Needs of people living with dementia and their informal caregivers for activating interventions

Netta van 't Leven

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The studies presented in this thesis were conducted at the Research Center Innovations in Care of Rotterdam University of Applied Sciences, in cooperation with the Department of Clinical, Neuro- & Developmental Psychology at the Vrije Universiteit Amsterdam and the Amsterdam Public Health research institute, the Netherlands.

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CHAPTER 1 –

General introduction

Background

Challenges to maintain activities after a dementia diagnosis

Worldwide, the number of people with dementia is expected to increase exponentially in the coming decades due to an increased life expectancy. In the Netherlands, 270,000 people currently live with dementia, with more than 620,000 people projected for 2050.[1] An even larger increase is expected worldwide, from 46 million in 2015 to 131.5 million in 2050.[2] Dementia is characterized by a progressive decline of cognitive functions, profoundly limiting the activities of daily living and social functioning.[3] As there is no cure for dementia, psychosocial interventions are important to maintain quality of life by coping with the consequences of dementia.[4,5]

Community-based care and support for people with dementia will continue to be needed in the coming decades.[6] About 74% of Dutch people with dementia live in their own homes and receive support and care from informal caregivers.[7] These informal caregivers are most often spouses and adult children, though they may occasionally be neighbors or close friends. About 60% of informal caregivers live with the person with dementia.[1] With the increase of people with dementia and the current trend for them to live at home longer, informal caregivers are projected to play a more substantial future role in dementia care. Being a caregiver, which includes making decisions for the person with dementia, changes the nature of the relationship with the partner, child, friend, or neighbor. Caring is time consuming and the ongoing demand and unpredictability of dementia's progression is burdensome.[8,9] Interventions which support both people with dementia and the caregiver are seen as most effective in maintaining the quality of life for both.[10-12] Awareness of dementia's effect on the relationship between people with dementia and their informal caregivers has increased in recent years, especially when it comes to communication, shared activities, reciprocity, and happiness.[13-15] The behaviors of the informal caregiver and his or her sense of competence can greatly influence behavioral changes in people with dementia.[14,16] Dyadic interventions enable them to discuss relationship issues, such as dealing with emotions and practicing skills for coping with declines in capacities.[15,17]

Continuing to participate in meaningful activities is important for people with dementia and their caregivers, but not easy. These activities can have a positive effect on the well-being and health of people with dementia, building self-esteem and satisfaction, while also providing life continuity.[18-20] Although some people with dementia develop strategies to remain active and continue activities they previously enjoyed, many frequently report a lack of company and daytime activities, both at home and elsewhere.[21-25] Informal caregivers report difficulties in helping the person with dementia maintain their activities, while also keeping up with their own.[7,9,26] Informal caregivers have repeatedly expressed a need for professional advice regarding continuing activities.[23,27]

Person-centered dementia care

The focus of this research, the need for meaningful activities, is one of the domains of person-centered care, along with comfort, attachment, inclusion and identity.[4] Kitwood includes these five domains of psychological needs to fulfil the central need to be a loved and respected person when living with dementia. They are all essential for maintaining a sense of personhood or 'continuation of self'.[4,28,29]
In a person-centered approach, needs are interpreted from the viewpoint of the person with dementia, the individual course of the dementia process and their individual life history.[4,29,30] This also includes the person's experiences with the interdependency and reciprocity that are inherent in caring relationships.[31] Therefore, needs within the domains may vary per individual.
Person-centered care is directed at maximizing the individual's potential by optimally using their individual capacities and creating a physical and social environment that supports the person with dementia in living with meaning and dignity.[4,30] People with dementia make their own choices where possible, and are not seen as passive recipients of standard care services.[4,29] Self-evidently, an informal caregiver also has an individual biography, lifestyle, and coping strategy.[13,14,32] In a person-centered approach, the needs, characteristics and preferences of both the people with dementia and the caregivers are equally important in offering appropriate care and support.

Three dyadic, activating interventions

The primary investigator and co-authors have been involved in three promising activating interventions based on the available evidence at the start of this project, which focus on the activity needs of people with dementia and their informal caregivers, in line with a person-centered approach. These interventions emphasized potential adaptations of activities to fit the remaining capacities of the people with dementia. The interventions include psycho-education, emotional support, the practice of various activities, and communication skills for caregivers. The interventions consist of six to ten home visits. These interventions are: the Pleasant Events Program; the Exercise and Support Intervention; and Community Occupational Therapy in Dementia (COTiD) (Chapter 3, Table 1, p. 60).

The Pleasant Events Program focuses on finding enjoyable activities for the dyad, planning them, and when necessary, simplifying these activities for the person with dementia. Examples are: walking around the neighborhood; taking public transport to a historic part of the city; watching a specific television program.[33-35] The Exercise and Support Intervention aims to increase the physical health and the mood of both people with dementia and caregivers while decreasing the caregiver's burden. The intervention includes joint exercises and planning pleasant activities. The exercises focus on flexibility, balance, strength and/or endurance.[36,37] Community Occupational Therapy in Dementia (COTiD) aims to generally improve the performance of daily activities. Activities that are relevant to the dyad are chosen, then practiced, often in combination with environmental adaptations. Examples are: using a remote control with orientation marks for the television, completing a bicycle ride on a safe route, and maintaining daily structure through an individualized agenda.[38,39] These interventions showed positive effects[a] on the mood, daily activities, general health and quality of life of people with dementia, as well as on the mood, competence, and quality of life of their caregivers.[33,34,37,44,45]

Current usual care to maintain activities

People with dementia and their informal caregivers often consult their general practitioner or a geriatrician for memory complaints when they suspect dementia. In the Netherlands, people with dementia are offered a case manager, although, only 35% of recently diagnosed people with dementia actually have a specialized dementia case manager.[7,46] The general practitioner, geriatrician, and case manager are the leading professionals for coordinating care and support for people with dementia and their informal caregivers after diagnosis.

Despite reported difficulties in maintaining daily activities, not many people with dementia are referred to dyadic, activating interventions.[47-50] For a person-centered approach, care services should meet personal activity needs. Currently, criteria for referrals to interventions are lacking. Physicians report a need for more refined criteria that help to refer people with dementia to interventions.[51,52]

In effect studies of psychosocial interventions, there is often a call to find a better intervention to fit the specific needs of the individual with dementia and the informal caregiver who supports them.[53,54]

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[a] Later studies did not always duplicate the evidence found in these studies [40-43].

Aim and research questions of this thesis

The aim of this thesis was to study (1) the impact of dyadic, activating interventions for people with dementia and their caregivers, and (2) the appropriateness of criteria for referring dyads to these interventions.

Research questions in Part I

Question 1
What evidence supports psychosocial, dyadic interventions for community-dwelling people with dementia and their caregivers, and what is the relationship with treatment components?

Question 2
How do the three promising dyadic, activating interventions match the needs, characteristics and preferences of the participating dyads?

Question 3
What do people with dementia, their caregivers and coaches perceive as working mechanisms in the three dyadic, activating interventions?

Research questions in Part II

Question 4
Which criteria describing activity needs, characteristics, and preferences of people with dementia and their informal caregivers are recognizable for physicians and case managers in their daily practice?

Question 5
Are these criteria helpful for assessing activity needs, characteristics, and preferences of community-dwelling people with dementia and their caregivers?

Outline and methodology

Part I The impact of dyadic, activating interventions for people with dementia and their informal caregivers

Chapter 2 describes dyadic psychosocial interventions in a systematic literature review. We followed the guidelines from the Cochrane Handbook for Systematic Reviews of Interventions. We applied a quantitative analysis with a qualitative approach to search for similarities and differences in the treatments of the different interventions. Finally, we compared the characteristics and treatments with significant effects of the interventions on the outcome domains.

Chapter 3 explains the matching of the three dyadic, activating interventions with the needs, characteristics and preferences of the participants and their caregivers. In a qualitative study, we investigated the experiences of the dyads and their coaches in these three dyadic, activating interventions. We used semi-structured interviews to gather in-depth information.

Chapter 4 describes the working mechanisms of the interventions, as perceived by people with dementia, their caregivers, and coaches. We used the same qualitative interviews from Chapter 3.

Part II The appropriateness of criteria for referral to dyadic, activating interventions

The findings of Chapter 3 provided input for the studies of Part II of our research. From the qualitative descriptions in the interviews, the research team operationalized the factors as observable criteria. Each criterion describes a need, characteristic or preference of people with dementia and/or their caregivers. After thoroughly discussing clarity and consistency, we drafted 31 conceptual criteria.

Chapter 5 answers the question which criteria physicians and case managers recognize in their daily practice with people with dementia and their caregivers. Using the 'RAND Appropriateness Method', an expert panel, consisting of geriatricians, general practitioners and dementia case managers, rated the recognizability of these criteria.

Chapter 6 explores the usefulness of the criteria for real-life assessment of activity needs, characteristics and preferences. We performed a secondary analysis of needs assessments-interviews conducted by a case manager with community-dwelling people with dementia and their caregivers. We interpreted text fragments in the context of the whole interview.

Chapter 7 is a general discussion of the thesis and summarizes the main findings, reflects on the findings and the methodology, and formulates implications for clinical practice and future research.

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PART I

The impact of dyadic, activating interventions for people with dementia and their informal caregivers

CHAPTER 2 –

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

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Background

In this review, we study the effects of dyadic psychosocial interventions focused on community-dwelling people with dementia and their family caregivers, and the relationship of the effects with intervention components with 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.[12] 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 programme, and the study design.

Conclusion

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.

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.[1-3] 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.[3-5] Many psychosocial supporting interventions for people with dementia and their caregivers have been developed in the last decades.[6,7] Evidence for the effectiveness of these interventions, being even more effective than pharmacological therapies, has been published.[8-10] In recent years, psychosocial 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.[11] The effects of psychosocial intervention programs have been studied in a previous review that included publications up to 2005.[12] 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 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 we searched 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* OR dementia) AND (caregiv* 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.[13-15] Any systematic reviews 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., 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).

Table 1 Inclusion and exclusion criteria

	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 caregiver.
Language	English, Dutch, German, and French.
	Exclusion criteria
Study aim	Cost-effectiveness.
Pooled data	Combination of intervention studies.

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.

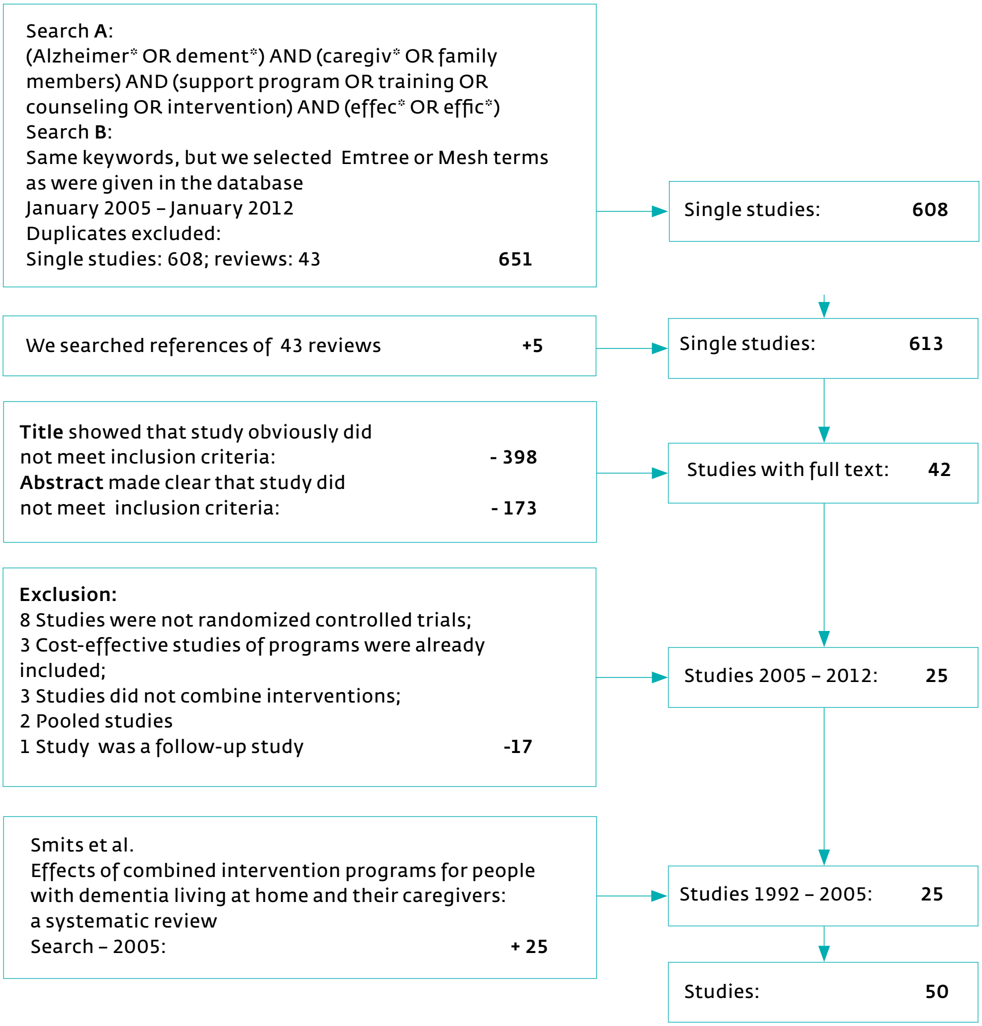

Figure 1 Flow chart of identification of studies

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 review) for methodological quality by using the Cochrane rating criteria for RCTs.[14] 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 (http://www.cebm.net): the specific components of the intervention should be described, and the experimental and control groups must each have a minimum of 30 participants (Table 2).[16] 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.[17] 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".[10] 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.[14] 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. If the data warranted it, we quantitatively compared studies for the same targeted psychosocial outcome with the Review Manager (software version 5.1).[14] 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 statitical heterogeneity between the studies.

Table 2 Quality assessment of studies meeting the inclusion criteria

Criteria	1	2	3	4	5	6	7	I	II		
Columns 1-7: Cochrane criteria and columns I, II: Oxford Centre of Evidence-based Medicine Guideline for assessing methodological quality 2012-2005	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 drop-outs described?[i]	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**
Jansen et al., 2011[31]	+	+	+	+	+	+	+	+	+	+	1
Clare et al., 2011[32]	+	+	+	+	+	?	+	+	-	-	
Chien & Lee, 2011[33]	+	?	+	+	+	+	+	+	+	+	2
Carbonneau et al., 2011[34]	+	?	?	+	+	+	+	+	-	-	
Bakker et al., 2011[35]	+	+	-	+	+	+	+	+	+	+	3
McCurry et al., 2011[36]*	+	+	+	+	+	+	+	+	+	+	4
McCurry et al., 2010[37]	+	?	?	?	?	+	+	-	+	-	
McCurry et al., 2005[38]	+	+	+	-	-	+	+	+	-	-	
Logsdon et al., 2010[39]*	+	?	?	+	+	+	+	+	+	+	5
Logsdon et al., 2006[40]	+	?	?	+	+	+	+	+	-	-	
Gitlin et al., 2010A[22]#	+	+	+	+	+	+	+	+	+	+	6
Gitlin et al., 2010B[23]	+	+	+	+	+	+	+	+	+	+	6
Neely et al., 2009[41]	+	-	-	+	+	+	+	+	-	-	
Eloniemi-Sulkava et al., 2009[42]	+	+	-	?	+	+	+	+	+	+	7
Gitlin et al., 2008[21]	+	+	+	?	+	+	+	+	+	+	8
Dias et al., 2008[43]	+	+	+	+	+	?	+	+	+	+	9
Onor et al., 2007[44]	+	?	?	?	+	+	+	+	-	-	
Callahan et al., 2006[45]	+	+	+	-	+	+	+	+	+	+	10
Dröes et al., 2006[46]	-	-	-	+	-	+	+	+	-	-	
Voigt-Radloff et al., 2011[20]#	+	+	+	+	+	+	+	+	+	+	11
Graff et al., 2007[29]*	+	+	+	+	+	+	+	+	+	+	11
Graff et al., 2006[19]	+	+	+	+	+	+	+	+	+	+	11
Onder et al., 2005[47]	+	+	+	?	+	+	+	+	+	+	12
Martin-Cook et al., 2005[48]	+	?	?	+	-	+	+	+	-	-	
Hepburn et al., 2005[49]	+	+	-	-	+	+	+	+	+	+	13

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>> **Table 2** Quality assessment of studies meeting the inclusion criteria

Criteria	1	2	3	4	5	6	7	I	II		
Columns 1-7: Cochrane criteria and Columns I, II: Oxford Centre of Evidence-based Medicine Guideline for assessing methodological quality **2005-1992**	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 drop-outs described?[i]	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**
Berger et al., 2004[50]	-	+	?	+	+	+	+	+	-	-	
Dröes et al., 2004a[51]* Dröes et al., 2004b[52]	-	+	+	-	+	+	+	+	-	-	
Dröes et al., 2000[53]	-	+	+	-	+	+	+	+	-	-	
Gitlin et al., 2003[54]#	+	+	?	+	+	+	+	+	+	+	
Gitlin et al., 2001[55]	+	+	?	+	+	+	+	+	+	+	14
Teri et al., 2003[56]	+	+	+	+	+	+	+	+	+	+	15
Romero&Wenz, 2002[57]	-	-		-		-	-		-	-	
Eloniemi-Sulkava et al., 2001[58]	+	+	+	+	+	?	+	+	+	+	16
Quayhagen&Quayhagen, 2001[59]	+	?	?	+	-	+	+	+	-	-	
Chu et al., 2000[60]	+	?	?	+	+	+	+	+	+	+	17
Aupperle&Coyne, 2000[61]	-	-	?	+	?	+	+	+	-	-	
Ostwald et al., 1999[62]	+	?	?	+	?	+	+	+	+	+	18
Logiuduce et al, 1999[63]	+	+	-	+	+	+	+	+	-	-	
Miller et al., 1999[64]* Newcomer et al., 1999[65] Yordi et al., 1997[66]	+	+	+	+	+	+	+	+	-	+	19
Moniz-Cook et al., 1998[67]	-	+	?	+	+	+	+	+	-	-	
Riordan & Bennett, 1998[68]	-	+	-	+	-	+	+	+	-	-	
Teri et al., 1997[69]	+	-	?	+	+	+	+	+	-	-	
Brodaty et al., 1997[70]* Brodaty&Gresham, 1989[71]	+	?	?	?	+	+	+	+	+	+	20
Hinchcliffe et al., 1995[72]	+	-	+	+	+	+	+	+	-	-	
Vernooij-Dassen et al., 1995[73]*	+	?	?	?	?	?	?	-	-	-	
Vernooij-Dassen, 1993[74]	+	+	+	+	+	+	+	-	+	-	

Notes: Criterium 5; 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 #Programs are studied again in a new study design and population.

