (2011)	+	2	+	+	+	+	+	+	+	+	2
Carbonneau <i>et al.</i> 2011	+	?	5	+	+	+	+	+	_	_	-
Bakker <i>et al.</i> $(2011)$	+	+	_	+	+	+	+	+	+	+	3
McCurry <i>et al.</i> $(2011)^*$	+	+	+	+	+	+	+	+	+	+	4
McCurry <i>et al.</i> (2010)	+	?	?	?	?	+	+	_	+	_	
McCurry <i>et al.</i> (2005)	+	+	+	_	_	+	+	+	_	_	
Logsdon <i>et al.</i> $(2010)^*$	+	2	2	+	+	+	+	+	+	+	5
Logsdon et al. $(2007)$	+	?	?	+	+	+	+	+	_	_	2
Gitlin <i>et al.</i> $(2010a)^{\#}$	+	+	+	+	+	+	+	+	+	+	6
Gitlin et al. (2010b)	+	+	+	+	+	+	+	+	+	+	6
Neely et al. (2009)	+	_	_	+	+	+	+	+	_	_	
Eloniemi-Sulkava et al. (2009)	+	+	_	?	+	+	+	+	+	+	7
Gitlin et al. (2008)	+	+	+	?	+	+	+	+	+	+	8
Dias et al. (2008)	+	+	+	+	+	?	+	+	+	+	9
Onor <i>et al.</i> (2007)	+	?	?	?	+	+	+	+	_	_	
Callahan et al. (2006)	+	+	+	_	+	+	+	+	+	+	10
Dröes et al. (2006)	_	_	_	+	_	+	+	+	_	_	
Voigt-Radloff et al. (2011a)#	+	+	+	+	+	+	+	+	+	+	11
Graff et al. (2007)*	+	+	+	+	+	+	+	+	+	+	11
Graff et al. (2006)	+	+	+	+	+	+	+	+	+	+	11
Onder et al. (2005)	+	+	+	?	+	+	+	+	+	+	12
Martin-Cook et al. (2005)	+	?	?	+	-	+	+	+	-	_	
Hepburn et al. (2005)	+	+	_	_	+	+	+	+	+	+	13
2005-1992											
Berger $et al.$ (2004)	_	+	?	+	+	+	+	+	_	_	
Dröes <i>et al.</i> $(2004a)^*$	_	+	+	_	+	+	+	+	_	_	
Dröes et al. (2004b)	_	+	+	_	+	+	+	+	_	_	
Dröes et al. (2000)											
Gitlin et al. (2003) <sup>#</sup>	+	+	?	+	+	+	+	+	+	+	14
Gitlin et al. (2001)	+	+	?	+	+	+	+	+	+	+	14
Teri et al. (2003)	+	+	+	+	+	+	+	+	+	+	15
Romero and Wenz (2002)	_	_		_		_	_		_	_	
Eloniemi-Sulkava et al. (2001)	+	+	+	+	+	?	+	+	+	+	16
Quayhagen and Quayhagen (2001)	+	?	?	+	_	+	+	+	_	_	
Chu et al. (2000)	+	?	?	+	+	+	+	+	+	+	17

 Table 2. Quality assessment of studies meeting the inclusion criteria

Table 2	<b>2.</b> Cor	tinued.
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	1	2	3	4	5	6	7	Ι	II		
COLUMNS 1-7: COCHRANE CRITERIA, AND COLUMNS I, II: OXFORD CENTRE OF EVIDENCE-BASED MEDICINE GUIDELINES FOR ASSESSING METHODOLOGICAL QUALITY	WAS ALLOCATION RANDOMIZED?	WAS RANDOMIZATION PROCEDURE ADEQUATE AND TRANSPARENT?	WAS DATA COLLECTION BLINDED (INDEPENDENT ASSESSOR)?	WERE BASELINE CHARACTERISTICS OF STUDY GROUPS COMPARABLE?	WERE FOLLOW-UP DATA AVAILABLE, AND WERE DROPOUTS DESCRIBED? <sup>a</sup>	WERE DATA FOR ALL RESPONDENTS ANALYZED IN THE GROUP OF RANDOMIZATION? WAS INTENTION- TO-TREAT DATA ANALYZED?	WERE EXPERIMENTAL AND CONTROL GROUPS TREATED THE SAME WAY EXCEPT FOR THE INTERVENTION?	WAS A DETAILED DESCRIPTION OF THE INTERVENTION GIVEN?	WERE THE EFFECTS ON AT LEAST 30 PATIENTS ASSESSED?	INCLUSION	PROGRAM
Aupperle and Coyne (2000)	-	_	?	+	?	+	+	+	_	-	
Ostwald et al. (1999)	+	?	;	+	?	+	+	+	+	+	18
Logiudice et al. (1999)	+	+	_	+	+	+	+	+	-	-	
Miller <i>et al.</i> (1999)*	+	+	+	+	+	+	+	+	-	+	19
Newcomer et al. (1999)											
Yordi et al. (1997)											
Moniz-Cook et al. (1998)	_	+	?	+	+	+	+	+	-	_	
Riordan and Bennett (1998)	_	+	-	+	-	+	+	+	-	_	
Teri et al. (1997)	+	-	?	+	+	+	+	+	-	_	
Brodaty et al. (1997)*	+	?	?	?	+	+	+	+	+	+	20
Brodaty and Gresham (1989)											
Hincliffe et al. (1995)	+	-	+	+	+	+	+	+	-	_	
Vernooij-Dassen et al. (1995)*	+	?	?	?	?	?	?	_	-	_	
Vernooij-Dassen (1993)	+	+	+	+	+	+	+	-	+	_	

Notes: "Were follow-up data for a sufficient proportion of all included patients available and were dropouts described? (loss of 20% for short-term follow-up and 30% for long-term follow-up (>6 months)).

+: Low risk, -: high risk, ~: not applicable, ?: no information given.

\*Programs are published in more than one publication.

<sup>#</sup>Programs are studied again in a new study design and population.

reducing the time to institutionalization [12, 16, 17, 19, 20].

All 20 programs claim to tailor their interventions to the dyad's needs. Eight of the 20 programs start with a needs assessment for the caregiver, and some programs also assess the needs of the person with dementia, using an interview or structured observation, followed by individual goal setting [1, 2, 4, 6, 8, 11, 12, 18]. In contrast, the other 12 programs immediately start with treatment sessions and tailor the content to the clients during the program.

## Study characteristics and strength of the body of evidence

The studies varied with regard to measurement instruments, control conditions, and/or time to follow-up (Table 3). "Usual care" and "waiting list" are the most often used control conditions [1, 4a, 5, 6a, 7, 8a, 9, 10, 11, 15, 17, 19, <u>18</u>, <u>20</u>]. Some studies use information leaflets for the informal caregiver [3, 4b, 8b, 12, 13, 16], or one to three face-toface contacts, or telephone contacts [2, 6b, 12, 14, 20] in the control condition. Following the GRADE approach, four limitations influence the strength of the body of evidence. Two of them, lack of blinding of participants and therapists as well as indirectness of evidence (the control condition is usual care), are realistic for studies in the current field. The other two limitations are apparent in the studies: a short follow-up period or heterogeneity of results (e.g. significant outcomes at different follow-up moments) [12, 14, 19, 20]. Although all studies targeted both members of the dyad, two studies