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. included 25 publications from the period 1992 to 2005.[12] 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 the delivery characteristics, programs can be classified in following three categories:

1. 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: 18,19,20]. 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 [18]. The supporting program and the training program include residence for both members of the dyad for ten days, with the focus on both [19,20]. (Numbers of short-period programs are written in standard font, long-lasting programs in italics, and other programs are underlined.

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 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.

Table 3 Description of programs and studies included in the review

	PROGRAM						**STUDY**			
	Delivery characteristics			**Functional domain**	**Treatment components**				**Measurement instruments for PD**	**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**	**Component 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 & Lee, 2011[33])	6 months 4 HVs for needs assessment (weekly), 10 GSs max. (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	P=46 C=46 Usual care 6, 12, 18 months	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 et al., 2011[36])	8 weeks 6 HVs of 60 mins each (3)	Professional with master degree level	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 - aytime sleep or inactivity	SDI
3 Early-Stage Memory Loss Support Groups (Logsdon et al. 2010[39])	9 weeks 9 GSs of 90 mins each for caregivers and persons with dementia, partly separated during the session (3)	Professional with master degree level	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	P=96 C=46 Educational leaflets from Alzheimer's Association 10 weeks	P 23.2 (4.7) C 24.0 (3.8)	- QoL-AD*** - SF-36 - GDS** - COM- FAM - PSS - Self-efficacy scale	RMBPC*

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	PROGRAM						STUDY			
	Delivery characteristics			**Functional domain**	**Treatment components**				**Measurement instruments for PD**	**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**	**Component 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 Advanced Caregiver Training ACT (Gitlin et al., 2010A[22])	6 months max 9 HVs of 90 mins 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 communi-cation - Psycho-education, stress manage ment	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** - CES-D, *4 months** - Perceived Change Index, s *4 month****, *6 months**** - TMSI, *4 months****, *6 months***
4b Care of Persons with Dementia in their Environ-ments COPE (Gitlin et al., 2010B[23])	4 months maximum 10 HVs of 90 minutes each (OT)in month 1-4 1 HV N, 1TC N (3)	see 4a	see 6a	PD: Functional dependence CG Confidence in using activities	see 6a	see 6a	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**	- Perceived Change Index, *4 months*** - Confidence in using activities, *4 months***
5 Tailored Activity Program TAP (Gitlin et al., 2008[21])	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

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	PROGRAM						STUDY			
	Delivery characteristics			Functional domain	Treatment components				Measurement instruments for PD	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	Component 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*
6a Community Occupational Therapy in Dementia COTiD (Graff et al., 2006[19], 2007[29])	5 weeks 10 HVs of 60 minutes each (3)	Occupational therapist	PD-CG mild, moderate	PD: Daily functioning CG: Competence	- Interview preferences and goal setting - Structured observation - Training of meaningful activities with compensation strategies - Environmental adaptations	- Interview preferences and goal setting - Information, - Skill training, - Psycho-education (behavioral management) - 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***
6b (Voigt-Radloff et al., 2011[20])							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	- SCQ - CES-D - Dqol - SF-12 physical, mental - ADL care (hours per day)
7 Partners in Caregiving: A Psychoeducation Program (PIC) (Hepburn et al., 2005[49])	6 weeks 6 weekly GSs of 120 mins each (3)	Multidisciplinary team	CG mild	PD: - 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 the Occupational therapist 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 et al., 2003[54])	12 months 5 HVs of 90 mins 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: - Stressreduction - 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 withmemory-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**

	PROGRAM						STUDY			
	Delivery characteristics			Functional domain	Treatment components				Measurement instruments for PD	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	Component 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 et al., 2001[55])	3 months 5HVs 90 mins 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 et al., 2003[56])	3 months, total of 12 HVs of 60 mins each (4)	Experienced home health professionals	PD-CG moderate	PD: - Physical function - Affective status/ depression CG: -	- Aerobic, strength, balance and flexibility training	- Aerobic, strength, balance, and flexibility training - Psycho-education (behavioral management) - Pleasant activities	P=76 C=77 Usual care 3, 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 et al., 1999[62])	7 weeks 7 weekly GSs 120 mins (3)	Multidisciplinairy 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

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	PROGRAM						**STUDY**			
	Delivery characteristics			**Functional domain**	**Treatment components**				**Measurement instruments for PD**	**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**	**Component 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***
11 *Case management* (Jansen et al., 2011[31])	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[42])	Max. 2 years flexible HVs (mean 3 x a year) flexible TCs (mean 15x year) 5 GSs for spouse CG 5 GSs for PD (4)	Family care coordinator (trained public health nurse)	CG mild, moderate	PD: Delay of institutionalization 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 info - 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 costs of care services, *24 months**
13 *Home Care Program Goa, India* (Dias et al., 2008[43])	6 months HV minimum, bi-weekly (total 12 HVs or more); TC GS (voluntary) (3-4)	Home care advisor (being literate, preferably higher sec. 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

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	PROGRAM						STUDY			
	Delivery characteristics			Functional domain	Treatment components				Measurement instruments for PD	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	Component 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*
14 *Collaborative care for Older Adults with Alzheimer Disease* (Callahan et al., 2006[45])	1 year face-to-face consultations in primary care clinic and TCs when needed (mean 1 per month) (4)	Primary care physician and 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	- Communicating diagnosis - Information, legal and financial advice - Skill training in communication - Psycho-education (coping skills) - facultative: 1-8 behavioral intervention protocols	P= 84 C= 69 Augmented usual care: face-to-face counseling communicating the diagnosis and written information 6,12,18 months	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**
15 *Reality Orientation with cholinesterase inhibitors* (Onder et al., 2005[47])	25 weeks [by caregiver: three times a week (30 minutes)] (1)	Training by physicians, psychologists and therapists	CG mild, moderate	PD: Cognitive functioning CG: Well-being	- Three reality orientation sessions by caregivers each week (30 mins) 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[60])	18 months minimum 1 TC or HV a month, more when needed (4)	Case manager (nurse) and multidisciplinairy 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	P=37 C=38 Usual care + information package 3,6,10.14.18 months	P 22.7 (3.8) 22.8 (4.2)	Days to admission	- ZBI, *6 months** - RMBPC, *6 months**

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	PROGRAM						STUDY			
	Delivery characteristics			**Functional domain**	**Treatment components**				**Measurement instruments for PD**	**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**	**Component 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***
17 *Medicare Alzheimer's Disease Demonstration Evaluation MADDE* (Miller, Newcomer et al., 1999[64]) (Newcomer, Miller et al., 1999[65])	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	P 1 3965 P2 4130 C 3944	± 18	Time to admission	
							P1+P2 2731 C 2576 Usual care 6,12,18, 24,30, 36 months			- Hours of caregiving - ZBI, 6 months* - GDS, 18,24 months*
18 Integrative Reactivation and Rehabilitation Program IRR (Bakker et al., 2011[35])	Clinical stay of 13 weeks in a psychiatric nursing home unit (4)	Multi-disciplinary team	PD mild	PD: Neuro-psychiatric 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**
19 Supporting program (Eloniemi-Sulkava et al., 2001[58])	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: -	- 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*	-

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	PROGRAM						STUDY			
	Delivery characteristics			Functional domain	Treatment components				Measurement instruments for PD	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	Component 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*
20 Training program (Brodaty, Gresham 1989[71]) Prince Henry Hospital program (Brodaty et al., 1997[70])	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% C2?* *8 years: P79% 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 = Asessment 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; HV = home visit; HRDS = Hamilton Rating Depression Scale; 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; Qol-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

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*, 18, 20]. Some studies use information leaflets for the informal caregiver [3, 4b, 8b, *12*, *13*, *16*], or one to three face-to-face 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 had outcome measures for the person with dementia only [9] or for the caregiver only [7].

Effects of dyadic psychosocial programs

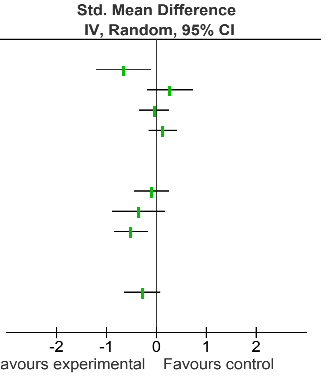
Eleven of the 23 studies concerning ten programs showed statistically significant positive effects for both members of the dyad [1, 3, 4a, 4b, 5, 6a, 8b, *14*, 18, 19, 20]. Four studies showed statistically significant effects for the person with dementia only [2, 9, *12*, *15*], and six studies found 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 long-lasting 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 relation 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.

	Experimental			Control			Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**IV, Random, 95% CI**
1.1.1 Intensive, limited							
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]



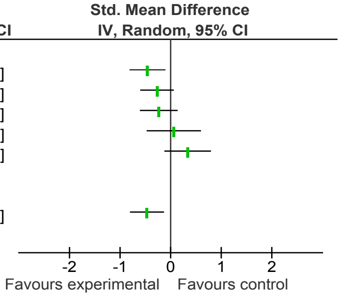
(1) Ostwald; groupprogram
SD: Standard Deviation; CI: Confidence Interval

Figure 2 Person with dementia outcomes: 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 short-period programs: one group program for early-stage 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.

Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Std. Mean Difference IV, Random, 95% CI
1.2.1 Intensive, limited							
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]

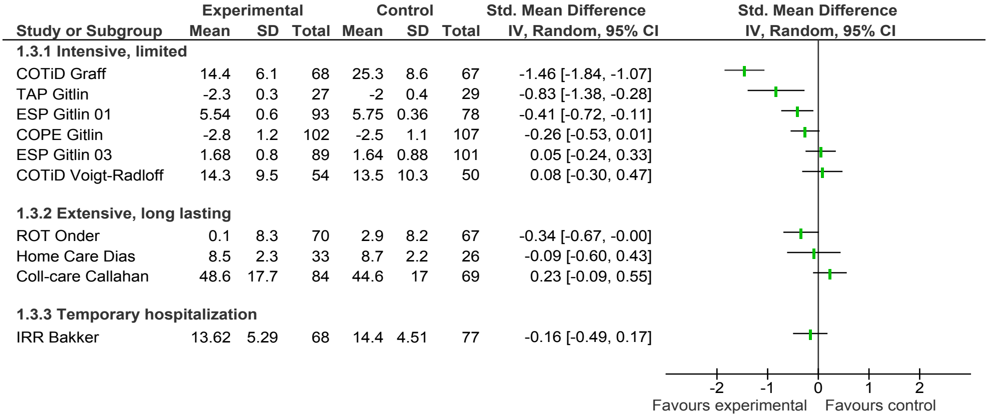


(1) Logsdon: groupprogram
SD: Standard Deviation; CI: Confidence Interval

Figure 3 Person with dementia outcomes: mood

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*, 18] (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 as 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.



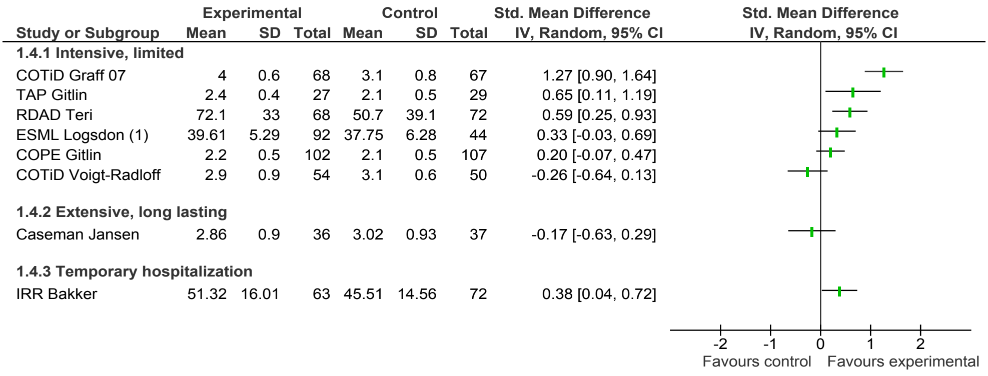
Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Std. Mean Difference IV, Random, 95% CI
1.3.1 Intensive, limited							
COTiD Graff	14.4	6.1	68	25.3	8.6	67	-1.46 [-1.84, -1.07]
TAP Gitlin	-2.3	0.3	27	-2	0.4	29	-0.83 [-1.38, -0.28]
ESP Gitlin 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]
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]
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]

SD: Standard Deviation; CI: Confidence Interval

Figure 4 Person with dementia outcomes: ADL/IADL

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, 18] (Figure 5). The body of evidence for this outcome is moderate to strong. Four of the eight showed a statistically sig-nificant better quality of life of the person with dementia [3, 5, 6a, 9]. Another study 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, 18]. 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].



Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Std. Mean Difference IV, Random, 95% CI
1.4.1 Intensive, limited							
COTiD Graff 07	4	0.6	68	3.1	0.8	67	1.27 [0.90, 1.64]
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]
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]

(1) Logsdon groupprogram
SD: Standard Deviation; CI: Confidence Interval

Figure 5 Person with dementia outcomes: quality of life

Institutionalization

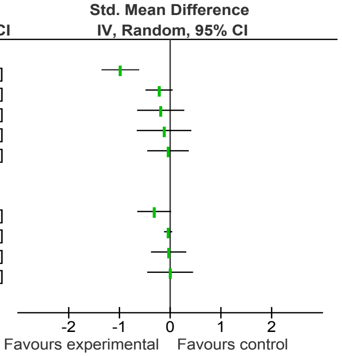
We studied “institutionalization” or “time to admission” for seven studies [1, 9, 12, 16, 17, 19, 20]. The body of evidence for this outcome is moderate to strong. One short-period program [1], one long-lasting program [12], and two programs with hospitalization [19,20] significantly reduced institutionalization 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.

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 longlasting 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, psycho-education, 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*].

	Experimental			Control			Std. Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**IV, Random, 95% CI**
2.1.1 Intensive, limited							
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]



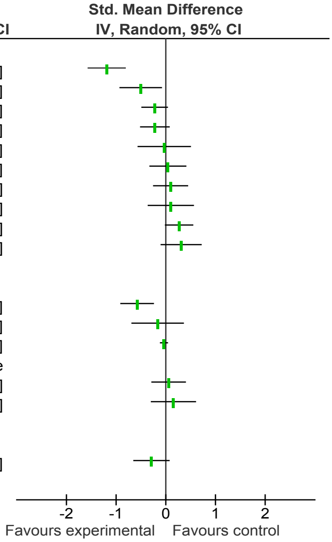
(1) Ostwald groupprogram
SD: Standard Deviation; CI: Confidence Interval

Figure 6 Caregiver outcomes: mood

Perceived burden and competence

Seventeen studies involving 15 programs measured the perception of providing care with burden and/or competence questionnaires: burden [1, 3, 4a, 5, 7, 8a, 8b, 10, 11, 13, 14, 15, 16, 17, 18], competence [4a, 4b, 5, 6a, 6b, 7, 8a, 11, 18], or both [4a, 5, 7, 8a, *11*, 18] (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 long-lasting 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 [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].

Study or Subgroup	Experimental Mean	Experimental SD	Experimental Total	Control Mean	Control SD	Control Total	Std. Mean Difference IV, Random, 95% CI
2.2.1 Intensive, limited							
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]
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]
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]
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]
Caseman Jansen	-47.4	6.44	41	-48.4	6.4	38	0.15 [-0.29, 0.60]
2.2.3 Temporary hospitalization							
IRR Bakker	36.75	25.81	60	44.58	28.24	65	-0.29 [-0.64, 0.07]



(1) Chien partly groupprogram
(2) Logsdon groupprogram
(3) Ostwald groupprogram

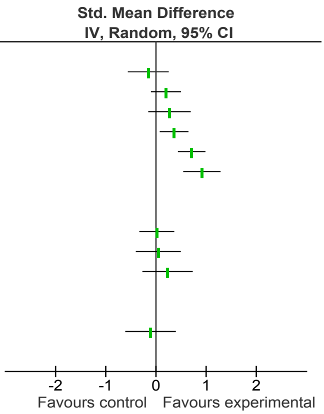
SD: Standard Deviation; CI: Confidence Interval

Figure 7 Caregiver outcomes: burden and/or competence

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.

Study or Subgroup	Experimental Mean	 SD	 Total	Control Mean	 SD	 Total	Std. Mean Difference IV, Random, 95% CI
2.4.1 Intensive, limited							
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]
Home Care Dias	-2.6	2.3	34	-3.3	3.6	31	0.23 [-0.26, 0.72]
2.4.3 Temporary hospitalization							
Training Brodaty	5.3	6.2	33	6.1	8.4	31	-0.11 [-0.60, 0.38]



SD: Standard Deviation; CI: Confidence Interval

Figure 8 Caregiver outcomes: quality of life

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 Asaratnam[9], this meta-analysis builds on previous reviews by extending the focus to also include outcomes for the people with dementia. The terms "nonpharmacological" 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. conclude that "general health appears to be the most promising target for dyadic programs" for caregivers.[12] 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 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 have already mentioned the domain-specific effects of intervention components for the caregiver, such as counseling and psychoeducation for active engagement of the caregiver.[18] 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 the 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 the 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, and Brodaty et al. found that longer interventions are more likely to improve mood of the caregiver.[18,10] Next, Brodaty and Arasaratnam recommend in their review on caregiver interventions that short-period programs were most effective for behavioral and psychological problems of the person with dementia, and also the most effective for botheration, stress, or self-efficacy of the caregiver.[9]

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. 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.[19,20] Next, Gitlin et al. have demonstrated a decrease in behavioral occurrences of the person with dementia in two studies [4a, 5].[21,22]; however, the Care of Persons with dementia in their Environments (COPE) study [4b], with comparable intervention components, does not show this effect.[23] 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. advocate a process evaluation of the sampling quality and of the intervention quality of trials[24]. Such evaluations guarantee valid outcomes and, in the case of effective programs, guide implementation of the program.[25,26] 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, psycho-education 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.[27] 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.[28]

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.[21,29] 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 process may decrease the effects of long-lasting programs more than the effects of short-period 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 follow-up, 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 the huge costs for institutional care for a growing number of people with dementia in the next decades. For some programs cost-effectiveness studies are available [5, 6a, 17], and results about cost-effectiveness are needed for choosing appropriate programs for clients with dementia and their caregivers. The heterogeneity of results in this review raises several questions. Did the psychosocial interventions meet the specific needs of the caregivers and people with dementia who were involved in the different studies? Have 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 in order 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.[30] 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 with 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.

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CHAPTER 3 –

How do activating interventions fit the personal needs, characteristics and preferences of people with dementia living in the community and their informal caregivers?

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Abstract

Background

Psychosocial interventions aim to mitigate the serious consequences of dementia for the daily life of people with dementia and their informal caregivers. To deliver a person-centred approach, it is crucial to take needs, characteristics and preferences of people with dementia and their informal caregivers into account. However, these factors are generally not systematically checked in order to determine which intervention will be most appropriate. Additionally, little is known about which intervention suits which needs, characteristics and preferences. Therefore, this study examined how three multiple-component, activating dyadic interventions fitted needs, characteristics, and preferences of both the people with dementia and their informal caregivers: the Pleasant Events Program, the Exercise and Support Intervention for People with Dementia and Their Caregivers, and Occupational Therapy.

Methods

Semi-structured interviews were held with participants in either one of the interventions, 34 dyads and 19 professionals. The constant comparative method was used for the analysis.

Results

Five factors influenced the dyad's 'fit': timing, need for activity, lifestyle, apart-or-together and meaning of (lost) activity. The factors 'timing' and a 'need for activity' were conditional for these activating interventions. Dyads in an early stage of dementia, who were aware of the effects on daily life, were open to a change in routine, and had a need to maintain activities profited from these interventions. Three distinctive factors were important for the fit of one of the three interventions in particular: 'lifestyle', 'apart or together' and 'meaning of (lost) activity'. The Pleasant Events program and the Exercise and Support intervention properly addressed the need for activities that afforded daily pastimes or structure. The Exercise and Support Intervention addressed the need for physical activity and emphasized shared activity. Occupational Therapy properly addressed the need for self-sufficiency, maintaining activities and adjustment to physical limitations.

Conclusion

The five identified factors can contribute to a more person-centred application of the interventions.

Introduction

Dementia reduces the quality of life of people with dementia and their informal caregivers.[1-3] Psychosocial interventions aim to mitigate the results of this process. The importance of a person-centred approach of these interventions has been increasingly recognised. Person-centred care was introduced almost two decades ago by Kitwood who emphasized the importance of addressing the psychological needs of people with dementia and the maintenance of their personhood.[4] Understanding the history and individual needs, characteristics and preferences of people with dementia is crucial for a person-centred approach.[5] Unfortunately, when interventions are offered to people with dementia in clinical practice or research trials, their needs, characteristics and preferences are generally not systematically checked to determine which intervention will be the most appropriate one. Insight into the applicability, or 'fit', of an intervention with the needs, characteristics, and preferences may help to apply interventions in a more person-centred manner. Fit indicates the extent to which an intervention fulfils individual needs and is attuned to characteristics and preferences.

In recent years, psychosocial interventions have increasingly focused on 'dyads', consisting of both the person with dementia and the primary informal caregiver, often a spouse or child. This was the result of an increasing awareness that the functioning of people with dementia was related to the functioning of their primary informal caregivers.[6,7] Dyadic interventions take this mutual influence between the person with dementia and the informal caregiver into account. The effects of dyadic psychosocial intervention programs have been studied in previous reviews.[8,9] Results indicate the beneficial potential of these interventions for maintaining independency in activities of daily living and competence for caregivers, contributing to a better quality of life.

This study is focused on three dyadic, multi-component interventions, to support the dyad in recognizing which activities are still possible to engage in, despite the challenges posed by dementia. Those were: the Pleasant Events Program[10], the Exercise and Support Intervention for People with Dementia Living at Home and their Caregivers[11], and Occupational Therapy according to the 'Community Occupational Therapy in Dementia Guideline' (COTiD).[12] These interventions make use of various activities, offer psycho-education, and provide emotional care that help the dyad adapt to the effects of dementia in their daily lives.
The person with dementia and the informal caregiver practise these activities

together. The interventions have a basic structure to start with and are adjusted to the dyad's wishes and needs. All three are short-term interventions consisting of six to ten home visits. They differ in the nature of their activities. In the next paragraph we describe each of the three interventions in more detail. For additional details of the interventions, see Table 1.

Table 1 Interventions: content, evidence and provision

	Pleasant Events Program	**Exercise and Support Intervention for People with Dementia and their Caregivers**	**Community Occupational Therapy in Dementia (COTiD)**
Original interventions	This program is based on Teri et al.[13] The Dutch manual for the program was published by Nivel [Dutch Institute for Primary Healthcare][10], and is supplemented by examples from Gitlin et al. 's program.[14]	This intervention is based on Teri et al.[15] After a pilot study with the original program, this program was adapted. Attributes like a ball, weights, and elastic equipment made the exercises more attractive for people with dementia. The amount of sessions was limited to eight. The training for activating events, beliefs, and consequences (ABC) was skipped and this program emphasized the pleasant events component more.[11]	This therapy is described in Graff et al.[12,16,17]
Primary goal	Maintaining activity, having pleasant activities, and preventing depression of people with dementia and the informal caregiver.	Preventing depression of people with dementia and the informal caregiver.	Improving the performance of daily activities of people with dementia, and mitigating the care burden of the informal caregiver.
Components	- Choosing and planning pleasant activities for the person with dementia, the informal caregiver or both, - Practicing these activities, - Adjusting activities to the capabilities of the person with dementia, - Psycho-education, - Homework: pleasant activities.	- Exercises for flexibility, balance, power, and stamina of the person with dementia and the informal caregiver, supervised by a coach at home. - Identifying pleasant activities for both, - Psycho-education and communication training to manage behavioral problems, - Homework: repeating mobility exercises and pleasant activities (preferred at least 3 times a week).	- Needs assessment and observation, - Practicing meaningful, daily activities (self sufficiency) with compensation strategies and adjustments for the person with dementia, - Psycho-education, - Practicing different ways of approaching the person with dementia for the informal caregiver, - Homework: individual appointments for practicing activities and approach.

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	Pleasant Events Program	Exercise and Support Intervention for People with Dementia and their Caregivers	Community Occupational Therapy in Dementia (COTiD)
Duration	A maximum of 6 home visits of 1,5 hours each.	A maximum of 8 home visits of 1 hour each.	A maximum of 10 home visits of 1 hour each.
Evidence	Positive effects on depression for people with dementia and informal caregivers and on occupational engagement and agitated behavior.[13,14]	Positive effects on depression and general health of people with dementia.[15] An RCT with the adjusted program found only a quantitative effect on cognition.[18]	Positive effects on daily functioning of people with dementia and competence of informal caregivers, as well as on depression, general health and quality of life of both.[17,19] These effects were not demonstrated in studies by Voigt-Radloff, Graff, Leonhart, Schornstein,et al. and Döpp et al.[20,21]
Provision	The program was offered as part of the University Collaborative Centre for Dementia, which entails the collaboration of Rotterdam University, the Home Care Organization 'De Zellingen' and the Van Kleef Institute (for generating and disseminating knowledge for home care professionals). The coaches were students graduating in healthcare studies and home-care workers from De Zellingen. They were supervised during the intervention. The project leader and case manager in the region recruited participants.	The program was offered within an RCT from the Department of Clinical Psychology, VU University, Amsterdam.[11,15] The coaches were Master students from the Department of Clinical Psychology, VU University, who completed a special training program for geropsychology. They were supervised during the project. The project leader recruited participants for the program with the help of caregiver organizations, local Alzheimer cafes (public meetings for people with dementia, their caregivers, and others) and case managers throughout the Netherlands.	Occupational Therapy is regularly offered and delivered by certified occupational therapists, who followed an additional training for this program. The participants were referred by medical doctors and geriatricians as well as case managers throughout the Netherlands.

RCT = Randomized Controlled Trial

The Pleasant Events Program provided support in adapting and planning pleasant activities, e.g. learning to use skype with children and grandchildren with a stepwise manual, occasionally taking public transport to a historic city part when going shopping instead of the usual shops, watching national geographic on television or having a walk in the neighbourhood. The Exercise and Support Intervention contained exercises for flexibility, balance, strength and/or endurance exercises using a ball, weights and elastic bands and combined this physical exercise with support for planning pleasant activities, as well as psycho-education and communication skill-training. Occupational Therapy consisted of the improvement of self-care in a broad spectrum, such as learning to use the remote control for the television with orientation marks, making a bicycle-tour that is worry-free for the informal caregiver at home by taking a well-known route and using a mobile phone, helping to keep a daily structure and schedule with an individually adapted agenda.

The three dyadic, multi-component interventions described above have been proven effective in scientific research.[13-15,17,19] However, recent studies could not confirm the original results.[18,20,21] This might be due to the adaptation or implementation of the interventions or to the different characteristics of the settings in which they were re-tested.[21-24] Process evaluations of these trials showed positive experiences of participants with these intervention.[22,23,25] Finding no significant results of interventions might also be a result of not fitting the needs, characteristics and preferences of people with dementia. When choosing an intervention, 'Which intervention works?' is not the only question, but also 'What works, for whom, and at what times?[9,26-28] Therefore our research question for this study was: which factors explain the appropriateness or fit of the three interventions with the needs, characteristics, and preferences of the participating dyads?

Method

We used a qualitative design with semi-structured interviews to gather in-depth information about the fit of these interventions in relation to the needs, characteristics and preferences of the dyads.[29-32] We wanted to integrate the perspectives of people with dementia, their informal caregivers, and the professionals who guided them through the intervention, and we included and studied them as cases.

The Pleasant Events Program and the Exercise and Support Intervention were both evaluated in a larger study (see Table 1). Ethical approval for the interviews in our study was already included in the study designs (Pleasant Events Program: Medical Ethics Review Committee of the Erasmus Medical Center, number 2009-117; Exercise and Support Intervention: Medical Ethics Review Committee of the VU University Medical Center, number 2008/320).

For the interviews about the Occupational Therapy Intervention ethical approval was attained separately (Medical-Ethical Review Committee for Mental Health Care, number 11.123).

Participants

We recruited participants who had either taken part in the Pleasant Events project, the trial for the Exercise and Support Intervention, both already research participants, or had Occupational Therapy according to the COTiD-guideline as a clinical service. The participants had been recruited for or referred to that particular intervention (they were not offered a choice of which intervention they thought would best suit them). Participants for the Pleasant Events Program and the Exercise and Support Intervention were recruited via the project managers, coordinating those studies. Participants for occupational therapy were recruited via occupational therapists. The project managers asked participants in both studies, after the intervention had ended, if they were open for an interview with an independent researcher. The occupational therapists asked their clients after the intervention if they were open for an interview too. They had leaflets with information about the study and the interviewer available for a dyad. When participants were positive to an interview they asked permission to share their name and telephone number with the interviewers. After receiving names, the researcher contacted the dyad per telephone, explaining again the goal of the interview and the study. If the dyad was still open for an interview, an appointment was made. This appointment was confirmed by post with an informative letter and a form for informed consent for the interview and audio-recording was already sent. Four dyads still cancelled their interviews, because of illness or being otherwise engaged. At the time of the interview at home the information was repeated and the informed consent was signed. We used one form with both names of the dyad. The people with dementia signed if they wanted and it did not confuse them. The informal caregiver also signed. If the people with dementia could not sign, the informal caregiver signed for both of them as a couple.

Our intention was to obtain a variety in cases to include a broad spectrum of experiences, needs and characteristics in the data. So we asked them for both successful and less successful cases and also those that had not finished the program. In this way convenient samples were composed for each intervention.

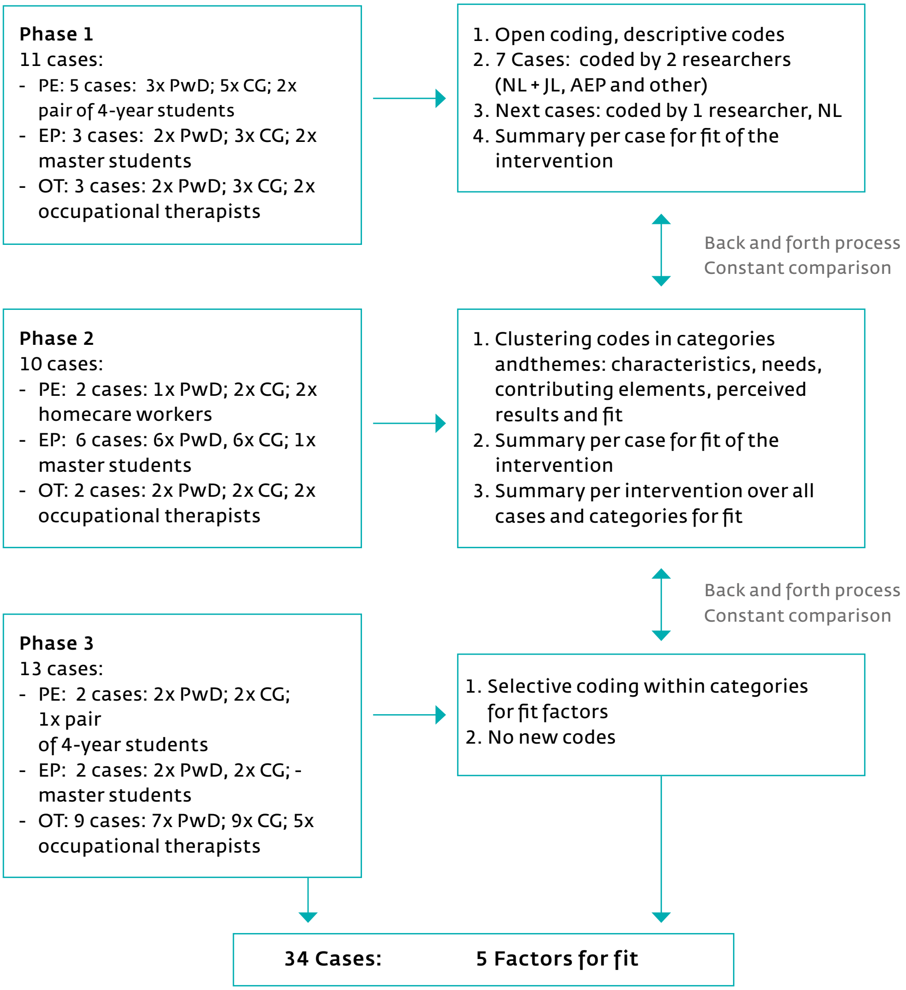
Data collection

We aimed to interview both members of the dyad, either together or separately, depending on their preference, so that they would feel at ease. Seven informal caregivers indicated that their partner or parent with dementia could no longer reflect on their experiences and a joint interview would be too burdensome for them. These informal caregivers agreed to an interview on a day that the person with dementia was in day care. The interviews with people with dementia and informal caregivers took place in the participants' homes. An interview with a couple started with an open question about the interviewees' experiences with the intervention. Follow-up questions addressed initial expectations, continuation of exercises and activities, usefulness of the advice, what the couple had gained from the intervention, and what was still missing. Especially in the interviews with people with dementia, the interviewers used short sentences and prompts, and tried to follow their reasoning through, repeated parts of their answers to stick to their story, and sometimes presented a photo of the professional. They spent sufficient time with small talk between questions to let the person with dementia rest and followed their track of thought.[33,34] We did not mention the term dementia or Alzheimer unless the person with dementia or caregiver had first used this term. Some caregivers added their perspective afterwards. The interviews lasted 50 to 120 minutes. The first and third authors (NL, AEP) conducted the interviews. In case the need for information or a helpful conversation emerged, we had leaflets for the dyads for telephone support, a service of the national Alzheimer's Association, where they could talk with peers.

The interview with the professional took place after the interviews with the dyad, at their workplace or at a public space. Some professionals were interviewed about their experiences with several dyads during one appointment, but each dyad was discussed separately. This interview started with an open question about the professional's experience of the intervention related to the dyad. Follow-up questions addressed what results were achieved, how the professional tailored the intervention to the needs and preferences of the dyad, and what was not achieved. These interviews lasted 20 to 30 minutes. The recordings of the interviews were transcribed verbatim and imported into Atlas-ti-6/7.1 for qualitative analysis.[35]

Analysis

Data collection and analysis was an iterative and reflexive process, based on the constant comparative method.[32,36,37] An interview with a person with dementia and a caregiver was linked to the interview with the professional, and was included



PE=Pleasant Events program, EP=Exercise program,
OT=Occupational Therapy program
PwD= Person with Dementia, CG=Caregiver

Figure 1 Cases and analysis process

as a case (Figure 1). Transcripts were read to capture an overall impression and a preliminary summary was made with the perspectives of the person with dementia, caregiver and professional, similarities and differences. The transcripts were unravelled with open codes, to describe all aspects of the content.[29]

The analysis consisted of three phases in a back and forth process. In the first phase, eleven cases were analysed exhaustively with open coding. Some codes referring to the same phenomenon were already grouped together to include convergence and divergence. We summarized the degree of fit for each case.

In the second phase, we grouped the codes into categories under the themes: needs, personal characteristics, contributing elements, perceived results, and fit. NL coded 10 new cases and recoded the 11 earlier cases. We extracted within these themes what kind of needs and which characteristics were important for the fit of the intervention. This led to an analytical framework with preliminary factors that affected the fit. In the third phase, we used the remaining 13 cases to test this analytical framework and to search for new perspectives. No new codes were needed, which showed that saturation had been reached. The preliminary factors were condensed to five factors that were important for the fit of the interventions for the participants.

Methods to enhance credibility in the analysis

Three researchers (NL, JL, AEP) independently coded the interviews of four cases. They discussed any coding differences. NL analysed all data in detail. NL and JL frequently discussed results during all phases for plausibility and consistency. Several independent researchers conducted peer reviews on preliminary results. We offered every respondent at the end of the interview the possibility to read the transcript or receive a copy of the article at the time of publishing. All authors discussed methods, summaries, analyses and results in the study process.
Table 2 shows details of the participating couples and professionals to conclude on the degree of transferability.