				PR	OGRAM		STUDY				
		DELIVE	ERY CHARACTER	ISTICS	FUNCTIONAL DOMAIN	TREATMENT	COMPONENTS			MEASUREMENT INSTRUMENTS FOR PD	MEASUREMENT INSTRUMENTS FOR CG
		DURATION CONTACTS/HOME VISITS (DOSAGE)	PROVIDED BY	EMPHASIS ON PD AND CG AIMED AT MILD OR MODERATE DEMENTIA	PRIMARY GOAL: –FUNCTIONAL DOMAIN PD – FUNCTIONAL DOMAIN CG	COMPONENTS FOR PD	COMPONENTS FOR CG	GROUP SIZE P = PROGRAM C = CONTROL CONTROL CONDITION INTERVAL AFTER BASELINE	MMSE MEAN (SD) P-C BASELINE	STATISTICALLY SIGNIFICANT OUTCOMES WITH*	STATISTICALLY SIGNIFICANT OUTCOMES WITH*
1	Dementia Family Care Program for home-residing persons with dementia (DFCP) (Chien and Lee, 2011)	6 months 4 HVs for needs assessment (weekly), 10 GSs maximum (bi-weekly) (2–3)	Case manager Social worker	CG: mild to moderate	PD: none CG: Health status, Quality of life	-Needs assessment -Environmental adaptations and memory aids	-Needs assessment -Information -Psycho-education -Problem solving, sharing with peers -Support from health resources -Improvement of home care -Finance skills	$\begin{array}{l} P=46\\ C=46\\ Usual \ care\\ 6,\ 12,\ 18\\ months \end{array}$	P: 17.5 (4.7) C: 17.3 (3.9)	-MMSE -Institutionalization***	-FCBI*** -WHO QoL BREF*** -SSQ 6 -FSSI** -NPI**
2	Night-time Insomnia Treatment and Education in Alzheimer's disease (NITE) (McCurry <i>et al.</i> , 2011)	8 weeks 6 HVs of 60 minutes each (3)	Professional with master's degree	PD-CG mild	PD: Sleep-wake activity CG: Distress with nocturnal behaviors	-Individual sleeping plan with -Walking -Light exposure	-Information -Psycho-education -Daily sleep log	P1 = 32 P2 = 34 P3 = 33 C = 33 Three sessions, not directed at sleep problems, walking, or light 2, 6 months	P 19.2 (7.7) P 17.9 (7.0) P 19.1 (5.8) C 18.7 (6.9)	-Total sleep/awake time at night, P1,* P2,* P3** -Number of awakenings -Time in bed -Daytime sleep or inactivity	SDI
3	Early-Stage Memory Loss Support groups (Logsdon <i>et al.</i> , 2010)	9 weeks 9 GSs of 90 minutes each for caregivers and persons with dementia, partly separated during the session (3)	Professional with master's degree	PD-CG mild	PD: Quality of life Health status Mood CG: Quality of life Mood Stress	-Information -Developing strategies for coping with dementia	-Information -Psycho-education	$\begin{array}{l} \mathbf{P}=96\\ \mathbf{C}=46\\ \mathbf{Educational}\\ \mathbf{leaflets}\\ \mathbf{from}\\ \mathbf{Alzheimer's}\\ \mathbf{Association}\\ 10 \ \mathbf{weeks} \end{array}$	P: 23.2 (4.7) C: 24.0 (3.8)	-QoL-AD*** -SF-36 -GDS** -COM-FAM -PSS -Self-efficacy scale	RMBPC*

# Table 3. Description of programs and studies included in the review

# Table 3. Continued.

				PI	ROGRAM			STUDY					
		DELIV	'ERY CHARACTE	RISTICS	FUNCTIONAL DOMAIN	TREATMEN	Г COMPONENTS			MEASUREMENT INSTRUMENTS FOR PD	MEASUREMENT INSTRUMENTS FOR CG		
		DURATION CONTACTS/HOME VISITS (DOSAGE)	PROVIDED BY	EMPHASIS ON PD AND CG AIMED AT MILD OR MODERATE DEMENTIA	PRIMARY GOAL: -FUNCTIONAL DOMAIN PD - FUNCTIONAL DOMAIN CG	COMPONENTS FOR PD	COMPONENTS FOR CG	GROUP SIZE P = PROGRAM C = CONTROL CONTROL CONDITION INTERVAL AFTER BASELINE	MMSE MEAN (SD) P-C BASELINE	STATISTICALLY SIGNIFICANT OUTCOMES WITH*	STATISTICALLY SIGNIFICANT OUTCOMES WITH*		
4a A	dvanced Caregiver Training (ACT) (Gitlin <i>et al.</i> , 2010a)	6 months maximum 9 HVs of 90 minutes each (OT), 1 HV N in month 1–4; 3 TCs OT, 1 TC N in months 5–6 (3)	Occupational therapist (OT) Nurse (N)	PD-CG moderate	PD: Frequency of behavioral occurrences CG: Upset Confidence in managing care	-Assessment undiagnosed medical conditions -Structured observation strategies -Environmental adaptations -Assistive devices -Engagement in activities	-Interview preferences and goal setting -Information -Skill training: simplifying task and communication -Psycho-education, stress management	P = 137 C = 135 Usual care 4–6 months	P: 13.1 (8.2) C: 12.8 (8.1	Behavioral occurrences**	-Caregiver upset, 4 months,** 6 months*** -Confidence in managing care, 4 months,*** 6 months* -ZBI (12 items), 4 months* 6 months* 6 months* -Perceived change index, 4 months,*** 6 months*** -TMSI, 4 months,*** 6 months***		
4b C	are of Persons with Dementia in their Environments (COPE) (Gitlin <i>et al.</i> , 2010b)	4 months maximum 10 HVs of 90 minutes each (OT) 1 HV N, 1 TC N (3)	See 4a	See 4a	PD: Functional dependence CG Confidence in using activities	See 4a	See 4a	P = 102 C = 107 -Three telephone calls -Educational materials 4, 9 months	P: 13.1 (8.2) C: 13.6 (7.9)	-Qol-AD -Activity Engagement, 4 months* -ABID -Functional dependence ADL, IADL, 4 months*	<ul> <li>-Perceived change index, 4 months**</li> <li>-Confidence in using activities, 4 months**</li> </ul>		
5 T	ailored Activity Program (TAP) (Gitlin <i>et al.</i> , 2008)	4 months maximum 6 HVs of 90 minutes each 2 TCs of 15 minutes (2–3)	Occupational therapist	PD–CG moderate	PD: Frequency of behavioral occurrences Activity engagement CG: Burden Mastery	-Structured observation -Pleasant event schedule -Training for three activities -Environmental modifications	-Pleasant event schedule -Psycho-education -Skill training in communicative techniques	P = 30 $C = 30$ Waiting list 4 months	P: 11.0 (7.3) C: 12.2 (8.8)	-ABID, 4 months** -CSDD -Activity engagement, 4 months* -Pleasure in recreation -QoL scale -Ability to keep busy, 4 months*	-ZBI, -Hours doing for the patient, 4 months*** -Hours feel on duty, 4 months**** -CES-D -Confidence in using activities, 4 months* -TMSI		