Findings

Characteristics of the participants

We included a total of 34 cases, although some cases missed the interview of the person with dementia, and some the interview of the coach (Table 2).
The interviewees indicated that the onset of the dementia's symptoms had begun between 1 to 5 years ago at the time of the intervention, although the syndrome was often formally diagnosed later. The Pleasant Events Program included comparatively more participants with advanced dementia and poor communication ability, who needed assistance for personal care and attended day-care for several days. The Occupational Therapy intervention included more people with physical limitations, such as poor eyesight or difficulty with walking, than the other interventions. Sometimes physical limitations were the reason for the referral rather than cognitive limitations. The overall professional support for the participating dyads ranged from supervision by a geriatrician and case manager only, to day-care

Table 2 Participants

Program		**Pleasant Events Program** **9 Cases:**	**Exercise and Support Program** **11 Cases:**	**Community Occupational Therapy** 14 Cases:	34 Cases:
People with dementia	Mean age (years),	78.1	75	80	
	Sex	7 M/2W	6 M/5W	9 M/5W	
	Onset of dementia: Range (Mean)	1–4 Years (2.4)	1–5 Years (2.9)	1–4 Years (2,4)	
	Interview	6 PwD	10 PwD	11 PwD	27 PwD
Caregivers	Mean age (years),	Partners: 76	Partners: 72.6 Child: 53	Partners: 77.3 Children: 53	
	Sex	2 M/7 W	4 M/7 W	3 M/10W	
	Relation	9 x Partners	10 Partners 1 Parent/child	9 Partners 5 Parent/child	34 CG
Coaches/ Professionals	Background	3 Pairs of 4-year students; 2 Homecare workers, 9 cases	2 Master students clinical psychology, 5 cases	9 Occupational therapists, 14 cases	19 Coaches/ professional, involved in 28 Cases
	Dyads per professional	1or 2 Dyads per pair; 2or 3 Dyads per homecare worker	2 or 3 Dyads per coach	1, 2 or 5 Dyads per OT	

PwD = Person with dementia; CG = primary informal caregiver, M= Men, W= Women

and personal care several times a week. Most of the participating dyads were partners, others parent-child. The majority of the people with dementia were men in all three interventions.

Five factors for fit of the interventions

The analysis of the interviews led to five client-related factors that affected the fit of the interventions to needs, characteristics, and preferences of a dyad: two conditional factors, 'timing' and 'need for activity', and three distinctive factors, 'lifestyle', 'apart or together', and 'meaning of (lost) activities' (Table 3).

Timing

Most interviewees who took part in the intervention when the dementia was in an early stage claimed that it had helped them continue their activities. The

professionals confirmed this in their interviews. Those who could accept change in order to cope with the consequences of the dementia process and were willing to put suggestions into practice benefitted considerably from the intervention. Some people with dementia said they wanted to slow down the dementia process as much as possible. They felt responsible for their health. The intervention offered them the opportunity to help combat the onset of the dementia disease.
One man with dementia explained:

> *It's simply a nasty disease. We have to face many problems. But my wife gets the most of it. And I simply can't help all the time… The good news is that there are some small stepping stones (such as this intervention, the Exercise and Support Intervention), where I can make an effort 'to slow the dementia down'. I do hope so.*

We concluded that participating in the intervention and perform the exercises were meaningful for him. It supports him in coping with his illness.
Many informal caregivers stated that they had already actively sought information or other help. One informal caregiver said:

> *I believe that the more tips and help and guidelines you can obtain for dementia, the better it is for everybody. I have often seen informal caregivers in my network who have the notion that they have to be able to do it all on their own, because accepting help is a sign of weakness. I've never seen it that way myself.*

Some participants in the Pleasant Events Program and the Exercise and Support Intervention did not want to emphasize 'problems' they needed help with, but were very positive about the intervention. They perceived it as a course in staying active and learning about living with dementia. For them, the intervention had been offered well on time.
Many professionals mentioned that openness towards the intervention was related to addressing the real needs of a dyad. It was quite a challenge for them because a question often illustrated a deeper need. When they managed to make this deeper need explicit, most dyads were open and willingly to get involved in the intervention. Most of the professionals stated that the intervention should have been available for their clients at an earlier stage. An occupational therapist explained:

> *Ideally, we would like to get involved when people with dementia can still learn a bit and we can anticipate future problems. For example, it can be worthwhile to install a*

> *telephone with photo buttons in a fixed location when they can still make a telephone call themselves. This makes it easier for them to operate. The same is true for the timely installation of a date clock. We're often brought in too late. My colleagues and I consider cases where the family needed to 'turn off the gas for safety' the most difficult. This means you are a little too late. Perhaps in an earlier phase we could have helped the person find a way to compensate.*

The intervention was deemed too late if a person with dementia could no longer absorb new information or could no longer retain focus. The intervention was also too late if the informal caregiver was overburdened and lacked the energy to attempt new behaviour, which was particularly important for these activating interventions. These informal caregivers did feel the professional supported them, but they had benefitted little from the intervention.

In contrast, the intervention came too early for some dyads. One dyad needed more time to acknowledge the diagnosis and primarily needed information at that point in time. Another dyad wished to retain their normal way of life for as long as possible, and was not yet open to the advice. Dyads that were less able to change had fewer results. These interventions, that mobilised them to adapt to the effects of dementia in their daily lives, called for the adjustment of their existing habits. Some found that the activities and advice did not apply to their situation, despite the professional's attempts to motivate them. An informal caregiver reported that the advice was not very useful for her because she just wanted her husband to do the activities the way he always did them:

> *I was advised to ask him directly for activity because of his lack of initiative. I did try this. He helps dry the dishes, but puts everything on the counter, right, rather than where it's supposed to go… That makes me think, "Well, I'll just do it myself".*

Need for activity

The interventions addressed the dyads' need to maintain activities. People with dementia often mentioned activity in general, such as 'doing what I was used to doing', or 'keeping a hold of things'. Some caregivers explained that the people they cared for had difficulty with various activities: hobbies, daily tasks or getting out. CGs also had general questions about ´how to support the person with dementia best to perform activities´. One informal caregiver spoke about the problems she encountered:

> *Recently I asked you "Could you make a cup of tea?" Then you did your utmost best and came back with two plates of strawberries. And then I repeated, "You need to make a cup of tea, dear." And then, you came back with… another bowl of strawberries. The third one! And usually, you've never had a problem doing something, and now, when I ask you for something, you just can't figure it out.*

This caregiver required help in helping her husband complete activities by himself, as many informal caregivers did. The informal caregivers needed advice for their new role of supporting the person with dementia in carrying out activities. The problems included 'Which instructions are required?' and 'Should I take charge or let him/her figure it out and do it alone?' Many informal caregivers also mentioned their difficulty with the apathy of the person with dementia: 'He just sits on the couch'. They needed advice about how to motivate the person with dementia and how to adapt activities to their limitations.

All professionals mentioned efforts to explore the latent needs of a dyad for activities.

There were also a few dyads who did not experience a need for activities, and for them, the intervention had less impact. An informal caregiver reflected:

> *Yes, we are very busy. We have a pretty large family. We are both married for the second time. So we've got four families... And the kids, of course. Plenty of work to go around... She (the partner with dementia) is still pretty present. We go everywhere. So we said to each other: "Actually, we do not think this (the intervention) is for us." We are not far enough along yet.*

Lifestyle

Lifestyle was shown to be a factor for the fit of the interventions. In this context, lifestyle means activities and habits. Some dyads explained how they usually spent their time, both in the past and in the present. This gave us insight into their interests and what was important to them. Expressions such as 'Well, you know, staying active, that's important...' or 'we like to make an outing regularly, visit a museum for example' or 'My wife and I have always taken part in sports' or: 'He's a real outdoor man' show their activity preferences. Many dyads shared values such as 'keeping active', 'staying mobile', or 'getting out of the house every day'. Some dyads shared interests, whereas others had differing interests. Either way, the professional could adapt the intervention to address different needs. At least one of them should have an active lifestyle for the fit of these interventions. It appeared that the caregiver tried to facilitate the person with dementia in continuing his or her usual activities, but also tried to activate the person with dementia with activities the caregiver liked to do him- or herself.

Table 3 Factors affecting how the interventions fit the needs and characteristics of the dyad

	Fit-factors	**Pleasant Events Program**	**Exercise and Support Intervention for People with Dementia Living at Home and Their Caregivers**	**Occupational Therapy According to the COTiD Guideline**
Conditional factors	Timing	Early phase of dementia Openness to change Accepts change to cope with consequences of dementia		
	Need for activity	Maintain activity Training of lost activities Support for caregiver to instruct the PwD to carry out activities		
Distinctive Factors	Lifestyle, For both or for one of them	Active Link to: all kinds of activity at home or outside; conviviality	Active Link to: exercise, sports, walking, etc.; physically active	Active Link to: all kinds of daily activities at home or outside; "do what you can yourself"
	Apart or together	Apart or together	Together	Apart or together
	Meaning of (lost) activities	Need for maintaining activity, daily pastimes, structure	Need for training and physical activity, daily pastimes, structure	Need for doing things oneself and self-sufficiency, adjustment to physical limitations, daily pastimes, structure

Apart or together

The interventions seemed to satisfy the need to do something together very well. Many of the people with dementia enjoyed spending time with their informal caregivers; they felt at ease. The informal caregivers expressed this need another way. They often spent a lot of time caring for the person with dementia, but missed the contact and mutuality they had before. Particularly, informal caregivers of dyads who were used to doing a lot together were still looking for moments to share their experiences. The intervention helped them to do things together and to get a feeling of togetherness again. Some informal caregiver s had no need for additional joined activities. The time spent on providing care was enough. For them, it was especially important to keep the person with dementia busy for a while or do the exercises on their own so they could attend to their own activities. The professionals adjusted the intervention to these needs of a dyad.

All three interventions required input from both the person with dementia and the informal caregiver, and they required some togetherness and cooperative action. If there was a limited need to do things together the Occupational Therapy and the Pleasant Events Program was more applicable than the Exercise and Support Intervention. The Exercise and Support Intervention requires participants to do the exercises together three times a week and to plan pleasant activities. Some of the dyads particularly appreciated having an additional shared activity. For them, the intervention fulfilled the need to do something together. One professional said: 'They were keen on doing something together, being active, so the exercise program was a good offer for them'. For other dyads, practicing three times a week was a burden on the informal caregiver and did not fit their needs for togetherness and independence. The Pleasant Events Program is oriented on fun pastimes and Occupational Therapy on the ability of people with dementia to do activities more independently. Depending on their needs and abilities, a dyad can choose to do more or less together, and the therapist can choose to be more or less oriented on joint activities.

Meaning of (lost) activity

The result of the activity itself, such as making a cup of coffee, or going outside for a walk was important for a dyad, of course. However, the corresponding meaning of these activities for a person with dementia or the informal caregiver determined the degree of feeling a loss of activities. Making a cup of coffee could mean independency but could also mean caring for the partner, while going for a walk could mean just passing time but could also mean being physically active or having social contact. The activity could mean a pastime, maintaining structure, being physically active, having social contact, being self-sufficient, or may add to satisfaction and self-appreciation. For example, for one lady with dementia who lived by herself, the lack of activities meant a lack of structure in the day. She was facilitated in performing some activities again through memory-aids and a telephone call from her daughter. The rhythm and structure in the day was enough for her to also pick up other activities like making coffee and making bread, so she could maintain living on her own. If the lost activities primarily were related to the meaning of the activity, couples often did not specifically call it loss of an activity. For example, the dementia patients said they had nothing to do anymore, or caregivers explained

they felt powerless to handle the situation. For others the result of the activity itself was important. In those cases, people tended to name specific activities during which they experienced a lack of self-sufficiency: hobbies, household activities, getting dressed, or operating devices in the house.
One woman with dementia said:

> *I like watching television. I tend to turn it on for a bit in the morning, and then at the end of the afternoon. Well, that didn't go well any more.*
> *Her daughter added: My mother had another device with a remote control, and she had a remote control for the television. She couldn't keep them apart.*

Some of the participants also suffered from physical limitations, apart from the cognitive or behavioural problems caused by the dementia. This made it difficult for them to maintain the same level of activity. They needed to adjust their standard activities to both their physical and cognitive limitations.

Discussion

Main findings and reflections

This study presented five factors that reflect the fit of the three studied interventions to the dyads' needs, characteristics and preferences. Timing and a need for activities are both conditional factors for the fit of any of these activating multiple-component interventions with dyads' needs and characteristics. The factors lifestyle, the need to do something together or apart, and the individual meaning of activities are indications of the fit of one of the three interventions in particular. The Pleasant Events Program was well suited to dyads that enjoyed various activities at home or outside, together, but also apart, for pleasure and daily pastimes. The Exercise and Support Intervention was appropriate for dyads of whom one of the two preferred exercise or sports, were open to exercise together a few times a week, and had a need for daily pastimes and keeping active. Occupational Therapy was well suited to dyads for which self-sufficiency of the person with dementia was the primary goal, in shared as well as individual activities. Occupational Therapy also took into account the need of advice about activities for dyads with physical limitations.

In clinical practice and in inclusion for trials these factors are often not taken into account. Characteristics such as age, level of education, social economic status and social network may be collected, but it is not common to discuss preferences, habits and values systematically with a dyad. In this study we also collected data about socio-economic status, level of education, (former) job and religion of the participating dyads, but these data did not reveal factors for the fit of the interventions. The five factors found in this study are all related to preferences (although lifestyle is related to educational level and socio-economic status too).

Clinicians need to take a person-centred approach by carefully considering a dyad's needs, characteristics, and preferences to determine the intervention that is likely to be the best fit. Based on the results of this study, a two-step process may be advised. The first step, for professionals like physicians and case-managers who would like to refer people with dementia and their caregivers to an activating intervention, is about assessing the needs of a dyad before referral to a specific intervention. Clinicians need to be alert on the dyad's openness or readiness for change and ask what their need for activities is. The 'timing' requires careful monitoring of a dyad, because their needs for support are not static and change due to the progress of dementia. In a second step, a specific activating, multi-component intervention needs to be selected. Clinicians need to ask both the person with dementia and the caregiver whether they prefer to do things together or apart, what there life-style has been (active, physically active, doing sports, outings) and the meaning of activity for them conviviality, pastime, self-sufficiency). This might be a challenge for clinicians, because although some dyads ask for advice or support in a direct way, often help is needed to make their latent needs explicit.[38]

The three interventions aim at maintaining the functional abilities of people with dementia, supporting the caregiver, and helping both to cope with dementia progression. The preventive character of these programs, which are limited in both duration and cost, makes them suitable for all dyads who recognize difficulty with activities. Emphasising possibilities despite apparent limitations may strengthen a dyad, as well as attention to maintaining activity; but this has not been made a part of standard care yet. Some dyads who participated in the Exercise and Support Intervention did not want to talk about 'problems'. They stated that the intervention trained them to cope with their situation by improving their capacities instead of emphasising problems. In line with Haberstroh and colleagues the term 'support' was associated with helplessness, whereas the term 'training' was associated with maintaining capacities and empowering.[39] This finding suggests offering these interventions to dyads as training to improve their skills in dealing with the effects of dementia, as to distinguish this type of support from other support such as respite care. Such an approach may stimulate openness to an intervention.

Strengths and limitations of the study

The dyads involved in this study may not be representative for the total group of people with dementia and their informal caregivers who participated in the three interventions, although the respondents did represent a group of people of diverse age, education, work, and dementia duration. Both the dyads and the professionals in this study were willing to be interviewed because they wanted to contribute to good care for people with dementia. Furthermore, only a few of them dropped out during the intervention. In recruitment of dyads for this study we asked specifically for dyads and professionals with positive and negative experiences. We included five dyads (3 Pleasant Events Program, 2 Occupational Therapy) who ended the intervention after one or two home visits. The caregiver was overburdened, there was no need for activity (not yet or not anymore) or there were personal problems. So most dyads found enough benefit of the intervention to continue to apply it to at least some degree. We recommend that future studies interview more dyads who chose not to take part or dropped out early, because they can afford more insight into the fit of interventions.

One particular strength of the study is the involvement of people with dementia. A significant number of interviewees with dementia related their intervention experiences in the interview. Some were no longer able to reflect on the intervention, but they could still indicate what activities were important to them and why. The period between the completion of the intervention and the interview varied from 1 to 10 months. Many people with dementia who were able to participate in an interview could still talk about the intervention or the professional, even after 6 or 9 months, which enabled us to include experiences over a longer time.

It is unclear to what extent a joint interview versus separate interviews affected the study. The informal caregivers who were present frequently added to accounts of the people with dementia and helped them express themselves. However, the people with dementia or the informal caregivers may have felt difficulty expressing themselves freely in joint interviews. Some informal caregivers resolved this by speaking to the interviewer alone after the interview to freely express their opinion. In some of the cases we realized at the time of (re)reading the transcript that the content of what the caregiver said was not supportive for the person with dementia’s mood, although the atmosphere and non-verbal signs had been positive. Based on this and other experience we would prefer to interview both members of the dyad separately in future situations, perhaps performing three interviews, both separately and jointly.[23]

Implications for practice

In clinical practice, programs with treatment components that are more or less comparable to the studied interventions are becoming increasingly available. The experiences of participants in this study address the importance for researchers and clinicians to take a person-centered approach and assess the needs, preferences, and characteristics of dyads first, both separately and jointly, to decide through shared decision-making which intervention would best suit these dyads. Referring professionals may use the two conditional factors to discuss with a dyad the appropriateness of any of these activating interventions.

Timing concerns questions like:

- is the dyad still overwhelmed by the diagnosis? Then referral to an activating intervention may come too early.
- do both persons have enough energy to participate in an activating intervention? For example, when the CG is overburdened, an activating intervention may be too late.

Need for activity may hold questions like:

- does the person with dementia need to maintain activities or pick them up again? Is he or she able to do more activities?
- does the caregiver need support in assisting or instructing the person with dementia to perform activities?
- does the caregiver need more insight into the capacities of the person with dementia, what he or she is able to do?

The other factors could help to choose an intervention in particular.

Lifestyle holds questions like:

- does the dyad or one of them (person with dementia or caregiver) have, or did he have an active lifestyle?
- what kind of activity he or she used to do: physical activity, sports, days outings?

Apart-together concerns questions like:

- is the person with dementia accustomed to spending time alone?
- does the person with dementia depend on the caregiver?
- does the person with dementia and/or the caregiver like to have shared activities?
- does the caregiver need time for him-/herself?

Meaning of (lost) activity concerns questions like:

- is there a need for more daily routine in the activities of the person with dementia?
- are lost activities related to a lost pastime or self-sufficiency for the person with dementia?
- is there a need for more safety inside or outside the house in order to be able to continue activities?
- is there a need for adaptations of activities to the physical limitations of the person with dementia in order to be able to continue these activities?

Conclusions

Dyads in an early stage of dementia, who were open to change their habits and routines because of the consequences of the dementia process and had a need to maintain activity, especially profited of these interventions. The intervention Pleasant Events as well as the intervention Exercise and Support properly addressed the need for daily pastimes, structure, and fulfilment. The Exercise and Support Intervention addressed the need for physical activity and emphasised shared activity of the dyad as well. Occupational Therapy (COTiD) properly addressed the need for additional self-sufficiency, maintaining activities and adjustment to physical limitations.

Further study of the validity and feasibility of these factors is needed before they can be used for choosing the appropriate intervention. With the results of this study we are able to formulate hypothetic indications for these activating interventions directed at maintaining daily activity and coping with changing roles and diminishing capacities. Consequently, it would be possible to design a tool for the needs assessment of the activities for a dyad.

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CHAPTER 4 –

Working mechanisms of dyadic, psychosocial, activating interventions for people with dementia and informal caregivers: a qualitative study

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Background:
People living with dementia and their informal caregivers often report difficulties in maintaining their usual activities. Several dyadic, psychosocial, activating interventions were developed to create insight into how to cope with limitations in a practical way and to increase skills for maintaining personal activities. Effects of these interventions varied so far. More knowledge on the working mechanisms of activating interventions might help to increase their impact. This study will provide more insight into the working mechanisms of three dyadic, activating interventions as the participating people with dementia, caregivers, and coaches perceived them during the intervention.

Methods:
We used a qualitative design with semi-structured interviews of 34 dyads that included 27 persons with dementia, 34 caregivers, and 19 coaches. The data were analyzed with the constant comparative method.

Results:
Many people with dementia and caregivers found capacity-building approaches beneficial. We identified *empowerment* as the core theme. Three working mechanisms explained why the interventions were perceived having a beneficial impact. They were: 1. enabling activities without providing false hope; 2. exploring the most important personal activity needs of the people with dementia and caregivers; and 3. a solution-focused approach to adapt, test, and practice activities. An individualized approach contributed to positive change.

Conclusion:
For the overarching working mechanism empowerment, expertise in the field of dementia and psychological skills of coaches seem to be important. Assessing the needs, capacities, and limitations of both people with dementia and caregivers to take part in activities seems to be key, as well as the communication about it and the skills to teach a solution-focused approach. Studies on the impact of psychosocial and activating interventions might benefit from considering outcome measures directed at empowerment, along with aspects such as hope and belief in one’s own capacities versus traditional outcome measures as mood, burden, or quality of life.

Introduction

Worldwide, 50 million persons with dementia have to cope with the daily consequences.[1] There is currently no cure for dementia. Dyadic psychosocial interventions aim to support both people living with dementia and their informal caregivers (usually spouses or children).[2,3] People with dementia often report difficulties in performing their usual activities.[4,5] Daily activities are important because they can create structure, satisfaction, and continuity in life, and they contribute to well-being and health.[6-8] It is difficult for caregivers to engage in joint social activities with people with dementia.[9] Furthermore, due to their care-giving tasks, they have difficulty maintaining their own activities as well.[10,11] Some psychosocial interventions take these challenges as a starting point and are focused on engaging both people with dementia and caregivers in activities.[12-20] They aim to increase skills for maintaining participation in activities and how to cope with declines capacities in a practical way, to increase self-management.[21,22] These multicomponent interventions comprise performing activities, psycho-education, and emotional support. In this study, we label these interventions “activating interventions”.

Studies show benefits of activating interventions, but the effects vary widely, from no effects at all to large effects on people with dementia-outcomes, such as outcomes for mood, behavior, activities of daily living (ADL) dependency, and quality of life. This is also true for caregiver outcomes such as mood, burden, competency, and quality of life.[12-15,18,19,23-29] Some authors address the issue that knowledge on the impact of the different components in multi-component interventions is lacking.[3,30-32] A few studies provide information about the relation between treatment components and effects. Pinquart showed positive effects of counseling and psycho-education for the caregiver’s active engagement.[33] Van ‘t Leven et al showed a relation between skills training of people with dementia and their ADL independence, and a relation between training of caregivers’ communication skills and their competence.[3] Furthermore Brodaty and Asaratnam reported indications for delivery characteristics of successful multi-component interventions. These indications are the interventions are multi-component, tailored to the needs of people with dementia and caregivers, include 9–12 sessions, and are delivered at home. They are interspersed with telephone sessions and individual or group follow-ups.[30] Olazeran et al., however, could not conclude that any relation existed between the effects of either treatment components or delivery characteristics in their review.[32]

More knowledge on working mechanisms of the interventions may add to more effective support for people with dementia and caregivers. In this study, we concentrate on dyadic, psychosocial, activating interventions because of the people with dementia's and caregivers' activity losses that are consequences of dementia in daily life. We used data from studies about three activating interventions: the Pleasant Events Program, the Exercise and Support Intervention for People with Dementia and their Caregivers, and the Community Occupational Therapy in Dementia guideline.[12,16,17,19,20] These interventions aim at increasing skills to cope with the consequences of dementia. They are all dyadic, training activities, and they are delivered at home. Table 1 provides a detailed description of the treatment components, the evidence found in effect studies, and the organizational structure in which the interventions were offered to person with dementia–caregiver dyads.

Table 1 Interventions: Treatment components, evidence and provision of the interventions

	Pleasant Events Program [12,19,20]	**Exercise and Support Intervention for People with Dementia and their Caregivers**[17,18]	**Community Occupational Therapy in Dementia (COTiD)**[16,24,29]
Primary goal	Maintaining activity, having pleasant activities, and preventing depression of PWD and CGs.	Improving mood and physical health of PWD and CGs. Decreasing burden of CGs.	Improving the performance of daily activities of PWD, and mitigating the care burden of CGs.
Components	- Choosing and planning pleasant activities for PWD and CGs or both, - Practicing these activities, - Adjusting activities to the capabilities of PWD, - Psycho-education, - Homework: pleasant activities.	- Exercises for flexibility, balance, power, and stamina of PWD and the CGs, supervised by a coach at home. - Identifying pleasant activities for both, - Psycho-education and communication training, - Homework: repeating mobility exercises and pleasant activities (preferred at least 3 times a week).	- Needs assessment and observation, - Practicing meaningful, daily activities (self-sufficiency) with compensation strategies and adjustments for PWD, - Psycho-education, - Practicing different ways with CGs of approaching PWD, - Homework: individual appointments for practicing activities and approach.
Duration	A maximum of 6 home visits of 1.5 hours each, weekly and biweekly.	A maximum of 8 home visits of 1 hour each, 4x weekly, 4x biweekly.	A maximum of 10 home visits of 1 hour each, 2x a week, weekly and biweekly.

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	Pleasant Events Program [12,19,20]	**Exercise and Support Intervention for People with Dementia and their Caregivers**[17,18]	**Community Occupational Therapy in Dementia (COTiD)**[16,24,29]
Original interventions	This program is based on the behavioral treatment of depression in dementia program.[19] The Dutch manual for the program was published by Dutch Institute for Primary Healthcare[20], and is supplemented by examples from Gitlin et al.'s program[12]	This intervention is based on Reducing Disability in Alzheimer's Disease.[18] After a pilot study with the original program, this program was adapted. Attributes like a ball, weights, and elastic equipment made the exercises more attractive for people with dementia. The amount of sessions was limited to eight. This program emphasized the pleasant events component and the training for activating events, beliefs, and consequences (ABC) was included in the psycho-education for CGs.[17]	This therapy is described in Graff et al.[16,24,45] Four sessions of diagnostics and goal defining to priorities meaningful activities. Next compensatory strategies to adapt activities for PWD and the use of environmental modifications are trained, the CG is trained in supervision skills.
Evidence	Significant effects (post treatment) for PWD on - Depression (CDS p<.001; ES 1.7) and for CG Depression (HDRS p<.01) N (I/C): 23/20.[19] Significant effects (4 months) for PWD on - Activity engagement (p .029; 95% CI 0.02-0.41) - Frequency of agitated behavior (p .009; 95% CI -.55 - -.09) and for CG on - Mastery (p .013; 95% CI 0.08 – 0.60) - Confidene using activities (p .011; CI 0.41 – 2.94) N (I/C): 27/29.[12]	Significant effects (3 months) for PWD on - Depression (CDS p .02; MED -1.03 (95% CI -0.17-1.19) - General health (SP-36 p <.001; MED 19.29 (95% CI 8.75-29.83). N (I/C): 76/77.[18] Significant effect (3, 6 months for PWD on - Attention span of PWD (p .04; ES 0.25) N (I/C): 57/54 [26] Effects were not demonstrated in a RCT with the adjusted program[25,27]	Significant effects (3 months) for PWD on - Daily functioning (AMPS process: p <.0001; ES 2,7) - Depression (CDS: p<.0001; ES 0,7) - General health (GHQ: p<.0001; ES 0,7) - Quality of life (Dqol: p<.0001; ES 1,1) and for CGs - Competence (SCQ: p<.0001; ES 0,8) - Depression (CES-D: p<.0001; ES 1.3) - General health (GHQ: p .001; ES 1.1) - Quality of life (Dqol: p<.0001; ES 1,5) N (I/C): 68/67.[24,29] These effects were not demonstrated in other studies.[23,28]

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	Pleasant Events Program [12,19,20]	**Exercise and Support Intervention for People with Dementia and their Caregivers**[17,18]	**Community Occupational Therapy in Dementia (COTiD)**[16,24,29]
Organizational structure	The program was offered as part of the Academic Collaborative Centre for Dementia, which entails the collaboration of Rotterdam University, the Home Care Organization De Zellingen and the Van Kleef Institute (for generating and disseminating knowledge for home care professionals). The coaches were students graduating in healthcare studies and home-care workers from De Zellingen. They were supervised during the intervention. The project leader and case manager in the region recruited participants.	The program was offered within an RCT from the Department of Clinical Psychology, VU University, Amsterdam [17] The coaches were Master students from the Department of Clinical Psychology, VU University, who completed a special training program for geropsychology. They were supervised during the project. The project leader recruited participants for the program with the help of caregiver organizations, local Alzheimer cafes (public meetings for people with dementia, their caregivers, and others) and case managers throughout the Netherlands.	Occupational Therapy was regularly offered and delivered by certified occupational therapists, who followed an additional training for this program. The participants were referred by general practitioners and geriatricians as well as case managers throughout the Netherlands.

PWD = people living with dementia; CG = informal caregiver
RCT = Randomized Controlled Trial; p = p-value; ES = effect size; CI = Confidence Interval;; MED = Mean Estimated Difference; N (I/C): Study population Intervention/Control group;
AMPS = Asessment of Motor and Process Skills; CDS = Cornell Depression Scale; CES-D = Centre of Epidemic Studies – Depression; Dqol = Dementia Quality of Life instrument; GHQ = General Health Questionnaire; HDRS = Hamilton Depression Rating Scale; SCQ = Sense of Competence Questionnaire; SP-36= Sickness Profile-36

The aim of our study was to provide more insight into the working mechanisms of three dyadic, activating interventions as the participating people with dementia, caregivers, and guiding coaches perceived them during the intervention? We define "working mechanisms" as "specific processes within psychosocial interventions which appear to contribute to positive changes", according to Dugmore and colleagues.[31]

Participants and methods

Design

We used a qualitative design with semi-structured interviews to gather in-depth information about intervention processes that contributed to positive change for the participating dyads.[34,35] We wanted to explore the perspectives of participating people with dementia and caregivers, as well as the perspective of the coaches who guided them during the intervention.

Ethical considerations

Ethical approval for interviews with the participating dyads was obtained as part of the approving process of the ethics committees for the Pleasant Events Program and the Exercise and Support Intervention [Medical Ethics Review Committee of the Erasmus Medical Center, Rotterdam, The Netherlands (number 2009-117), and the Medical Ethics Review Committee of the VU University Medical Center, Amsterdam, The Netherlands (number 2008/320)]. Ethical approval was obtained separately for the interviews with participants in the Occupational Therapy Intervention [Medical–Ethical Review Committee for Mental Health Care, Rotterdam, The Netherlands (number 11.123)]. The dyads consented to the study procedures, including participation in evaluative interviews. The approval for the Pleasant Events Program and Occupational Therapy Intervention included written informed consent from the caregiver who signed for the dyad. The approval for the Exercise and Support Intervention included written informed consent from both the people with dementia and the caregivers.

Recruitment and participants

For the Pleasant Events Program and the Exercise and Support Intervention, the project managers asked the participants (a total of 23 dyads) and the coaches if they were willing to participate in an interview. All but one dyad agreed to be interviewed. For the Occupational Therapy intervention, which was reimbursed under the Dutch Health Insurance Act, we contacted occupational therapists and asked them to identify clients willing to participate in an interview. We contacted 51 occupational therapists. Nine of them identified 16 dyads who were willing to participate in an interview. Thus, a convenience sample was composed of 38 cases, consisting of a person with dementia, a caregiver and a coach in each. The other occupational therapists had no referrals for these activating interventions for people with dementia (26), some indicated they were too busy to take part (3), and others thought it too burdening for the dyad(s) they coached (2), or the dyad(s) had quit early (1), and the reason is unknown (10).

Upon receiving names and contact details, the interviewer (NL or AEP) phoned the dyad, explaining again the goal of the interview and the study. If both the person with dementia and the caregiver were still willing to be interviewed, an appointment was made. Four dyads cancelled their interviews because of the burden or illness. Eventually 34 dyads (9 for the Pleasant Events Program, 11 for the Exercise Intervention, and 14 for the Occupational Therapy Intervention) were interviewed. We interviewed 19 coaches, who guided 28 dyads. The coaches consisted of professional occupational therapists, master students of geropsychology, 4th-year healthcare students, and homecare workers, all with the supervision of an experienced psychologist or occupational therapist. Table 2 provides more information about the participants.

Table 2 Participants

34 Cases	Mean age (years),	Male/ Female	Relation	Onset of dementia: (Mean)	Care services used by dyads	Interviewed in cases
Persons with dementia	78 (62-93)	22 / 12 (65/35%)		1–5 Years (2.6)	Geriatrician /general physician 24 x Case manager 17 x Meeting centre or day care 8 x Home care 3 x Speech therapy 1 x Pastoral worker 9 x Informal care support/ volunteer/ Alzheimer café	27*
Caregivers	Partners: 75 (61-88) Children: 53 (45-65)	9 /25 (27/73%) -	28 Partners 6 Children			34
	Professional Experience:					
Coaches	0-30 Years					28 coaches in 34 cases**

* Not all PWDs were able to participate in an interview
**Some coaches were involved in more than one case

Data collection

We aimed to interview both members of the dyad, either together or separately, whichever they preferred. Seven caregivers said that the partner or parent with dementia could no longer reflect on their experiences, and a joint interview would be too burdensome for them. Only the caregivers in these dyads were interviewed. In two interviews, a daughter was present in addition to the person with dementia and caregiver. All interviews started with an open question about their experiences with the intervention. The follow-up questions for the persons with dementia addressed the main topics or activities in the intervention and what they had learned from participating. Non-verbal signs such as frowning were interpreted

as prompts to pose a question in another way or to investigate the answer further. Follow-up questions for the caregivers addressed the topics, activities, what had been learned, what had been changed and how or why. The interviews with the dyads varied from 50 to 120 minutes, with a mean of 75 minutes.
The interviews took place at the homes of the dyads, except for one caregiver who was interviewed by phone. AEP conducted seven interviews with dyads in the Exercise and Support Intervention. NL conducted all the other interviews.

The interviews with the coaches took place after the interview with the dyad, and they also began with an open question about the coach's experience with the intervention with that particular dyad. Follow-up questions addressed the achieved results, how the coach tailored the intervention to the needs and preferences of the dyad, and what was not achieved. The interviews with the coaches lasted 20 to 30 minutes. These interviews took place at their workplaces (12), homes (4), a public place (2), or by phone (1).

Field notes were taken during all interviews. All face-to-face interviews were digital-audio recorded and transcribed verbatim. Notes were taken during the two interviews by phone and transcribed extensively immediately afterwards. All transcripts and field notes were imported into Atlas-ti-6/7.1 to facilitate qualitative analysis.[36]

Data analysis

We performed a conventional content analysis, following an iterative and reflexive process based on the constant comparative method.[37,38]

Stage 1

Three researchers (NL, JL, and AEP) coded the interviews for the first four cases independently. There was agreement about the selection of significant sections. The codes used for the treatment components were given in the intervention manuals, such as those for the chosen activities or exercises, instructions for persons with dementia, homework, needs inventory, adaptations, and open codes for the persons with dementia, like telling their story and being heard, and staying active; for caregivers, practical advice and reinforcement; for coaches, communication, revealing needs, and memory aids. We also coded the effects as the person with dementia–caregiver dyad perceived them; these were effects such as self-confidence, pleasure, new ideas, and more knowledge. Differences were discussed, and a preliminary code tree was composed. NL used this code tree to analyze seven cases again. After 11 cases had been done, each case was summarized, and the working mechanisms of each case and the effects as perceived by the interviewees were described.

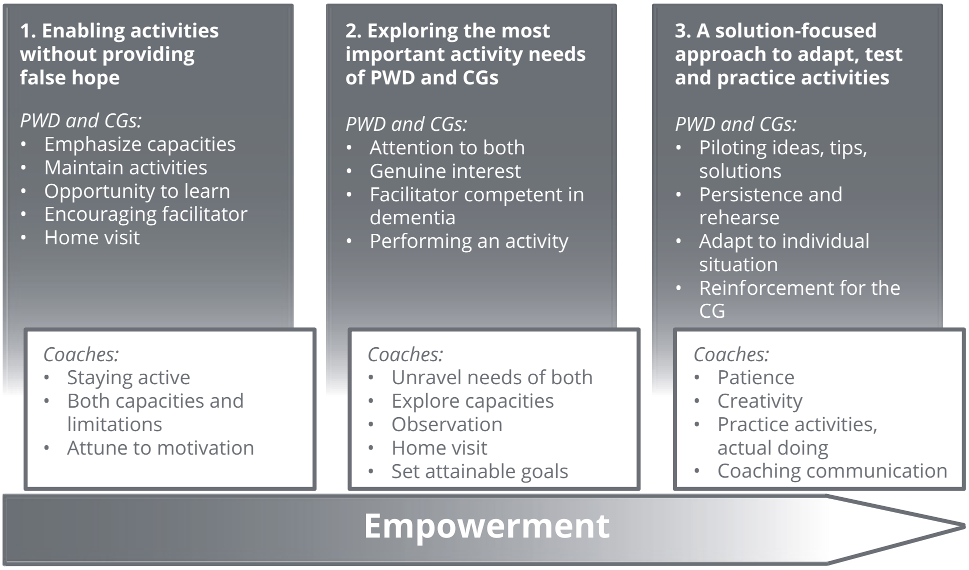
Stage 2.
The research team discussed these results based on these eleven cases. The codes were grouped into more abstract categories that covered what contributed to positive change for the dyads, such as the importance of activities, attention for both capacities and limitations, confidence in the coach, hope, and individualized adaptations. The code tree was changed as necessary. Next, ten new cases were coded and the 11 cases that had been coded were re-coded in accordance with the new code tree. After re-coding the 21 interviews, more categories were formulated, such as actually doing things together with the person with dementia, emphasis on potential possibilities, the coach's expertise in dementia, and the coach's creativity. We recognized three themes in these categories.