6a, 6b	Community Occupational Therapy in Dementia (COTiD) (Graff <i>et al.</i> ,	5 weeks 1 10 HVs of 60 minutes each (3)	s Occupational s of 60 therapist utes	PD–CG mild, moderate	PD: rate Daily functioning CG: Competence	-Interview preferences and ing goal setting -Structured ce observation -Training of meaningful activities with compensation	-Interview ces and preferences and ing goal setting 1 -Information, ion -Skill training, of -Psycho-education ful (behavioral s with management) sation -Stress management	P = 68 C = 67 Usual care 6, 12 weeks	P: 19.0 (5.7) C: 19.0 (4.0)	-AMPS*** -IDDD*** -CSDD*** -Dqol*** -GHQ***	-SCQ*** -CES-D*** -GHQ*** -Dqol*** -Mastery scale***
7	2006, 2007) (Voigt-Radloff <i>et al.</i> , 2011a)					meaningful activities with compensation strategies -Environmental adaptations	(behavioral management) -Stress management	P = 54 $C = 50$ One home visit counseling; leaflet on coping with dementia 6 weeks, 4, 6, 12 months	P 20.4 (3.1) C 19.0 (3.3)	- PRPP - IDDD - CSDD - Dqol - SF-12 physical, mental	<ul> <li>SCQ</li> <li>CES-D</li> <li>Dqol</li> <li>SF-12 physical, mental</li> <li>ADL care (hours per day)</li> </ul>
7	Partners in Caregiving: A Psycho- education Program (PIC) (Hepburn <i>et al.</i> , 2005)	6 weeks 6 weekly GSs of 120 minutes each (3)	Multidisciplinary team	CG mild	PD: none CG: Distress Burden	-Activity groups (occupational or music therapist)	P1: psycho-education P2: same as P1, but completed with a decision-making framework paying attention to values and preferences -Homework -Demonstrations of effective management techniques by occupational or music therapist	P1 = 79 P2 = 72 C = 64 Usual care 6, 12 months	P: 19.22 C: 17.12	-	-Distress measure, 6 months* -BACS, 6 months* -Competence, 12 months*
8a	Environmental Skill-building Program (ESP) (Gitlin <i>et al.</i> , 2003)	12 months 5 HVs of 90 minutes each, 1 TC in months 1–6; 1 HV, total 3 TCs in months 6–12 (3)	Occupational therapist	CG-PD moderate	PD: Behavioral occurrences Dependence ADL Dependence IADL CG: Stress reduction Competence	-Environmental adaptations -Assistive devices	-Interview preferences and goal setting -Information, -Psycho-education -Skill training: simplifying task and communication	P = 89 C = 101 Usual care 6 months	P: 11.6 (7.3) C: 12.5 (7.1)	-RMBPC -FIM ADL -FIM IADL	-RMBPC: upset with memory-related behaviors, 6 months* -RMBPC: upset with disruptive behaviors -Hours providing care -Days receiving help, 6 months* -Mastery index -TMSI -Perceived change index (QoL) affect, 6 months*

# Table 3. Continued.

				PR	OGRAM					STUDY	
		DEL	IVERY CHARACTERIS	TICS	FUNCTIONAL DOMAIN TREATMENT COMPONENTS					MEASUREMENT INSTRUMENTS FOR PD	MEASUREMENT INSTRUMENTS FOR CG
		DURATION CONTACTS/HOME VISITS (DOSAGE)	PROVIDED BY	EMPHASIS ON PD AND CG AIMED AT MILD OR MODERATE DEMENTIA	PRIMARY GOAL: FUNCTIONAL DOMAIN PD - FUNCTIONAL DOMAIN CG	COMPONENTS FOR PD	COMPONENTS FOR CG	GROUP SIZE P = PROGRAM C = CONTROL CONTROL CONDITION INTERVAL AFTER BASELINE	MMSE MEAN (SD) P-C BASELINE	STATISTICALLY SIGNIFICANT OUTCOMES WITH*	STATISTICALLY SIGNIFICANT OUTCOMES WITH*
8b	Environmental Skill-building Program (ESP) (Gitlin <i>et al.</i> , 2001)	3 months 5HVs 90 minutes each, bi-weekly (2)	Occupational therapist	CG-PD moderate	PD: Behavioral occurrences Dependence ADL Dependence IADL CG: Upset Self-efficacy with behavior and ADL/IADL	-Environmental adaptations -Assistive devices	-Interview preferences and goal setting -Information -Psycho-education -Skill training: simplifying task and communication	P = 93 $C = 78$ Usual care, educational materials, booklet with tips for safety in the house 3 months	?	-RMBPC -FIM ADL -FIM IADL*	-Behavior self-efficacy -ADL self-efficacy -IADL self-efficacy -Behavior upset -ADL upset -IADL upset
9	Reducing Disability in Alzheimer Disease (RDAD) (Teri <i>et al.</i> , 2003)	3 months, total of 12 HVs of 60 minutes each (4)	Experienced home health professionals	PD–CG moderate	PD: Physical function Affective status/depression CG: none	-Aerobic, strength, balance and flexibility training	-Aerobic, strength, balance, and flexibility training -Psycho-education (behavioral management) -Pleasant activities	P = 76C = 77Usual care3, 6,12,18,24 months	P: 17.6 (6.8) C: 15.9 (7.4)	-SF36* -SIP* -CSDD* -Time to admission	-
10	Minnesota Family Workshop (MFW) Psycho- educational Intervention (Ostwald	7 weeks 7 weekly GSs 120 minutes (3)	Multidisciplinary team	CG–PD mild to severe	PD: Behavioral problems CG: Burden Mood	-Test on cognitive functioning -Activities: minimum of 2 GSs	-Information -Psycho-education	P = 52 $C = 31$ Waiting list 6 weeks 3, 5 months	P: 17.81 (7.10) C: 19.20 (7.33)	RMBPC	-ZBI, 5 months* -RMBPC -CES-D

11	Case management (Jansen et al., 2011)	12-month minimum: 2 HVs + TC every 3 months; more contact if necessary (1–2)	District nurse	CG–PD mild	PD: Quality of life CG: Competence, Quality of life	-Assessment -Information -Informing the primary care physician Facultative: -Referring to other health care professionals	-Assessment, -Information, -Planning, organizing, collaboration, and monitoring of care; Facultative: -Group support program	P = 54 $C = 45$ Usual care 6, 12 months	P: 22 (4.2) C: 22.7 (3.8)	DQol	-SCQ -SF-36 -CES-D -SPPIC
12	Multicomponent support program (Eloniemi et al., 2009)	Maximum 2 years Flexible HVs (mean 3 times a year) Flexible TCs (mean 15× year) 5 GSs for spouse CG 5 GSs for PD (4)	Family care coordinator (trained public health nurse)	CG mild, moderate	PD: Delay of institu- tionalization CG: Use of services	-Exercise training	-Interview preferences and goal setting -Tailored support plan in collaboration with couple GS: -Information -Emotional support -Psycho-education -Individualized services	P = 63 C = 62 -Written information, -Referrals to community services -Contact with study nurse during assessments (0, 6, 12 months) 6, 12, 24 months	P: 13.4 (6.2) C: 14.2 (6.6)	Time to long-term institutionalization, 18 months*	Use and cost of care services, 24 months*
13	Home Care Program Goa, India (Dias et al., 2008)	6 months HV minimum, bi-weekly (total 12 HVs or more); TC GS (voluntary) (3–4)	Home care advisor (being literate, preferably higher secondary school) Psychiatrist	CG mild, moderate	PD: Behavioral problems CG: Burden Health status	-Consult psychiatrist -When useful: medication	-Information and advice for regulations -Emotional support -Psycho-education -Practical support -Family networking	P = 41 C = 40 Education on dementia 3, 6 months	Mild, moderate	-EASI -NPI	-GHQ* -ZBI* -NPI
14	Collaborative care for Older Adults with Alzheimer Disease (Callahan et al., 2006)	1 year face-to-face consultations in primary care clinic and TCs when needed (mean 1 per month) (4)	Primary care physician Geriatric nurse practitioner	CG mild	PD: Behavioral problems CG: Stress Health status	-Cholinesterase inhibitors -Exercise guidelines with a guidebook and video -Voluntary group sessions for exercise	<ul> <li>-Communicating diagnosis</li> <li>-Information, legal, and financial advice</li> <li>-Skill training in communication</li> <li>-Psycho-education (coping skills)</li> <li>-Facultative: 1–8 behavioral intervention protocols</li> </ul>	$\begin{split} P &= 84\\ C &= 69\\ Augmented usual care: face-to-face counseling communicating the diagnosis and written information 6, 12, 18 months \end{split}$	P: 17.5 (5.2) C: 18.6 (5.9)	-NPI, 12, 18 months** -CSDD (by CG) -ADL-ADCS -Telephone version of MMSE -Pharmacological treatment -Health care resource use	-NPI, 12 months* -PHQ (9 it), 18 months*

Table 3. Co	ontinued.
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				PRO	OGRAM		STUDY				
		DELIVE	ERY CHARACTER	ISTICS	FUNCTIONAL DOMAIN TREATMENT COMPONENTS					MEASUREMENT INSTRUMENTS FOR PD	MEASUREMENT INSTRUMENTS FOR CG
		DURATION CONTACTS/HOME VISITS (DOSAGE)	PROVIDED BY	EMPHASIS ON PD AND CG AIMED AT MILD OR MODERATE DEMENTIA	PRIMARY GOAL: -FUNCTIONAL DOMAIN PD – FUNCTIONAL DOMAIN CG	COMPONENTS FOR PD	COMPONENTS FOR CG	GROUP SIZE P = PROGRAM C = CONTROL CONTROL CONDITION INTERVAL AFTER BASELINE	MMSE MEAN (SD) P-C BASELINE	STATISTICALLY SIGNIFICANT OUTCOMES WITH*	STATISTICALLY SIGNIFICANT OUTCOMES WITH*
15	Reality Orientation with cholinesterase inhibitors (Onder et al., 2005)	25 weeks [by caregiver: three times a week (30 minutes)] (1)	Training by physicians, psycholo- gists, and therapists	CG mild, moderate	PD: Cognitive functioning CG: Well-being	-Three reality orientation sessions by caregivers each week (30 minutes) and orientation prompts during the day -Donepezil	-Education: training ROT (one meeting) -Manual	P = 79 C = 77 Donepezil 6 months	P: 20.2 (3.3) C: 19.9 (3.0)	-MMSE, 6 months* -ADAS–Cognition, 6 months** -BI -Number impaired IADL -NPI	-Caregiver burden inventory -HRDS -SF-36
16	Early Home Care Program (Chu et al., 2000)	18 months minimum 1 TC or HV a month, more when needed (4)	Case manager (nurse) and multidiscip- linary team	CG–PD mild	PD: Long-term planning and use of services Time to admission CG: Burden Mood	When appropriate; -Home services, respite -Occupational therapy -Social worker	-Psycho-education (behavioral management) When appropriate; -Home services, respite, -Occupational therapy -Social worker	$\begin{split} P &= 37\\ C &= 38\\ Usual care + \\ information\\ package\\ 3, 6, 10, 14, \\ 18 \text{ months} \end{split}$	P: 22.7 (3.8) 22.8 (4.2)	Days to admission	-ZBI, 6 months* -RMBPC, 6 months*
17	Medicare Alzheimer's Disease Demonstration Evaluation (MADDE) (Miller, Newcomer et al., 1999) (Newcomer, Miller et al., 1999)	3 years Case management for Model A sites: 1:100 + less financial resources Model B sites: 1:30 + more financial resources (?)	Social worker or nurse	CG–PD mild to severe	PD: Time to admission CG: ADL/IADL Assistance Burden Mood	Case management Model A sites: 1:100 Model B sites: 1:30 When appropriate; -Home services, respite -Therapies -Adaptive and assistive equipment	Case management Model A sites: 1:100 Model B sites: 1:30 When appropriate; -Home services, respite -Therapies	P1: 3,965 P2: 4,130 C: 3,944 P1 + P2 2,731 C 2,576 Usual care 6, 12, 18, 24, 30, 36 months	±18	Time to admission	-Hours of caregiving -ZBI, 6 months* -GDS 18, 24 months*

<u>18</u>	Integrative Reactivation and Rehabilitation Program (IRR) (Bakker <i>et al.</i> , 2011)	Clinical stay of 13 weeks in a psychiatric nursing home unit (4)	Multidisciplinary team	PD mild	PD: Neuropsychiat- ric symptoms CG: Burden, Competence	-Diagnostic assessment -Individual care plan with counseling, cognitive behavioral therapy, behavioral therapy, support, rehabilitation, and psycho- education	-Psychological counseling -Family therapy	P = 81 C = 87 Usual care 3, 9 months	P: 20.04 (4.50) C: 20.58 (3.84)	-NPI symptoms, 3 months** 9 months* -NPI severity, 3 months** 9 months* -MMSE, 3 months* -BI, 3 months* -SF-20 -EQ 5D -Length of stay in nursing home	-NPI distress, 3 months* -CB, 3 months*** 9 months*** -CCL, 3 months*** 9 months**
<u>19</u>	Supporting program (Eloniemi-Sulkava et al., 2001)	2 years 10-day clinical training program Flexible HVs, flexible TCs, when needed Annual training courses, 5 days (4)	Family care coordinator (nurse)	CG–PD moderate	PD: Time to admission CG: none	-Advocacy -Comprehensive support -Assistance social and healthcare services	-Advocacy -Comprehensive support -Counseling -Assistance social and healthcare services -24-hour availability	P = 53 C = 47 Usual care 12, 24 months	P: 14.4 (6.2) C: 15.3 (5.5)	Time to long-term institutionalization, 12 months*	_
<u>20</u>	Training program (Brodaty and Gresham, 1989) Prince Henry Hospital program (Brodaty <i>et al.</i> , 1997)	10 days in-hospital training group TCs 2–6 weeks (4)	Program coordinator in psychiatric hospital, Multidisciplinary team	CG–PD mild, moderate	PD: Time to admission CG: Mental health Mood	-Memory training -Rot -Activities -Reminiscence -Recreation and outings	-Psycho-education -Skill training -Family therapy -Recreation and outings	P: 33 C1: 32 C2: 31 C1: memory training for PD and respite for CG C2 waiting list 3, 6, 12 months/8 years	P: 17.1 (6.5)	Time to admission, 30 months P: 65% lived in the community, C1: 26% C1, C2? 8 years: P: 79% in nursing home,* C1: 90%, C2: 83%	GHQ, 12 months*

Notes: Dosage/intensity: 1 = minimal; (1–2 sessions), 2 = moderate (3–5 sessions), 3 = medium high (6–10 sessions), 4 = high/intensive (>10 sessions; Brodaty *et al.*, 2003). \*Significant p = 0.05; \*\*p = 0.01, \*\*\*p = 0.001.

Explanation of abbreviations: ABID = Agitated Behavior In Dementia, Alzheimer Disease Cooperative Study; ADAS = Alzheimer Disease Assessment Scale; ADL-ADCS = Activities of Daily Living-Alzheimer Disease Cooperative Study Group; ADL = Activities of Daily Living; AMPS = Assessment of Motor and Process Skills; BACS = Beliefs About Caregiving Scale; BI = Barthel Index; CB = Caregiver Burden; CCL = Caregiver Competence List; CES-D = Centre of Epidemic Studies – Depression; CG = Caregiver; CSDD = Cornell Scale Depression in Dementia; COM-FAM = Communication and Interpersonal Relationships, subscale of Family Assessment Measure; DQoL = Dementia Quality of Life instrument; EQ5D = Euro-Quality of Life 5D; EASI = Everyday Abilities Scale for India; FCBI = Family Caregiving Burden Inventory; FIM = Functional Independent Measure; FSSI = Family Support Services Index; GDS = Geriatric Depression Scale; GHQ = General Health Questionnaire; GS = Group Session; HRDS = Hamilton Rating Depression Scale; HV = Home Visit; IADL = Instrumental Activities of Daily Living; IDDD = Interview for Deterioration in Daily Living Activities in Dementia; Performance scale; Initiative scale; MMSE = Mini-Mental State Examination; NPI = Neuro-Psychiatric Inventory; PD = Person with Dementia; PHQ = Patient Health Questionnaire; PRPP = Perceive Recall Plan and Perform System of Task Analysis; PSS = Perceived Stress Scale; QuL-AD = Quality of Life - Alzheimer's Disease Scale; RMBPC = Revised Memory and Behavioral Problems Checklist; SCQ = Sense of Competence Questionnaire; SDI = Sleep Distress Interview; SF-12 (20, 36) HSQ = Short Form Health Survey Questionnaire, Physical scale, Mental scale; SIP = Sickness Impact Profile; SPPIC Self-Perceived Pressure Informal Care; SSQ = Social Support Questionnaire; TC = Telephone Contact; TSMI = Task Management Strategy Index; WHO QoL BREF = World Health Organization Quality of Life Measure-Brief version; ZBI = Zarit Burden Interview. had outcome measures for the person with dementia only [9] or for the caregiver only [7].