Stage 3
These themes and categories were deepened with the experiences of the last 13 cases.

Stage 4
Then we identified one encompassing theme with three subthemes.

Results

We identified *empowerment* as the core theme in the stories of our participants, e.g. focusing on remaining capacities, searching for strengths that could compensate for limitations, and increasing self-confidence without denying limitations. Thus a dyad was enabled to get a grip on their situation and find out what works for them by themselves. The people with dementia and caregivers appreciated the positive approach of focusing on capabilities instead of failures. Some dyads saw the intervention as a training course to learn how to cope with their situation by improving their capacities instead of a therapy focusing on problems. The emphasis was on "getting a grip on their situation" rather than on "being in need of help". Some coaches noticed that the dyads had already discussed their daily problems with other care professionals. Often these professionals acknowledged that their problems were a consequence of dementia, but they had not proposed ways of dealing with the problems and compensating for limitations. Three working mechanisms emerged within the core theme of empowerment, which were present in all three interventions: 1. enabling activities without providing false hope; 2. exploring the most important personal activity needs of the person with dementia and the caregiver; and 3. a solution-focused approach to adapt, test, and practice activities. An individualized combination (rather than single components) of these working mechanisms, tailored to the needs and capacities of the dyad, contributed to positive change. Figure 1 shows working mechanisms and components.



Abbreviations: CG, informal caregiver; PWD, people living with dementia

Figure 1 Working mechanisms

Working mechanism 1. Enabling activities without providing false hope

This mechanism involves emphasizing capacities instead of limitations in a realistic way. This made the people with dementia and caregivers more aware of qualities that were still intact. The participants said they focused on maintaining activities, while acknowledging difficulties in the performance.

> *The therapist insisted that I should keep doing what I used to do. I felt inclined to pull back, but now I say to myself, if I stop, there will be nothing left.* [A person with dementia]

Some participants reflected on the intervention as “an opportunity to learn”, as if it was a training course to get better equipped for the situation.

Both people with dementia and caregivers often spoke of the coach’s encouragement and positive approach. As a result, the dyads were more accepting of the intervention and wanted to “give it a try”. All coaches emphasized the subtle and difficult balance between a focus on possibilities and staying active, but also recognized the reality of the dyad’s situation, including limitations. They found it challenging to explain that maintaining daily and recreational activities may help to cope with the dementia process, although the activities could not relieve grief and feelings of loss. They needed to show enthusiasm and optimism, but had to avoid creating false hope. Especially the first contact was important for exploring the participants’ interest in the intervention and attuning to their motivation. The dyads were more comfortable if the first contact took place in a home visit because they felt more at ease in their own homes.
Several respondents told us that the immediate aftermath of receiving the diagnosis was still affecting them at the time of the interview. In their perception, the physician had told them there was no therapy for them: “nothing can be done about it”. For some participants, this message confirmed their own premises of dementia that “it’s all over”. They had lost their belief in their own capacities and had become apathetic.

> *After the diagnosis, my father [with dementia] slept the whole day, while he used to be busy all the time. The geriatrician suggested day care on a farm, but my father felt ‘too good for this’. To gain insight into his activities, the occupational therapist asked him to write down what he did during the day.*
> *The result was that in the morning he wrote down all kinds of activities to do, and the rest of the day he actually performed them. [Daughter]*
> *When she (the occupational therapist) visited me again, I could show her my notes.* [Father]
> *So, this approach, directed at what he was still able to do, did help him.* [Daughter]

Working mechanism 2. Exploring the most important personal activity needs of people with dementia and caregivers
This mechanism is about accurate, detailed exploration of needs of both people with dementia and caregivers and assessing physical and cognitive limitations of the person with dementia, as well as identifying the remaining capacities and usable coping strategies of both. The dyads thought it important that their

personal needs formed the core of the interventions, rather than being offered a pre-defined intervention program. The people with dementia recognized the genuine interest in themselves as individuals; they did not merely represent instances of a disease. The caregivers, too, said that attention for them as individuals was more helpful than being regarded only as caregivers.

> *I could show people who I am in a way. Well, I liked that very much.* [A person with dementia]
> *In fact, it was the first time I told the story of your dementia from my perspective.* [His caregiver]

Feeling that the coach understood them was extremely important. Feeling understood meant that the coach listened well, was familiar with the diagnosis, understood the perceived difficulties, and maintained a positive attitude. Common was that the coaches inquired not only about the daily pattern of activities, but also about previous activities and important events in the lives of the dyad. This helped them uncover the dyad’s perspective and gain the dyad’s confidence.

The coach explored their needs and challenges with regard to activities. It was often difficult to puzzle out the dyad’s real needs. Although some caregivers asked concrete questions such as “Can he or she (person with dementia) learn to use a mobile phone?”, others asked general, sometimes unrealistic questions. The people with dementia said they wanted “to cope with memory problems” or wished “to be as the way they used to be before”. Several caregivers wanted to know how to support the person with dementia, how to keep him or her active, or how to cope with feelings of burden. Often needs were formulated as wishes. The coaches explored those wishes and activities in detail with them, and tried to uncover what a dyad really missed.

> *It took some effort finding out the needs of this caregiver and the right way to approach him. I had to make him find out for himself instead of telling him.* [Coach]

Nearly all the participants found actually doing activities or exercises with the coach helpful. Several persons with dementia could still reflect on this and had perceived it as a collaboration with the coach which made them feel more involved. However, one other person with dementia had experienced it negatively, as a way of being tested. Most of the caregivers were confident that the coach had a realistic picture of the capacities of the person with dementia. The coaches needed insight into capacities, including declines in cognitive and physical functioning, of both people with dementia and caregivers. This could be obtained by observation and performing activities together. Furthermore, this allowed insight into the communication between the person with dementia and the caregiver. Visiting a dyad at home helped the coaches build confidence and gave them insight into the individual daily routines. This information, together with the clarified needs, enabled the coach and the dyad to set attainable goals that matched in the intervention.

Working mechanism 3. A solution-focused approach to adapt, test, and practice activities

This mechanism is about the practical adjustment of meaningful activities to personal capacities, and experimenting with new ways of overcoming problems. Adapted ways of performing activities were established through repetition as a new routine. We recognized a solution-focused approach by piloting adaptations in collaboration with the coach, the person with dementia, and the caregiver. Patience and persistence were needed to find an individual, tailored approach. The coaches needed creativity when searching for appropriate activities, tailored exercises, and adaptations to the individual needs of the persons with dementia and caregivers. The actual doing often created ideas for possible adaptations of activities or exercises, which sometimes had not been foreseen. The coaches used expressions such as '*it turned out that…*', or after some attempts '*then suddenly we found out that…*'.

> *Her daughter wanted to encourage her because she was just sitting there the whole day. As a pianist, she had given concerts in earlier days. After a few visits, she was willing to sit with me at the piano, and fortunately she started to play (because I couldn't…). I asked her to write down in her diary: play a few times a week, and she wrote: 'Mind the piano!' Her neighbors told the daughter that they heard her playing. [Coach of a woman with dementia, living on her own with help from her daughter]*

The coaches encouraged the dyad and involved them actively, they took on a coaching attitude. The dyads mentioned a variety of actions that had been helpful to them: simplifying activities, using memory aids, changing routines, experimenting with an adapted attitude and adapted instruction, validation of providing good care for the caregivers, and enhancing informal or professional support. Some received adaptations for physical limitations.

Most caregivers felt insecure about their way of providing care, and they were worried that it might be improper or suboptimal. They felt that being empowered to try out several options to manage daily problems was important.

> *It provided me with the mindset just to try; if it doesn't work today, maybe I can try again tomorrow. [A caregiver]*

Several caregivers mentioned that they had already had made some changes themselves and that the intervention had not changed much, but it increased their self-confidence.

Discussion

We identified *empowerment* as the core theme that explained why the interventions were perceived as working according to people with dementia, caregivers, and their assisting coaches. More specifically, we found three working mechanisms for the beneficial impact of the interventions in the interviews:
1. enabling activities without providing false hope;
2. a detailed exploration of the most important activity needs; and
3. a solution-focused approach to adapt, test, and practice activities.

The first working mechanism, enabling activities without providing false hope taught people with dementia and caregivers to cope with their situation by improving their capacities instead of emphasizing problems. Several dyads reflected very positively on the intervention as a training course instead of needing support. The term “support” was associated with helplessness, whereas the term “training” was associated with maintaining skills.[39] Although people living with early dementia and their caregivers experience all kinds of difficulties, they often do not want to be seen as being in need of professional help, which they may perceive as negative and stigmatizing.[40] Emphasizing possibilities without providing false hope also means an opening to the future. Realistic beliefs help both people with dementia and caregivers to cope in a positive manner and to maintain better health and social relationships.[41] Especially in the case of progressive diseases like dementia there is a thin line between realistic hope and false hope. It is always uncertain whether the benefits of an intervention aiming to maintain capacities will surpass the decline. Coaches with positive experiences with the interventions can express a certain convincing attitude and enthusiasm.[42] The second working mechanism is essential for professionals to provide realistic expectations.

The second working mechanism to empower people with dementia and caregivers is a detailed exploration of their most important needs for activities and their capacities and limitations. Knowledge about dementia, understanding its consequences in daily life, and knowing how to communicate with people with dementia and caregivers are necessary to make dyads feel understood and, hopefully, to share their actual needs. Accurate needs assessment, including revealing latent needs, will clarify if and how person with dementia–caregiver dyads need support to maintain daily activities. In addition, a coach should display a positive attitude and be able to assess mental and physical capacities and limitations related to the performance of activities.[43]

The third working mechanism is a solution-focused approach to adapt, test, and practice activities, and it is directed at the activity needs of both the person with dementia and the caregiver. To enable activities it is important to find creative, but also realistic and pragmatic solutions for people with dementia and caregivers to continue to do activities they value but need adaptation as a result of the disease. Actually doing things and the performance of activities can elicit creative, realistic, and pragmatic solutions, that fit both the people with dementia and their caregivers.[44]

The respondents always mentioned more than one mechanism, rather than single components, that had been important for beneficial results and emphasized the process. An individualized approach, tailored to the needs and capacities of the dyad, contributed to positive change. Many of the people with dementia and caregivers shared in the interviews that they felt more self-confident, and that some people with dementia maintained meaningful activities. The dyads found solutions, which they could use for a longer time.

Strengths and limitations

A strength of this study is that we succeeded in interviewing 27 persons with dementia. Many of them could still talk about the intervention or the coach 6 or even 9 months later. It also helped that the caregiver was present at nearly all the interviews and often provided examples of activities that prompted the person with dementia to tell us about his or her experiences. Some people with dementia were no longer able to reflect on the intervention, but they could still indicate what activities were important to them and why. Since we had a convenience sample of dyads and coaches who were willing to participate in an interview, this sample may not be representative of the total group of people with dementia, caregivers, and professionals. Both dyads and coaches wanted to share their experiences to contribute to improving care for people with dementia. The intervention gave most dyads satisfactory benefits. For those dyads the interventions appeared to fit their needs and preferences rather well. We interviewed some dyads who stopped early in the intervention, too. They mainly needed information, were not ready at that moment for a practical approach, did not have activity needs, or the needs assessment had been to general. Those dyads afforded us information about preconditions for these interventions and what was not working. Furthermore, the heterogeneity in terms of age, education, relationship, work experience, duration of the dementia, and both positive and negative experiences may be representative for people with dementia and caregivers in general. The coaches had various background characteristics as well.

Recommendations for practice

Our findings can provide guidance for competences professionals need when they would like to provide an activating intervention to people with dementia and their caregivers. It is important to enable people with dementia and caregivers to continue to do activities taking into account any declines in capacities. Professionals have to be skilled in assessing the needs of people with dementia and caregivers and their capacities ánd limitations, and in training how to adapt activities and practice. Good communication skills are needed to engage both people with dementia and caregivers in the intervention. Starting from individual needs with a focus on possibilities requires the coaches to have an open and creative attitude in a collaborative process with the dyad.

Creativity and innovative thinking, may need more attention in training and education. Professionals may consider offering these interventions to people with dementia and caregivers in a training session to get a grip on the situation, rather than just giving care service, aligned with what people with dementia and caregivers perceive as the valuable mechanisms of these interventions.

Recommendations for research

Further study is needed to find out how the professionals guiding these interventions can achieve empowerment for people with dementia and caregivers, and how they can learn to develop these competencies. Studies on the impact of dyadic, psychosocial, activating interventions should focus on enabling activities despite declines in capacities and reinforcing self-efficacy. Therefore, outcome measures should also include self-efficacy, with aspects such as hope and belief in one's own capacities, along with outcome measures for mood, burden, and quality of life.

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PART II

The appropriateness of criteria for referral to dyadic, activating interventions

CHAPTER 5 –

Indicators to estimate the appropriateness of activating interventions for people living with dementia and for their informal caregivers

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Abstract

Objectives

Dyadic activating interventions support both people with dementia and their informal caregivers to maintain activities. For a person-centered approach referrers need insight in how specific interventions might meet individual needs, characteristics and preferences of a dyad. This study aimed to develop a set of indicators for three psycho-social dyadic, activating interventions.

Method

We used the 'RAND Appropriateness Method' directed at agreement on indicators within a panel of experts. Qualitative research had identified 31 relevant conceptual indicators. A panel of 12 experts in dementia care rated the extent to which these indicators are recognizable for them in their clinical practice. Indicators with median ratings in the top third segment of the nine-point-scale were considered recognizable.

Results

18/31 conceptual indicators (58%) were found recognizable in 75%-90% of the panelists' clients. Although consensus on the recognizability of some indicators about the need or preference for physical and social activities was lacking, the respondents nevertheless recommended including these in regular assessments. Other indicators were judged too difficult to recognize in clinical practice.

Conclusion

The selected indicators offer guidance to referrers on what intervention(s) to choose, and discuss the appropriateness in a shared decision making process, thus contributing to a person-centred approach.

Introduction

The need for community-based care of people living with dementia is anticipated to increase in the coming decades.[1] Many will be supported by informal caregivers to manage everyday life challenges. Tailored care and support for either is necessary because dementia affects their daily lives in different ways, depending not only on the type, stage and symptoms of the dementia, health and co morbidity but also life course, personality and coping, preferences and social situation.[2-6] As a person-centred approach has been found important, formal care-services should include both the person with dementia and the informal caregiver.[7,8] Integrated care pathway approaches for dementia in several Western-European countries include psychosocial and allied health interventions for both people with dementia and their caregivers to maintain occupational performance.[9,10] For one of the major problems in dementia is cognitive decline, and therewith the difficulty to maintain usual activities.[5,11,12] Several authors emphasize that continuous performance of familiar activities gives positive outcomes such as improved self-esteem, satisfaction and continuity in the life course.[13,14] Caregivers, on the other hand, have difficulty maintaining their own activities because their care giving consumes much time and energy.[4,15] Despite the centrality of deficits in social and occupational functioning, the assessment of dementia is too often limited to the medical domain.[12] Furthermore there is a lack of targeted interventions that are needs-based, without a negative or stigmatizing character, especially directed to acceptance, managing changing roles and self-management.[12,16-18] Therefore several interventions with a focus on what is possible whilst activating and enhancing strengths of the person with dementia-caregiver dyad have been developed.[19] Effect studies show heterogeneous outcomes, but positive outcomes for functional domains, such as ADL-dependency for people living with dementia and competence for caregivers.[20] Still, people receiving a diagnosis of dementia often are not advised about supportive interventions.[16,19] Possible reasons are that these interventions are not provided in the dyad's geographical area or if available, dyads are not referred to those interventions.[12,16-18] Referrers such as general practitioners, geriatricians and case managers should take the initiative to inform dyads about these interventions. To be able to do so they need insight into goals of interventions and how these might meet a dyad's needs.[21]

Earlier research about personalized dementia care has already indicated features that influence effects of psychosocial interventions, such as depression, loneliness, the caregiver's role perception, perceived level of control, gender, marital status and living situation, but these are not related to the referring process.[22] These features are still too global, however, to estimate the appropriateness of interventions in relation to personal needs, characteristics, and preferences of person with dementia-caregiver dyads, and are mainly related to the caregiver, not to the person with dementia. Hence, referrers need more detailed information to determine the best person-centred approach for a specific dyad and match individual needs, characteristics, and preferences of a dyad with an intervention.

This study focused on: the Pleasant Events Program[23], the Exercise and Support Intervention for People with Dementia Living at Home and Their Caregivers[24] and Occupational Therapy According to the Community Occupational Therapy in Dementia Guideline (COTiD)[25]. These interventions make use of various activities, offer psycho-education, and provide emotional care that help the dyad adapt to the effects of dementia in their daily lives. The person with dementia and the caregiver practise these activities together. The interventions have a basic structure to start with and are adjusted to the dyad's wishes and needs. The Pleasant Events Program provided support in adapting and planning pleasant activities, e.g. learning to use skype with children and grandchildren using a stepwise manual, occasionally taking public transport to a different part of the city when going shopping instead of going the usual shops, watching National Geographic on television or taking a walk in the neighborhood. The Exercise and Support Intervention contained exercises for flexibility, balance, strength and/or endurance exercises using a ball, weights and elastic bands and combined this physical exercise with support for planning pleasant activities, as well as psycho-education and communication skill-training. Occupational Therapy consisted of the improvement of self-care over a broad spectrum, such as learning to use the remote control for the television with orientation marks, going on a bicycle-tour that is worry-free for the informal caregiver at home by taking a well-known route and using a mobile phone, helping to keep a daily structure and schedule with an individually adapted agenda. All three are short-term interventions consisting of 6-10 home visits.

A qualitative study revealed five factors important for the fit of three dyadic, activating interventions to the needs, characteristics and preferences of dyads.[26] These factors may be helpful for referrers, but are still broad. Therefore we developed a set of indicators building on the factors found in the qualitative study.[26] The research aim was to identify which of those indicators referring professionals in their clinical practice recognize in people with dementia and their caregivers.

Methods

Design

We used the RAND Appropriateness Method (RAM), which was developed to assess quality of care with the help of indicators.[27,28] RAM defines appropriate care as 'the expected health benefit exceeds the expected negative consequences by a sufficiently wide margin that the procedure is worth doing, exclusive of cost'.[27] Although randomized control trials are seen as the golden standard for evidence-based care, they are often not available or do not meet the level of detail needed for a wide range of patients. Directed at agreement of a panel of experts, RAM combines expert opinion and empirical evidence. RAM has evidence of predictive validity of indicators.[29] Application of the method starts with drawing up a highly structured list of clinical indicators abstracted from existing scientific evidence.[27,30] In two rounds, a number of experts rate those indicators for their appropriateness on a scale from 1- 9. In the first round the experts rate the indicators in a survey. The individual ratings serve as input for a group discussion in which the content and the scope of the indicators are clarified. Both steps increase the validity of the final ratings in the second round, when the experts rate again the indicators individually. Then, appropriate indicators are selected on the basis of these second-round ratings. Appropriateness is based on agreement within the panel ánd scores in the top-third segment (7- 9).[27] Indicators for which there was no agreement or which were assigned low ratings are discarded. The process results in a set of valid indicators (Figure 1).