## Effects of dyadic psychosocial programs

Eleven of the 23 studies concerning ten programs showed statistically significant positive effects for both members of the dyad [1, 3, 4a, 4b, 5, 6a, 8b, 14, <u>18</u>, <u>19</u>, <u>20</u>]. Four studies showed statistically significant effects for the person with dementia only [2, 9, 12, 15], and six studies found statistically significant effects for the caregiver only [13, 7, 8a, 10, 16, 17]. This was partly because these studies had no effect on outcomes of interest for the other person of the dyad, and partly because outcomes were not measured for the other person of the dyad (Table 3). The two remaining studies did not show any statistically significant effects [6b, 11].

#### Effects on the person with dementia

#### BEHAVIORAL PROBLEMS

Eight of the 23 studies, concerning eight programs, measured behavioral problems [4b, 5, 8a, 10, 13, 14, 15, 18] (Figure 2). The strength of the body of evidence for this outcome is moderate. Three of the eight studies had positive outcomes for behavioral problems (neuropsychiatric symptoms) [5, 14, 18]: one short-period program, one longlasting program, and one program with hospitalization. The three programs comprised different intervention components for each member of the dyad. The other five studies that did not show statistically significant effects on behavioral problems involved programs with comparable intervention components, both short-period programs [4b, 8a, 10] and long-lasting programs [13, 15]. There was no evident relationship between intervention components and the outcome of "behavioral problems." The IRR program with hospitalization [18] showed positive effects on people with mild dementia, but high scores on behavioral problems. For example, the long-lasting Collaborative Care program [14] showed positive effects on people with moderate dementia and regular behavioral problems, and the short-period TAP program [5] showed positive effects on people with moderate dementia and regular behavioral problems.

## Mood

Six of the 23 studies, involving five programs, measured the mood of the person with dementia as a separate outcome [3, 5, 6a, 6b, 9, 14] (Figure 3). The body of evidence for this outcome is strong because of longer follow-up periods and comparison with a control condition other than usual care, although there is heterogeneity in the results of the studies on the Community Occupational Therapy

in Dementia (COTiD) program [6a, 6b]. Three of the six studies showed statistically significant positive effects on the mood of the person with dementia [3, 6a, 9]; these were all shortperiod programs: one group program for earlystage dementia, and two individual programs with home visits for mild and moderate dementia. In all three programs the professional involved the person with dementia actively in group sessions [3], activities [6a], or exercise [9]. The study on the long-lasting Collaborative Care program showed a trend toward positive effects on mood, although this was not statistically significant [14]. The two remaining studies, both involving a short-period program, did not show a statistically significant effect [5, 6b], although they comprise intervention components comparable to those of the programs with statistically significant effects.

## DAILY ACTIVITIES

Ten of the 23 studies, involving eight programs, measured independence and engagement in ADL [4b, 5, 6a, 6b, 8a, 8b, 13, 14, 15, <u>18</u>] (Figure 4). The strength of the body of evidence for this outcome is moderate. Five of the ten studies showed statistically significant positive effects [4b, 5, 6a, 8b, 18]. Four of these concern short-period programs in which the professional actively involves both the person with dementia and the caregiver in skill training [4b, 5, 6a, 8b]. The intervention components in these programs are daily activity training, choosing meaningful (pleasant or purposeful) activities, and environmental adaptations for the person with dementia; and psycho-education and skills training for the caregiver. Whereas these four studies measured instrumental ADL (IADL), the outcome of the fifth study [18], concerning the IRR program, was personal care, measured with the Barthel Index. One other study, the long-lasting Reality Orientation [15] program, shows a trend toward positive effect on personal care, also measured with the Barthel Index. Of the four remaining studies, two long-lasting programs [13, 14] showed no statistically significant effects. The other two were trials of COTiD and the Environmental Skill-Building Program [6b, 8a], and thus they had inconsistent results.

## QUALITY OF LIFE

Eight of the 23 studies, concerning seven programs, measured the quality of life of the person with dementia [3, 4b, 5, 6a, 6b, 9, 11, <u>18</u>] (Figure 5). The body of evidence for this outcome is moderate to strong. Four of the eight programs showed a statistically significant better quality of life of the person with dementia [3, 5, 6a, 9]. Another study

	Experimental			Control			Std. Mean Difference	Std. Mean Difference			
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% CI	IV, Random, 95% CI			
1.1.1 Intensive, limite	d										
TAP Gitlin	18.8	17.6	27	60.8	85.3	29	-0.66 [-1.20, -0.12]				
MFW Ostwald (1)	6.16	5.26	52	4.87	3.54	31	0.27 [-0.17, 0.72]	++			
ESP Gitlin 03	1.88	1.57	89	1.96	1.88	101	-0.05 [-0.33, 0.24]	-			
COPE Gitlin	6.7	10.6	102	5.5	8	107	0.13 [-0.14, 0.40]	+			
1.1.2 Extensive, long-lasting											
ROT Onder	0.9	15.8	70	2.5	17.1	67	-0.10 [-0.43, 0.24]				
Home Care Dias	6.6	4.8	33	8.4	5.1	26	-0.36 [-0.88, 0.16]				
Coll-care Callahan	8	12	84	16.1	19.4	69	-0.51 [-0.83, -0.19]	-+-			
1.1.3 Temporary hospitalization											
IRR Bakker	18.26	14.74	62	22.5	15.1	66	-0.28 [-0.63, 0.07]	-++			
							Fi	-2 -1 0 1 2 avors experimental Favors control			

(1) Ostwald; group program

SD: Standard deviation; CI: Confidence interval

Figure 2. (Colour online) Person with dementia outcomes: behavioral problems.

	Experimental		Control			Std. Mean Difference	Std. Mean Difference	
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% C	I IV, Random, 95% CI
1.2.1 Intensive, limite	d							
COTiD Graff 07	6.5	5.3	68	9.2	6.4	67	-0.46 [-0.80, -0.12]	-+-
RDAD Teri	5.2	3.6	76	6.2	3.8	77	-0.27 [-0.59, 0.05]	
ESML Logsdon (1)	5.05	3.47	92	5.91	4.03	44	–0.23 [-0.59, 0.13]	-++
TAP Gitlin	9	4.6	27	8.7	4.7	29	0.06 [-0.46, 0.59]	
COTiD Voigt-Radloff	12.7	7.8	41	10.3	6.1	37	0.34 [-0.11, 0.78]	++
1.2.2 Extensive, long-	lasting							
Coll-care Callahan	3.5	3.9	84	5.8	5.9	69	-0.47 [-0.79, -0.14]	
								-2 -1 0 1 2 Favors experimental Favors control

(1) Logsdon: groupprogram

SD: Standard deviation; CI: Confidence interval

Figure 3. (Colour online) Person with dementia outcomes: mood.

showed a trend toward better quality of life [4b]. These are all short-period programs: one group program for people with early dementia [3], and four individual programs with home visits and training [4b, 5, 6a, 9]. These studies also showed positive effects on two other outcomes: mood [3, 6a, 9] and ADL/IADL dependency [4b, 5, 6a]. The three remaining studies showed no statistically significant effects on the quality of life [6b, 11, <u>18</u>]. Two of these studies did not show any significant effect [6b, 11]. The third study of the IRR program with hospitalization did not show effect on quality of life, although it was effective for behavioral problems [18].

#### INSTITUTIONALIZATION

We studied "institutionalization" or "time to admission" for seven studies [1, 9, 12, 16, 17,

19, 20]. The body of evidence for this outcome is moderate to strong. One short-period program [1], one long-lasting program [12], and two programs with hospitalization [19, 20] significantly reduced institutionalization or the time to institutionalization. Another program, the long-lasting Early Home Care program [16], also had significant effects, although for a subgroup with a Mini-Mental State Examination (MMSE) of less than 23 only. The short-period Reducing Disability program [9] showed a trend toward delaying institutionalization. The Medicare Alzheimer's Disease Demonstration program [17] showed no significant effects. The data for this outcome were not suited for quantitative comparison. In more recent studies "institutionalization" is less often studied. Next, it is more often included as an outcome measure in studies of long-lasting programs.

	Expe	rimen	tal	C	Control		Std. Mean Difference	Std. Mean Difference		
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% C	I IV, Random, 95% CI		
1.3.1 Intensive, limite	d									
COTiD Graff	14.4	6.1	68	25.3	8.6	67	-1.46 [-1.84, -1.07]	- <b>-</b>		
TAP Gitlin	-2.3	0.3	27	-2	0.4	29	-0.83 [-1.38, -0.28]			
ESP Gitlin 01	5.54	0.6	93	5.75	0.36	78	-0.41 [-0.72, -0.11]	-+-		
COPE Gitlin	-2.8	1.2	102	-2.5	1.1	107	-0.26 [-0.53, 0.01]	-1-		
ESP Gitlin 03	1.68	0.8	89	1.64	0.88	101	0.05 [-0.24, 0.33]	+		
COTiD Voigt-Radloff	14.3	9.5	54	13.5	10.3	50	0.08 [-0.30, 0.47]			
1.3.2 Extensive, long	-lasting									
ROT Onder	0.1	8.3	70	2.9	8.2	67	-0.34 [-0.67, -0.00]			
Home Care Dias	8.5	2.3	33	8.7	2.2	26	-0.09 [-0.60, 0.43]	— <b>I</b>		
Coll-care Callahan	48.6	17.7	84	44.6	17	69	0.23 [-0.09, 0.55]	+-		
1.3.3 Temporary hospitalization										
IRR Bakker	13.62	5.29	68	14.4	4.51	77	-0.16 [-0.49, 0.17]			
								-2 -1 0 1 2 Favors experimental Favors control		

#### SD: Standard deviation; CI: Confidence interval

Figure 4. (Colour online) Person with dementia outcomes: ADL/IADL.

	Experimental			C	ontrol	5	Std. Mean Difference	Std. Mean Difference			
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% CI	IV, Random, 95% Cl			
1.4.1 Intensive, limite	d										
COTiD Graff 07	4	0.6	68	3.1	0.8	67	1.27 [0.90, 1.64]	<del>-</del> +-			
TAP Gitlin	2.4	0.4	27	2.1	0.5	29	0.65 [0.11, 1.19]				
RDAD Teri	72.1	33	68	50.7	39.1	72	0.59 [0.25, 0.93]				
ESML Logsdon (1)	39.61	5.29	92	37.75	6.28	44	0.33 [-0.03, 0.69]	<u>⊢∎−</u>			
COPE Gitlin	2.2	0.5	102	2.1	0.5	107	0.20 [-0.07, 0.47]	++-			
COTiD Voigt-Radloff	2.9	0.9	54	3.1	0.6	50	-0.26 [-0.64, 0.13]	-++			
1.4.2 Extensive, long-	lasting										
Caseman Jansen	2.86	0.9	36	3.02	0.93	37	-0.17 [-0.63, 0.29]				
1.4.3 Temporary hospitalization											
IRR Bakker	51.32	16.01	63	45.51	14.56	72	0.38 [0.04, 0.72]				
							-	-2 -1 0 1 2 Favors control Favors experimental			

(1) Logsdon groupprogram

SD: Standard deviation; CI: Confidence interval

Figure 5. (Colour online) Person with dementia outcomes: quality of life.

#### Effects for the caregiver

#### Mood

Nine studies involving eight programs measured the *mood* of the caregiver as a secondary outcome [4a, 5, 6a, 6b, 10, 11, 14, 15, 17] (Figure 6). The body of evidence for this outcome is moderate to strong. Two studies of short-period programs showed significant positive effects after the intervention [4a, 6a]; another study, the long-lasting Collaborative Care program, showed significant effects at 18 months, but not at earlier intervals [14]. A study of the Tailored Activity program showed a trend toward positive effects, but statistical significance

was not reached [5]. The intervention components of these four programs include information, psychoeducation, and communication skills training for the caregiver. The other five studies involving both short-period and long-lasting programs did not show statistically significant effects [11, 6b, 10, 15, 17]. Four of these programs lack the communication skills-training component [10, 11, 15, 17].

#### PERCEIVED BURDEN AND COMPETENCE

Seventeen studies involving 15 programs measured the perception of providing care with burden and/or competence questionnaires: burden [1, 3,

	Expe	erimen	tal	Control			Std. Mean Difference	Std. Mean Difference		
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% CI	IV, Random, 95% Cl		
2.1.1 Intensive, limite	d									
COTiD Graff 07	5.8	4.8	68	12.6	8.5	67	-0.98 [-1.34, -0.62]			
ACT Gitlin	8.85	5.85	117	10.13	5.87	121	-0.22 [-0.47, 0.04]	-+-		
MFW Ostwald (1)	17.16	4.07	51	17.98	4.84	30	-0.19 [-0.64, 0.27]	-++-		
TAP Gitlin	13.1	9.4	27	14.3	10.2	29	-0.12 [-0.65, 0.40]			
COTiD Voigt-Radloff	10.6	7.1	52	10.9	6.9	46	-0.04 [-0.44, 0.35]			
2.1.2 Extensive, long-lasting										
Coll-care Callahan	3.1	3.9	84	4.6	5.6	69	-0.31 [-0.64, 0.01]			
MADDE Newcomer	4.28	3.4	1705	4.42	3.68	1597	-0.04 [-0.11, 0.03]	*		
ROT Onder	0.9	3.35	70	1	3.27	67	-0.03 [-0.37, 0.30]	-+-		
Caseman Jansen	11.2	6.84	43	11.2	8.11	37	0.00 [-0.44, 0.44]			
							_			