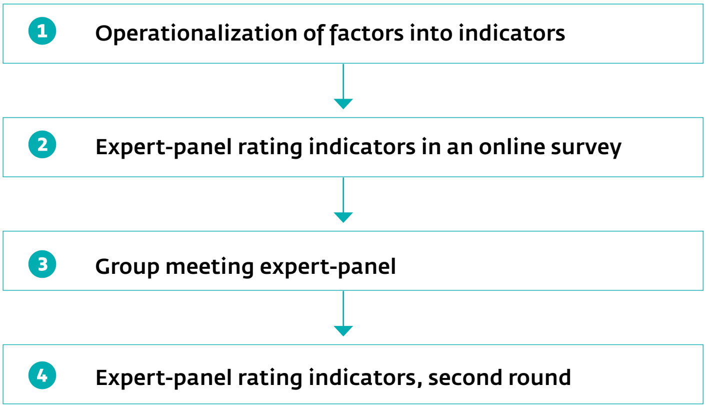

Figure 1 Steps of study method (based on RAND Appropriateness Method)

Participants

We aimed to compose a panel of 15 experts, representing different health care organizations in our region, the greater Rotterdam urban area. In the Netherlands geriatricians of a memory clinic as well as general practitioners disclose the diagnosis of dementia. Next they serve as gatekeepers in the healthcare system because they refer to other services, including psychosocial and allied health services, and they know when prescribing or referring is appropriate. Usually a case manager is assigned to a person with dementia-caregiver dyad, who provides support and coordinates care with the geriatrician or general practitioner. Care-services for people with dementia and their caregivers like Alzheimer cafes, support-groups and day care are widely available in The Netherlands. Therefore we invited geriatricians, general practitioners as well as case managers with at least several years' experience with community dementia care. We wanted to include experts of the 16 health care organizations in the region. Via our professional network candidate panel members within those organizations were identified. They were sent an email with information about the study and an invitation to participate. Four of them agreed to participate themselves, others forwarded the invitation to colleagues, and one did not react. After having been send reminders by email and telephone, 14 experts of 13 health care organizations were willing to participate. Unfortunately for one organization the proposed data were not compatible with their planning.

Procedures

Step 1: Operationalization of factors into indicators (preparation)

This study builds on the results of a qualitative study exploring the fit of three dyadic, activating interventions to needs, characteristics, and preferences of people with dementia and their caregivers.[26] For the present study, the research team (NL, JL, EP, AMP) operationalized the five factors in observable indicators based on the qualitative descriptions elicited from interviews. Each indicator describes a need, characteristic or preference of the person with dementia and/or the caregiver. A number of indicators concern characteristics such as the phase of dementia, awareness of the impact of the disease on daily life, and openness to a change in routine. Other indicators concern lifestyle characteristics such as doing sports and making outings. Yet other indicators describe needs for maintaining activities, needs for daily pastimes or structure, physical activity or self-sufficiency, and needs for adjustment to physical limitations and preferences for doing activities apart or together. The research team thoroughly discussed clarity and consistency of these indicators and then developed 31 conceptual indicators (Appendix, round 1).

Step 2: Expert-panel rating of indicators in an online survey (data collection and analysis)

The experts received a link to an online survey which also included a description of the interventions and an abstract of the findings of the qualitative study. They were asked to rate the indicators in the survey on a scale from 1- 9 for the question: 'For what percentage of the clients (people with dementia and their caregivers) in your clinical practice do you recognize the presence or absence of this indicator?' The rating scale is given in Table 1. The experts were additionally asked to suggest rewordings or other clarifications of items. The research team collected comments and scores of the online survey from all respondents and computed the median for each indicator (Appendix, round 1).

Table 1 Rating scale

Score*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
Percentage of clients	0%	10%	25%	40%	50%	60%	75%	90%	100%
In words	none of the clients	some	a small part	some less than half	half	some more than half	most	almost all	all clients

*A score of 1 means that it is not at all possible to recognize the presence or absence of this indicator in any client, signifying that this indicator is not accurate to recognize a certain need, characteristic or preference. A score of 9 means that it is possible to recognize the presence or absence of this indicator in all clients in their clinical practice, thus being a highly recognizable indicator 27.

Step 3: Group meeting (data collection and analysis)

The experts were encouraged to clarify their ratings in a group meeting. This step is designed to establish whether discrepant ratings are due to real disagreement in clinical judgment or to different interpretations of items. One expert who had agreed to participate and rated the survey could not attend the group meeting due to illness.

At the start of the meeting the panelists received a summary of the scores they had assigned in the survey and the median score of all experts for each indicator. Each indicator was discussed for recognizability in practice. The moderator (JL) first asked respondents if the indicator was clear and then invited them to clarify their scores in the online survey, especially those that diverged from the median. The arguments for a lower or a higher score than the median often led to a discussion. When necessary, indicators were clarified by the researcher (NL) using examples from the original qualitative study and sometimes reworded upon agreement within the panel. The discussion was audio-taped, and notes were made. The audio-tape was transcribed to collect relevant comments on the scoring of the indicators.

Step 4: Expert-panel rating indicators, second round (data collection and analysis)
Upon discussion of sets of 4-6 conceptual indicators the experts individually rated each indicator again. For each indicator, we computed the median of these scores. Our panel finally consisted of an even number of panelists. Therefore, the median could fall between two points; for example six scores under or up to 6 and six scores 7 and higher, thus at 6.5. In this case the indicator is still recognizable for a majority of clients, and we counted the median as a 7, and included the median in the higher appropriateness segment (7-9).[27]

Next, we calculated agreement/disagreement. For a panel of 12 panelists RAM defines agreement as: ‘a maximum of three panelists rating outside a three-point segment around the median’, and disagreement as: ‘four or more panelists rating outside the three-point segment around the median’.[27,30] Furthermore RAM uses two definitions of agreement: a strict and a relaxed one. We used the relaxed definition, which means: the median is located in the three-point segment (7-9), but ratings can be scored outside the segment, e.g. the median of 7 falls in the top third segment (7-9), but ratings are 6,7,8. We choose to use this definition, because with ratings of 6 and 7 the indicator is still recognizable in a majority of the clients, thus relevant for estimating the appropriateness (Appendix 1, round 2). Based on these second scores, we could discern recognizable indicators.

Results

Participants

The panel consisted of seven case managers (all women) and five physicians (three geriatricians from a general hospital, an academic hospital, and a nursing home, respectively, and two general practitioners; two men and three women). Their mean age was 50 years, and they had had on average 15 years’ experience with dementia care.

Textual adaptations to the wording of the indicators

Eight of the 31 indicators were reformulated. For example the indicator 'the dyad wants to maintain the current situation' was changed into: 'the dyad wants to *strongly* maintain their current *way of living*'. A further 13 indicators were adapted by adding 'is/is not' or an adjective, like in the indicator 'the person with dementia *is/is not* accustomed to spend time alone', and 'the person with dementia likes to have *enjoyable* shared activities with the caregiver'. Descriptions of the indicators, scores in rounds one and two, and all textual adaptations are given in the Appendix.

Appropriate and discarded indicators per factor

Factor I. Timing and openness for change (eight indicators).

The experts agreed on the recognizability of three indicators for circa 75% of their clients (I.3, I.5, I.6) (Table 2). These indicators concerned accepting change to cope with dementia. Five indicators were discarded because of disagreement between panelists (I.8) and low scores on recognizability (I.1, I.2, I.4,I.7). The indicators about being sufficiently informed were discarded because the words 'sufficient' or 'enough' were judged not clear enough. The indicators concerning the capacities of the person with dementia to establish new routines through repetition and energy of the caregiver to cope with a new approach were still found too subjective and difficult to check (Table 2). The experts were not able to estimate a person with dementia's capacity 'to establish new routines through repetition, and adapting manners to perform an activity or use memory-aids'. For example they were not able to estimate the feasibility of advices for memory-aids and indicated they did not have time for memory training. Therefore some of them discouraged the use of memory-aids for their clients. The experts disagreed about recognizing energy and burden of a caregiver. Some panelists were reluctant to trust what caregivers told about burden, feeling that caregivers tend to overrate themselves.

Factor II. Need for activities (four indicators).

All four indicators were recognizable in daily practice for circa 75%-90% of the clients.

Factor III. Lifestyle (five indicators).

The experts rated three indicators as recognizable in ±75% of their clients, namely those about an active lifestyle, used to sport and making outings (III.1, III.4, III.5). Two indicators were discarded because of disagreement (III.3) and a low score (III.2) on the recognizability of a preference for physical activity (Table 2). The experts commented that assessing a preference for physical activity or sports was currently not included in the intake interview or questionnaire.

Factor IV. Apart or Together (six conceptual indicators).
The experts scored four indicators as recognizable for ±75%-90% of their clients (IV.2, IV.3, IV.5, IV.6). These indicators were about the need to spend time together. Two indicators were discarded because of low scores on recognizability, including the caregiver's preference to do enjoyable shared activities with the person with dementia (IV.1, IV.4) (Table 2).

Factor V. Meaning of activities (eight conceptual indicators).
Four indicators of this theme were recognizable for circa 75% - 90% of their clients, including the need for self-sufficiency and safety (V.4, V.6, V.7, V.8). Four indicators, concerning activity as a means for pastime, daily routine, and social contacts, were discarded because of disagreement (V.1, V.2, V.3, V.5). There was disagreement about the recognizability of the indicators related to the meaning or goal of the activities for people with dementia, such as passing time, physical activity, having social contact and positive experiences. Some panelists told that their needs assessment was influenced through their own knowledge about the importance of activities and social contacts for people with dementia and caregivers. One indicator about preference for physical activity was scored low and there was disagreement on one about the meaning of an activity (Table 2). The experts argued that in the current situation these indicators were not recognizable, but should be easy to check if included in intake interview or questionnaire. In addition the experts mentioned that they habitually assessed the appropriateness of support services available in their region.

Furthermore the panelists commented that seeing a dyad several times and meeting clients at home helped recognizing the indicators. Safety in and around the house was a regular topic for the case managers, but was seldom addressed by general practitioners and geriatricians in their consultations.

Overall the panelists rated 18 of the 31 conceptual indicators as recognizable in 75%-90% of the clients, with the relaxed definition of agreement according to RAM.

Table 2 Recognizable and discarded indicators

Factor I. Timing and openness for change	**Appropriate**	***Discarded***	**Score**
I.1 *The dyad is sufficiently informed about the consequences of dementia for daily life*		x	**L**
I.2 *CG has an understanding of the consequences of dementia for the daily activities of the person with dementia*		x	**L**
I.3 The dyad has a pro-active attitude, they want to anticipate on future situations	x		
I.4 *The dyad wants to actively counteract decline as much as possible*		x	**L**
I.5 The dyad is not focused on limitations, but on possibilities	x		
I.6 The dyad wants to strongly maintain their current way of living	x		
I.7 *PwD still has the capacity to establish new routines through repetition (e.g. use a memory-aid)*		x	**L**
I.8 *CG is able to put energy into coping with a new approach, is not overburdened*		x	**D**
Factor II. Need for activities			
II.1 PwD has a need for a meaningful occupational routine	x		
II.2 CG has a need for advice about how to cope with the behavior of the PwD	x		
II.3 CG has a need for support in how to assist or instruct the PwD to perform activities	x		
II.4 CG has a need for more insight into the capacities of the PwD, what he or she is able to do	x		
Factor III. Lifestyle			
III.1 The dyad or one of them (PwD or CG) has or had an active lifestyle	x		
III.2 *PwD and/or CG likes physical activity*		x	**L**
III.3 *PwD and/or CG likes doing sports, in an institutional (group) setting or as a routine (running, bicycling)*		x	**D**
III.4 PwD and/or CG is used to doing sport	x		
III.5 PwD and/or CG likes outings like shopping or making a visit	x		
Factor IV. Apart or together			
IV.1 *PwD is/is not accustomed to spend time alone*		x	**L**
IV.2 PwD depends a lot/ limited on CG during the day	x		
IV.3 PwD likes to have enjoyable shared activities with CG	x		
IV.4 *CG has a need for enjoyable shared activities with PwD*		x	**L**
IV.5 CG has a strong/limited need for his or her own activities	x		
IV.6 CG has a need for more time for his or her own life	x		

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Factor V. Meaning of activities	**Appropriate**	***Discarded***	**Score**
V.1 *PwD has a strong/limited need for something to do for passing time*		x	**D**
V.2 *PwD has a strong/limited need for physical activity*		x	**D**
V.3 *PwD has a strong/limited need for social contacts*		x	**D**
V.4 PwD has a strong/limited need for self-sufficiency	x		
V.5 *PwD has a strong/limited need for positive experiences*		x	**D**
V.6 TPwD will benefit from adaptations or assistive devices for physical limitations	x		
V.7 CG has a need for advice about safety at home	x		
V.8 CG has a need for advice about safety outside	x		

PwD: person with dementia; CG: caregiver; L= low scores (median in 1-3 or 4-6); D= disagreement

Discussion

The indicators identified in this study can help referrers estimate the appropriateness of activating interventions for people with dementia and their caregivers. The indicators related to needs and preferences for self-sufficiency, adjustment to physical limitations, and activities either apart or together are useful to assess the appropriateness of the Occupational Therapy intervention. Indicators related to the Pleasant Events Program and the Exercise and Support Intervention were not recognizable sufficiently, according to the panel. Thus, the valid indicators do not allow discerning which of the three available interventions would be most appropriate. The panellists found some indicators not recognizable because these are not part of a needs assessment in usual care. The panelists stated that indicators about a preference for physical activity, doing sports and about a need for activities that afforded social contacts were useful and should be recognizable if included in a standard needs assessment. When added, the list of indicators could permit assessing the appropriateness of one of the three interventions in particular. Other discarded indicators dealt with the need or preference of a person with dementia to spend time alone as well as the need of a caregiver to have enjoyable shared activities with the person with dementia. Finally, the indicators about capacities of a person with dementia to establish new routines through repetition, necessary to use adapted ways of performing activities, and about energy of the caregiver to cope with a new approach, necessary to experience with different approaches in these activating interventions were not recognizable for referring professionals. Professionals involved in the interventions can explore those needs, preferences and capacities during the start of the intervention.

Needs assessment of both people with dementia and caregivers is gaining ground, but is still in its infancy, although it might contribute to a person-centred approach once it has been more developed. Our panellists found it challenging to make latent needs of a dyad explicit, as also has been found in earlier research.[5] Furthermore they recognized a trend in their needs assessment towards a more service-directed approach instead of a need-driven approach; they anticipated on frequently used and easy available support-services. Working in a routine fashion did not contribute to personalized support for people with dementia and caregivers.

It appeared that not only the quality of needs-assessment but also referral to activating interventions in regular care settings can be improved. Interventions may not have been available or the panelists were not aware of interventions being available.[12,16-18] This was illustrated by the panellists who discouraged the use of memory-aids for people with dementia. Referral to skills training, which is part of these activating interventions would be a valuable option in this case. Because our panel consisted of highly expert clinicians who were open for these interventions, we expect that the use of these interventions and inter-professional collaboration in this field is still more limited in care as usual. Implementation of activating interventions enhancing strengths of the dyad has not been achieved yet, despite existing evidence, albeit heterogeneous.[20,31]

Strengths and weaknesses of the study

The indicators are based on the results of a former qualitative study, and they are rooted in the reported data of people with dementia, caregivers and professionals, related to their lived experiences, using their words and expressions.[26] Next, the participating experts were open for discussion, and had long-standing experience of caring for people living with dementia. They represented a wealth of clinical experience in different care settings and care institutions.

Needs, characteristics and especially preferences are culturally sensitive. The respondents in the qualitative study were mostly native Dutch people. Cultural attitudes towards dementia and the caregiving role have implications for how people with dementia and CGs can best be supported.[32,33] Hence, these indicators might be different for people with dementia and CG from other ethnic populations in the Netherlands.

Next, indicators cannot simply be transferred between countries.[34] The healthcare system and care pathways for dementia affect the availability of interventions and the role of referring professionals who are in the lead for supporting people with dementia and CG after the diagnosis of dementia is disclosed. Furthermore we performed this study in one, urban, area, which possibly limits the representativeness for other regions.

Conclusion

The aim of this study was to develop a set of indicators with which referring professionals can estimate the appropriateness of dyadic activating interventions for people with dementia and for their caregivers. Eighteen of the 31 proposed indicators (58%) were found recognizable in 75%-90% of the clients, both people with dementia and the CG. These 18 indicators evaluate (aspects of) openness to change; need to maintain activities; former occupational performance and lifestyle; need for activities apart or together; and needs for self-sufficiency, assistive devices for physical limitations and safety in and around the house.

Implications for research

Further study is needed to evaluate if the valid indicators found in this study, including indicators for physical and social activity, are appropriate to identify the dyads that will benefit the most from these interventions, either apart or together, as well as the practical use of these indicators for referring professionals. If so, evaluation of the use for people with dementia and caregivers from different cultural backgrounds is needed.

Implications for practice

We recommend clinicians to include these indicators in their regular assessment, and add questions about the need for activities too. These indicators can be helpful for assessing needs, characteristics and preferences of a dyad, thus contributing to a person-centred approach to provide tailored advice, especially related to dyadic activating interventions.[7,8] The indicators offer geriatricians, general practitioners and case managers guidance to discuss the use of these interventions with a dyad in a shared decision-making process. Inter-professional collaboration in integrated care pathways may stimulate the use of activating interventions.[35] Professionals involved in performing the intervention programs, like occupational therapists and others, can use these indicators to inform referrers for what kind of couples and which needs these interventions might be appropriate.