(1) Ostwald groupprogram

SD: Standard deviation; CI: Confidence interval

#### Figure 6. (Colour online) Caregiver outcomes: mood.

	Experimental		Control		Std. Mean Difference		Std. Mean Difference			
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% C	I IV, Random, 95% CI		
2.2.1 Intensive, limite	d									
COTiD Graff 07	-104.6	13.4	67	-88.4	13.7	65	–1.19 [-1.56, -0.82]			
DFCP Chien (1)	56.9	14.8	46	64	13.1	46	-0.50 [-0.92, -0.09]	-+		
ACT Gitlin	19	8.5	117	21	9.3	122	-0.22 [-0.48, 0.03]			
ESP Gitlin 03	0.43	0.5	89	0.56	0.66	101	-0.22 [-0.51, 0.07]			
TAP Gitlin	20.3	8.8	27	20.6	10.4	29	-0.03 [-0.55, 0.49]			
ESML Logsdon (2)	1.07	0.7	92	1.04	0.7	44	0.04 [-0.32, 0.40]	+-		
PIC Hepburn	36.17	12.25	120	34.91	14.53	46	0.10 [-0.24, 0.44]	- <del> </del>		
MFW Ostwald (3)	56.82	11.83	50	55.43	15.91	30	0.10 [-0.35, 0.55]			
COPE Gitlin	7.5	1.9	102	6.9	2.5	107	0.27 [-0.00, 0.54]			
COTiD Voigt-Radloff	-103	18.7	50	-108.6	17.2	47	0.31 [-0.09, 0.71]	++-		
0.0.0 Extensive leng	looting									
2.2.2 Extensive, long	-lasting									
Coll-care Callahan	3.5	5.8	84	7.7	8.7	69	-0.58 [-0.90, -0.25]			
Home Care Dias	19	13	33	21.4	16.2	26	–0.16 [-0.68, 0.35]			
MADDE Newcomer	14.1	8.07	1702	14.4	8.62	1579	-0.04 [-0.10, 0.03]	1		
Early homecare Chu	27.1	0	27	29.5	0	21	Not estimable			
ROT Onder	2	11.71	70	1.3	12.27	67	0.06 [-0.28, 0.39]	- <b>H</b>		
Caseman Jansen	-47.4	6.44	41	-48.4	6.4	38	0.15 [-0.29, 0.60]	- <u>+</u>		
2.2.3 Temporary hospitalization										
IRR Bakker	. 36.75	25.81	60	44.58	28.24	65	-0.29 [-0.64, 0.07]			
								Favors experimental Favors control		

(1) Chien partly groupprogram

(2) Logsdon groupprogram

(3) Ostwald groupprogram

SD: Standard deviation; CI: Confidence interval

Figure 7. (Colour online) Caregiver outcomes: burden and/or competence.

4a, 5, 7, 8a, 8b, 10, 11, 13, 14, 15, 16, 17, <u>18</u>], competence [4a, 4b, 5, 6a, 6b, 7, 8a, 11, <u>18</u>], or both [4a, 5, 7, 8a, 11, <u>18</u>] (Figure 7). The strength of the body of evidence for this outcome is moderate. Thirteen studies, eight short-period programs [1, 3, 4a, 4b, 6a, 7, 8a, 10], four longlasting programs [13, 14, 16, 17], and one program with hospitalization [18] showed significant positive effects for burden/competence, although not at all moments of follow-up. The programs with statistically significant effects included varying intervention components. The remaining four studies without significant effects involve both short-period programs and long-lasting programs

	Exp	erimen	tal	Control			Std. Mean Difference	Std. Mean Difference		
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	IV, Random, 95% CI	IV, Random, 95% Cl		
2.4.1 Intensive, limite	d									
COTiD Voigt-Radloff	3	0.6	51	3.1	0.7	48	–0.15 [-0.55, 0.24]			
ESP Gitlin 03	3	0.54	89	2.89	0.56	101	0.20 [-0.09, 0.48]	++-		
DFCP Chien	74.1	14.8	46	69.8	16.7	46	0.27 [-0.14, 0.68]	++		
COPE Gitlin	3.1	0.6	102	2.9	0.5	107	0.36 [0.09, 0.64]			
ACT Gitlin	3.3	0.7	117	2.8	0.7	122	0.71 [0.45, 0.97]			
COTiD Graff 07	4	0.6	67	3.4	0.7	65	0.92 [0.56, 1.28]			
2.4.2 Extensive, long-	lasting									
ROT Onder	1.3	11.71	70	1.1	11.45	67	0.02 [-0.32, 0.35]			
Caseman Jansen	48.2	9.84	45	47.7	11.25	37	0.05 [-0.39, 0.48]	_ <b>_</b>		
Home Care Dias	-2.6	2.3	34	-3.3	3.6	31	0.23 [-0.26, 0.72]			
2/3 Temporary hospitalization										
Training Dreadet		0.0	00	0.1	0.4	01	0.11[0.00.0.00]			
I raining Brodaty	5.3	6.2	33	6.1	8.4	31	-0.11[-0.60, 0.38]			
							_			
								<u> </u>		
								Eavors control Eavors experimental		

SD: Standard deviation; CI: Confidence interval

Figure 8. (Colour online) Caregiver outcomes: quality of life.

[5, 8b, 11, 15]. It is not clear which intervention components of the 15 programs are effective and which are not. Six of the 17 studies measured burden and perceived competence. In three studies, the scores for the two concepts were in the same direction: both concepts had significant effects [4a, 18] or both had non-significant effects [11]. The other three studies had statistically significant effects for one outcome [5, 7, 8a].

#### QUALITY OF LIFE

Ten studies measured the quality of life of the caregiver [1, 4a, 4b, 6a, 6b, 8a, 11, 13, 15, 20] (Figure 8). The body of evidence for these studies is moderate. Seven of the ten studies found statistically significant effects [1, 4a, 4b, 6a, 8a, 13, 20]. The programs are from all three categories. These seven studies also showed significant effects on other outcomes. Three other studies showed no statistically significant effect on the quality of life of the caregiver [6b, 11, 15]. Two of the programs, Case Management [11] and COTiD program [6b] showed no significant effects on any outcome, and the Reality Orientation program only showed significant effects on outcomes for the person with dementia [15]. The intervention components of this program focus primarily on the "cognition" of the person with dementia, and do not involve caregiver feelings.

#### Discussion

Psychosocial interventions for both people with dementia and their caregivers may have a beneficial impact for both members of the dyad or only one of them. We targeted psychosocial interventions for the dyad in this review. In addition to the meta-analysis of Brodaty and Arasaratnam (2012), this meta-analysis builds on previous reviews by extending the focus to also include outcomes for the people with dementia. The terms "non-pharmacological" and "psychosocial" are commonly used interchangeably. In this study, we used the term psychosocial intervention to indicate interventions in which contact between the professional and both the person with dementia and the caregiver was central, with or without other treatment components. In practice these interventions are complementary to other interventions that may be pharmacological, technological, or providing respite care for the caregiver. We searched for effects for both members of the dyad, but unfortunately the data were too diverse, and it was not possible to relate outcomes for both the person with dementia and the caregiver.

Smits *et al.* (2007) conclude that "general health appears to be the most promising target for dyadic programs" for caregivers. In our review, we can be more specific: Programs with intervention components that are related to the targeted functional domains are promising, especially for the outcomes of ADL/IADL dependency and competence, adding to better quality of life for both members of the dyad. The increasing number of moderate to good effect studies of psychosocial interventions for people with dementia and their informal caregivers reflects the need for evidence-based interventions for this target group.

Many studies show domain-specific effects, that is, there are statistically significant effects on the outcomes corresponding with the functional domain that the intervention aims to improve. This is the case especially for the outcomes "activity and functional dependence of the person with dementia" and "competence of the caregiver" [4b, 5, 6a, 9], and for the outcome "sleep" in the study of the sleep program [2]. The effects of other outcomes are more heterogeneous, and any relation with the treatment components and delivery characteristics is less evident. Programs of all three categories, i.e. short-period programs, long-lasting programs, and programs with hospitalization, had positive effects on behavioral problems of the person with dementia and on mood and burden of the caregiver. Pinquart and Sorensen (2006) have already mentioned the domain-specific effects of intervention components for the caregiver, such as counseling and psychoeducation for active engagement of the caregiver. In this review we found support for the effectiveness of skills training for the activities of the person with dementia and communication skills training for the caregiver. This can explain the effect sizes being larger than those of other programs that merely emphasize the role of the caregiver to train the person with dementia. Active training for activities focused directly on both members of the dyad adds to beneficial effects. All psychosocial intervention programs in this review tailored the intervention to the needs and personal situation of the dyad. Based on this review, we did not find that a structured needs assessment at the start of an intervention is better than tailoring the intervention during the sessions. Further, no effects can be unequivocally attributed to the intensity and duration of the program. Perhaps this will depend on the needs of the person with dementia and/or caregiver and the targeted functional domain of the program. Pinquart and Sorensen (2006) and Brodaty et al. (2003) found that longer interventions are more likely to improve mood of the caregiver. Next, Brodaty and Arasaratnam (2012) recommend in their review on caregiver interventions that shortperiod programs were most effective for behavioral and psychological problems of the person with dementia, and also most effective for botheration, stress, or self-efficacy of the caregiver.

#### Heterogeneity of effects

Our review also yielded some conflicting results. COTiD is probably the most illustrative example of this. In the COTiD study [6], Graff *et al.* (2006) show large effect sizes for all outcome measures, including mood, quality of life, daily functioning, and competence, but these effects were not replicated in successive studies of the same program (Voigt-Radloff *et al.*, 2011a). Next, Gitlin *et al.* (2008, 2010a) have demonstrated a decrease in behavioral occurrences of the person with dementia in two studies [4a, 5]; however, the Care of Persons with dementia in their Environments (COPE) study [4b], with comparable intervention components, does not show this effect (Gitlin et al., 2010b). Differences in findings in interventions with comparable treatment components might be explained in several ways. Contrary to pharmacological treatment, psychosocial interventions in general and dyadic interventions in particular are of a different nature. The question is, can we expect to find clearly defined effects on the total group of caregivers of such complex interventions as included in this meta-analysis. These interventions consist of various treatment components, and the effects will depend on different aspects, such as the specific needs of the caregivers and people with dementia and the fit with the targeted functional domain of the program. In addition, the competencies of the professionals involved and the relationship between care professional, person with dementia, and informal caregiver may also play a role. Next, the quality of the intervention may influence outcomes. Leontjevas et al. (2012) advocate a process evaluation of the sampling quality and the intervention quality of trials. Such evaluations guarantee valid outcomes and, in the case of effective programs, guide implementation of the program (Moniz-Cook and Manthorpe, 2009; Grol and Wensing, 2011). Recruitment strategies have to take into account the fact that participants may differ in several respects, which results in different amounts of improvement. For example, the stage of dementia, the extent of behavioral problems, the mental health of the caregivers, their knowledge, skills, and earlier support may all differ. If caregivers do not know much about dementia, psychoeducation may be a very effective tool. However, if they already know all the ins and outs of the disease, one can expect that psycho-education will not be very effective. Often research participants are already involved in a support network and belong to a help-seeking group (Schoenmakers et al., 2010). The intervention quality depends on experienced trainers and support during the intervention. Next, cultural background of participants and trainers as well as the healthcare system in a country influences the effects of a program (Voigt-Radloff et al., 2011b).

We did not distinguish between the perceived burden and competence as separate outcomes because the instruments used to measure these concepts in the studies overlap in content. Since it may be important to differentiate between these concepts, developing a new instrument with good psychometric properties may be important. Perceived burden and competence may have different relationships with stressors such as behavior problems (Graff *et al.*, 2007; Gitlin *et al.*, 2008), and perceived competence might be easier to improve because it concerns a skill.

We found a relationship with other functional domains: Studies with positive effects on quality of life also had positive effects on other outcome domains for the caregiver as well as for the person with dementia.

# Limitations

Results should be interpreted cautiously because of the differences in the programs and studies. First, all studies used validated measurement instruments, but sometimes they used different combinations of subscales, which made results difficult to compare [4a, 4b, 5, 7, 8a, 8b]. Second, the duration of the programs was five weeks to two years. We chose to compare the results up to one year after the intervention because this was the time most likely to do justice to the program. The natural decline due to the dementia may decrease the effects of long-lasting programs more than the effects of shortperiod programs. Two long programs [12, 14] and one short program [7] had no significant effects directly after completion of the program, but they did at later follow-up times. The quantitative comparison was also made within more homogeneous subgroups according to the program characteristics, the stage of dementia, and the duration of followup, but that did not change the overall figure.

## Implications for research

Functional domains of a psychosocial intervention should focus on the needs of the dyad. A structured needs assessment of both members of the dyad before the start to determine whether the intervention is appropriate is challenging because of difficulties in recruitment. However, it might be expected that focusing an intervention on the needs of the dyad would lead to stronger and more realistic effects, which is important in daily practice.

More research into measuring the effects of different dosages, frequency, and intervention components or combinations of components is needed. The outcome "institutionalization" needs more attention. Although studies with a long follow-up are expensive, this is a minor problem compared to huge costs for institutional care for a growing number of people with dementia in the next decades. For some programs cost-effective studies are available [5, 6a, 17], and results about cost-effectiveness are needed for choosing appropriate programs for clients with dementia in this review raises several questions. Did the psychosocial interventions meet

the specific needs of the caregivers and dementia patients who were involved in different studies? Has the interventions been delivered and received in the proposed way? Were the appropriate instruments used for measuring the effects of the complex interventions included in this review, or do we need more individualized outcomes to measure the effects of this kind of interventions? Moreover, individualized analyses, such as time series, might also be an option, in which the person has its own control.

## Implications for practice

A generic conclusion about the program that works best is not possible because of the broad range of outcomes. Programs that target behavioral problems and/or ADL/IADL dependency seem to be promising. Active training for activities and communication skills improves results for both members of the dyad. This review underscores the need to evaluate key treatment variables and key characteristics of the dyad to determine which form of treatment may be more compatible and thus more likely to be beneficial to the person with dementia and the caregiver (Coon et al., 2003). Choosing an intervention depends on several arguments. The intervention has to meet the problems that a dyad experiences, thus the primary targeted functional domain should match those problems. Other criteria for choosing an intervention for a dyad are stage of mild or moderate dementia, costs, and availability and feasibility of the program. For example, the IRR program is effective for reducing behavioral problems for persons with relatively mild dementia, but the IRR program with (temporarily) hospitalization is an expensive and intrusive program [18]. Thus, this program should be restricted to persons with dementia with severe neuropsychiatric symptoms. Other programs are merely aimed at maintaining functional abilities for the person with dementia and supporting the caregiver to handle the behavioral symptoms and cope with the dementia process and their role as a caregiver [5, 6a, 4a, 4b, 3, 8a, 9, 10]. The preventive character of these less expensive programs over limited time makes these programs suitable for broad application for dyads that recognize these problems. Next, some interventions aimed chiefly at supporting the caregiver in his/her caregiver role for a longer time [1, 12, 19, 13, 14, 7, 17]. When needs of a couple on a certain moment primarily are experienced by the caregiver, these interventions are appropriate, when needed in combination with the limited, short-term programs.

Since a clinician has to determine which program works for which dyad, matching the goals of a program with the needs of both members of the dyad is necessary to support them in their daily lives. Reflection on the results during the program is also necessary, and adaptation or a change to other support programs may be required.

#### **Conflict of interest**

None.

# **Description of authors' roles**

Netta Van't Leven, Anna-Eva Prick, Jacomine de Lange, and Anne Margriet Pot contributed to the study design. Netta Van't Leven, Anna-Eva Prick, and Hanny Groenewoud screened the papers and extracted data from the studies. Pepijn Roelofs assisted analysis. Netta Van't Leven with Anna-Eva Prick drafted the manuscript; all the authors revised the manuscript critically, and read and approved the final version.

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