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Appendix. Scores by experts for conceptual indicators to estimate the appropriateness of activating interventions

	Scores round 1: Online survey											**Scores round 2: After group meeting**														
	Indicators	score									A/**D**/ V/Q/I	Indicators	Changed		score									A/**D**/ V/Q/I	DI	MI
		1	2	3	4	5	6	7	8	9			Major	Minor	1	2	3	4	5	6	7	8	9			
	I. Timing											**I. Timing**														
8	The dyad has clarity about diagnosis dementia				1	1	2	2	**6**		V: 90%	The dyad *is sufficiently informed about the consequences of dementia for daily life*	x					1	5	**2**	2	2		Q: 60%	5	3
	The dyad is aware of the consequences of dementia for their daily life		1	1	1	3	**4**		2		**D**	CG *has an understanding* of the consequences of dementia *for the daily activities of the person with dementia*	x				2	1	**6**	1	2			Q: 50%		
	The dyad has a pro-active attitude, they want to anticipate on future situations			4	2	**2**	1	2	1		**D**	The dyad has a pro-active attitude, they want to anticipate *themselves* on future situations		x				2	2	2	**5**	1		V: 75%		
	The dyad wants to actively counteract decline				3	**4**	4	1			Q:50%	The dyad wants to actively counteract decline *as much as possible*	x				1		3	**5**	3			Q: 60%		
	The dyad is not focused on limitations, but on possibilities in the current situation (like a course)			2	2	**4**	2	1	1		**D**	The dyad is not focused on limitations, but on possibilities		x			1		3	2	**5**	1		V: 75%		
	The dyad wants to maintain the current situation		1	1	1	3	**1**	3	2		**D**	The dyad wants to *strongly* maintain their current *way of living*	x						2	3	**3**	4		V: 75%		
	PwD still has the capacity to cut out with routines (e.g. use a memory-aid)		1	1	4	2	2	1	1		**D**	PwD still has the capacity to establish new routines through repetition (e.g. use a memory-aid)		x		2	4	**4**	1		1			Q: 40%		
	CG has enough energy to cope with a new approach, is not overburdened				2	4	**1**	5			**D**	CG *is able to put energy into* coping with a new approach, is not overburdened		x				1	**5**		5			**D**		

PwD: person with dementia; CG: caregiver
Median in bold
A= Agreement; V= Valid 🟪: Q=questionable 🟩: I=Invalid: (percentage) = recognizable in amount of patients D= Disagreement
MI= Maintained Indicators; DI= Discarded Indicators

	Scores round 1: Online survey											Scores round 2: After group meeting														
	Indicators	score									A/**D**/ V/Q/I	Indicators	Changed		score									A/**D**/ V/Q/I	DI	MI
		1	2	3	4	5	6	7	8	9			Major	Minor	1	2	3	4	5	6	7	8	9			
	II. Need for activities											**II. Need for activities**														
4	PwD has a need for structure and daily routine			1	2			3	**5**	1	V: 90%	PwD has a need for a *meaningful occupational routine*	x				2	1		3	**2**	4		V: 75%	0	4
	CG has a need for advice about how to cope with the behavior of the PwD					2	1	**6**	2	1	V: 75%	CG has a need for advice how to cope with the behavior of the PwD								1	5	**5**	1	V: 90%		
	CG has a need for support in how to assist or instruct the PwD to perform activities					1	3	**6**	2		V: 75%	CG has a need for support in how to assist or instruct the PwD to perform activities							2		**6**	4		V: 75%		
	CG needs more insight into the capacities of the PwD, what he or she is able to do					2		**5**	4	1	V: 75%	CG has a need for more insight into the capacities of the PwD, what he or she is able to do							2		3	**5**	2	V: 90%		
	III. Lifestyle											**III. Lifestyle**														
5	The dyad or one of them (PwD or CG) has or had an active lifestyle		1			2	2	**6**	1		V: 75%	The dyad or one of them (PwD or CG) has or had an active lifestyle							2	2	**5**	3		V: 75%	2	3
	PwD and/or CG deem physically activity important		2			4	**2**	3	1		Q: 60%	PwD and/or CG *likes* physical activity		x		1		1	4	**2**	3	1		Q: 60%		
	PwD and/or CG likes doing sports		4	1	1	**2**	1	2	1		**D**	PwD and/or CG likes doing sports, *in an institutional (group) setting or as a routine (running, bicycling)*	x				2		2	1	**3**	4		D		
	PwD and/or CG is used to sport		3	1		**3**	2	2	1		**D**	PwD and/or CG is used to doing sport					1			3	**4**	4		V: 75%		
	PwD and/or CG likes outings, like shopping or making a visit			1		2	1	**5**	3		V: 75%	PwD and/or CG likes outings like shopping or making a visit								1	8	**3**		V: 75%		

PwD: person with dementia; CG: caregiver
Median in bold
A= Agreement; V= Valid 🟪: Q=questionable 🟩: I=Invalid: (percentage) = recognizable in amount of patients D= Disagreement
MI= Maintained Indicators; DI= Discarded Indicators

	Scores round 1: Online survey											Scores round 2: After group meeting														
	Indicators	score									A/**D**/ V/Q/I	Indicators	Changed		score									A/**D**/ V/Q/I	DI	MI
		1	2	3	4	5	6	7	8	9			Major	Minor	1	2	3	4	5	6	7	8	9			
	IV. Apart or together											**IV. Apart or together**														
6	PwD is accustomed to be on his own		4	2	**4**		1	1			I: 40%	PwD is/is not accustomed to spend time alone	x			2	3	**5**	1		1			Q: 40%	2	4
	PwD depends on CG during the day			1	1			3	**7**		V: 90%	PwD depends a lot/ limited on CG during the day		x			1				3	**8**		V: 90%		
	PwD likes to have shared activities with CG			1	1		2	**6**	2		V: 75%	PwD likes to have *enjoyable* shared activities with CG		x				1			**8**	3		V: 75%		
	CG has a need for shared activities with PwD				2	4	**1**	4	1		Q: 60%	CG has a need for *enjoyable* shared activities with PwD		x					4	**2**	4	1		Q: 60%		
	CG has a need for own activities		1		1	1	2	**2**	5		V: 75%	CG has a *strong/limited* need for his or her own activities		x			1		1	1	2	**6**		V: 90%		
	CG has a need for more time for his or her own life			1	1	2	1	**2**	5		**D**	CG has a need for more time for his or her own life								3	3	**6**		V: 90%		
	V. Meaning of activities											**V. Meaning of activities**														
8	PwD has a need for something to do for passing time				1	3	2	**3**	3		**D**	PwD has a *strong/limited* need for something to do for passing time		x			1	1	2	**4**	2	2		**D**	4	4
	PwD has a need for physical activity		2	1	2	**3**	2	2			**D**	PwD has a *strong/limited* need for physical activity		x			2	2	2	**3**	3			**D**		
	PwD has a need for social contacts		1		1	3	1	**3**	3		**D**	PwD has a *strong/limited* need for social contacts		x				1	3	1	**4**	3		**D**		
	PwD has a need for self-sufficiency			2	2		**4**	2	2		**D**	PwD has a *strong/limited* need for self-sufficiency		x					1	3	**5**	3		V: 75%		
	PwD has a need for positive experiences	1	4	1	**1**	2	1		2		**D**	PwD has a *strong/limited* need for positive experiences		x		4	1	1	**3**	1	2			**D**		
	PwD has a need for adaptations or assistive devices for physical limitation		1	3	1	1	**2**	1	3		**D**	PwD *will benefit from* adaptations or assistive devices for physical limitations	x							2	4	**6**		V: 90%		
	CG has a need for advice about safety at home					2	3	**4**	3		V: 75%	CG has a need for advice about safety at home						1	1	1	**6**	2	1	V: 75%		
	CG has a need for advice about safety outside					1	3	**4**	4		V: 75%	CG has a need for advice about safety outside							1		**6**	5		V: 75%		

PwD: person with dementia; CG: caregiver Median in bold
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CHAPTER 6 –

Exploring the usefulness of indicators for referring people with dementia and their informal caregivers to activating interventions: a qualitative analysis of needs assessments.

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Background

People with dementia and their informal caregivers frequently report difficulties in maintaining their usual activities. We had previously developed a set of indicators to estimate whether dyadic, activating interventions can meet these needs for activity. This study investigates how people with dementia and informal caregivers talk about the indicators in interviews for needs assessments, and how professionals identify activity needs and preferences. Our research goal was to explore the usefulness of the indicators for assessing the activity needs of community-dwelling dyads. Such assessments are needed for appropriate referral to activating interventions.

Methods

A dementia case manager assessed the needs of community-dwelling people with dementia and their informal caregivers; we carried out secondary analyses on the dataset resulting from the audio-tapes and transcripts. We applied qualitative, deductive content analysis because we wanted to identify both explicit and implicit needs and preferences. We used the indicators that we had developed in previous research as codes.

Results

Both people with dementia and informal caregivers do explicitly mention needs, preferences, and characteristics related to the indicators in the needs assessments. Possible implicit needs and preferences were frequently identified in their stories.

Conclusions

Needs-driven care requires high-quality needs assessments. Both people with dementia and their informal caregivers need encouragement to express their latent needs and preferences. In addition, latent needs and preferences have to be further explored in needs assessments to find out the real meaning. The outcomes of this study highlight the significance of structured needs assessments for mapping the activity needs of people with dementia and their informal caregivers. Many people with dementia and informal caregivers reported activity needs, which suggests that activating interventions may be appropriate. The indicators can help professionals identify activity needs so that they can discuss matching activating interventions with the dyad.

Background

People with dementia encounter all kinds of difficulties in maintaining their activities of daily living and social functioning. They need support and care to manage their everyday life.[1] Informal caregivers often provide most of the care and support for community-dwelling people with dementia.[2] They may have difficulties helping the people with dementia with daily activities and maintaining their own activities at the same time due to stress and a lack of time.[2,3] The people with dementia and their informal caregivers often have difficulty adapting the daily routine to their changing capacities.[4-6]

Dyadic activating interventions aim to increase a dyad's skills to continue meaningful activities and cope with diminishing capacities.[7-11] The overall evidence for their efficacy is heterogeneous.[12,13] Nevertheless, dyads who participated in these interventions, felt empowered by having been offered solutions for their most important activity needs. Such solutions came from in-depth assessments of their capacities and limitations.[14] After disclosure of the diagnosis, people with dementia receive little advice about dyadic activating interventions that focus on maintaining daily functioning and social roles.[15,16]

Dyadic activating interventions should match dyads' needs, characteristics, and preferences.[17,18] Individual needs and preferences for support vary largely, depending on the personal setting, health and comorbidity, and the coping style of both people with dementia and their informal caregiver.[19-21] In a qualitative study, we found that dyads who wish to remain active and are open to alternative ways of going about their daily activities, might profit from these interventions.[22] Identifying activity needs, personal characteristics, and preferences is a prerequisite for estimating the appropriateness of interventions for a dyad.[17] Because needs and preferences may be latent or expressed implicitly, probing questions can help reveal them.[23,24]

To help professionals explore the activity needs, characteristics, and preferences of dyads, we developed a set of indicators for referral on the basis of the findings of the qualitative study. The set of 31 indicators was divided into five themes: 'Need for activities', 'Timing and openness', 'Lifestyle', 'Doing things apart or together' and 'Meaning of activities' (Table 1).

Table 1 Presence of indicators in needs-assessment

Indicators	Present
1. Need for activities	
1 The PWD has a need for a meaningful occupational routine	**14**
2 The CG has a need for advice how to cope with the behavior of the PWD	**9**
3 The CG has a need for support in how to assist or instruct the PWD to perform activities	**6**
4 The CG has a need for more insight into the capacities of the PWD, what he or she is able to do	**1**
2. Timing and openness for change.	
1 The dyad is informed sufficiently about the consequences of dementia for daily life	**4**
2 The CG has an understanding of the consequences of dementia for the daily activities of the PWD	**2**
3 The dyad has a pro-active attitude, they want to anticipate themselves on future situations	**7**
4 The dyad wants to counteract decline actively as much as possible	**-**
5 The dyad is not focused on limitations, but on possibilities	**9**
6 The dyad wants to strongly maintain their current way of living	**3**
7 The PWD still has the capacity to cut out with routines (e.g. use a memory-aid)	**-**
8 The CG is able to put energy into coping with a new approach, is not overburdened	**1**
3. Lifestyle	
1 The dyad or one of them (PWD or CG) has or had an active lifestyle	**8**
2 The PWD and/or CG likes physical activity	**15**
3 The PWD and/or CG likes doing sports, in an institutional (group) setting or as a routine (running, bicycling)	**6**
4 The PWD and/or CG is used to sport	**5**
5 The PWD and/or CG likes outings like shopping or making a visit	**9**
4. Apart or together	
1 The PWD is/is not accustomed to spend time alone	**-**
2 The PWD depends a lot/ limited on CG during the day	**7**
3 The PWD likes to have enjoyable shared activities with CG	**3**
4 The CG has a need for enjoyable shared activities with PWD	**6**
5 The CG has a strong/limited need for his or her own activities	**8**
6 The CG has a need for more time for his or her own life	**10**
5. Meaning of activities	
1 The PWD has a strong/limited need for something to do for passing time, See **1**.1.	**14**
2 The PWD has a strong/limited need for physical activity , See **3**.2.	**15**
3 The PWD has a strong/limited need for social contacts	**5**
4 The PWD has a strong/limited need for self-sufficiency	**7**
5 The PWD has a strong/limited need for positive experiences	**-**
6 The PWD will benefit from adaptations or assistive devices for physical limitations	**8**
7 The CG has a need for advice about safety at home	**2**
8 The CG has a need for advice about safety outside	**2**

PWD: person with dementia; CG: caregiver

The theme ‘Need for activities’ appeared to be the central theme, and the other themes provide guidance for determining the type of activities that may be most appropriate. The indicators of ‘Timing and Openness’ are related to acceptance and readiness for interventions that make use of adaptations of activities and environment and encourage changing daily routines. The ‘Lifestyle’ indicators facilitate choosing the type of activities that motivate the dyad. The indicators of ‘Doing things apart or together’ relate to preferences and routines of a dyad in their relationship and to the changing interdependence between the person with dementia and informal caregiver. The indicators concerning the ‘Meaning of activities’ may help in identifying the goals and objectives that are important to the dyad, such as having a fixed routine in the day, just passing time doing something at hand, being physically active, maintaining social contacts, maintaining independency, addressing safety inside and outside the house, or addressing physical limitations that hinder activities. A panel of clinicians recognised most of the indicators in their clinical practices.[25] The panel confirmed that needs assessment is a multi-layered process in which needs and preferences often have to be coaxed out of the dyad’s stories.[25] To explore the usability of the indicators in clinical practice, the current study investigated how people with dementia and their informal caregivers talked about the indicators in needs assessments and how professionals identified these needs and preferences. Our research goal was to explore the usefulness of indicators in assessing the activity needs of community-dwelling people with dementia and their informal caregivers for appropriate referral to activating interventions.

Methods

Study design

We used a qualitative approach to identify needs, preferences, and characteristics as described in the indicators.[26] Latent needs and preferences can be interpreted from the stories told in the interviews.[27] For this study, we used data collected for the VitaDem project in our secondary analysis. The integral needs-driven approach developed in the 3-year VitaDem project (2015-2018) was intended to enhance functional independence and social inclusion of community-dwelling people with dementia and their informal caregivers.[28-30] The purpose of the needs assessment in the VitaDem project was to reveal individual needs and the dyad’s shared needs of self-sufficiency, vitality, and social inclusion. Needs to maintain daily activities were part of the semi-structured needs-assessment interviews, by dementia case managers. The level of education of the dementia case managers was comparable to higher professional education, completed with clinical experience (1-25 years). For this project they were trained to explore the stories of people with dementia and caregivers in depth and to avoid giving solutions before exploration. The people with dementia and caregivers were interviewed separately in their homes. A multi-disciplinary case conference followed for discussion of the principal needs and wishes of the dyad and brainstorming about the most appropriate tailored interventions, after clarification of these needs and wishes.

Ethical considerations

The Medical Ethics Review Committee of the Erasmus Medical Center, the Netherlands gave their ethical approval for the VitaDem project (MEC-2015-028). The people with dementia and informal caregivers consented to audio recording of the interviews and anonymous use of the data for research.

Data and study population

Our analysis included transcripts of the two interviews for each dyad and the first part of the case conference, in which the case manager answered questions to clarify dyads' needs. Complete data with the needs assessments of 20 dyads were available.

The case managers recruited dyads from their client databases. The inclusion criteria were the people with dementia had to have a diagnosis of dementia, both the person with dementia and their informal caregiver had to be 65 years old or older, and both had to be living in the case manager's practice area. The exclusion criteria were inability of the candidates to express themselves in Dutch or being on a waiting list for institutionalisation (Table 2).

Table 2 Study population

	Mean age (range)	**Men/Women**	**MMSE Mean (range)**	**Dyad-relation**
Persons with dementia	81 years (68-89)	14 men/6 Women	21.5 (10-29)	19 spouses 1 mother-daughter
Caregivers	76 years (48-84)	5 Men/15 Women		

MMSE: Mini Mental State Examination

There was an even distribution in education level, employment history and income in the study population. The needs-assessment interviews with persons with dementia lasted averagely 34 (12–80) minutes. The interviews with their informal caregivers lasted averagely 41 (18–75) minutes. The clarification part of the case conferences lasted averagely 15 (10–25) minutes. The interviews and case conferences took place between April 2015 and March 2017. The interviews and multi-disciplinary case conferences were transcribed verbally, anonymised, and imported into Atlas-ti 7.2 for qualitative analysis.

Data analysis

We used deductive content analysis to explore how the indicators appeared in the needs assessments.[31] We carefully read three transcripts per dyad (two interviews and the clarification in the case conference), and we listened to the audio recordings of the interviews to familiarise ourselves with the stories. We sought text fragments that represented a need, characteristic, or preference related to the indicators and used the indicators as codes. The text fragment could present an explicitly mentioned present or absent need, characteristic, or preference, and it could refer to a latent need or implicit preference. Three researchers (NL, JL, and a trainee) independently coded the transcripts for the first dyad, and they discussed differences in linking text fragments to indicators. Then NL and the trainee coded the transcripts for 10 dyads. NL coded the remaining transcripts. We summarised the text fragments for indicators into a condensed description, illustrated with quotes. After analysing the needs assessments for 16 dyads, we discussed the preliminary results for their plausibility and consistency with the researchers involved in the VitaDem project (NL, JL, HG, and a researcher). To make the trustworthiness more rigorous, three researchers (JL, HG, and a researcher) coded the transcripts for one dyad independently to check the consistency with NL's coding. The three researchers coded nine of the ten indicators that NL had coded in that the same transcript, and we concluded that our coding was consistent to a great extent. We counted the presence of the indicators as the last step.

Results

People with dementia and their informal caregivers do mention needs, preferences, and characteristics related to the indicators in the needs-assessment interviews (Table 1). Most presentations of the indicators related to the former 'Lifestyle' were explicit and clear. The indicators related to the other themes, however, were more often implicitly present in the clients' stories. These needs and preferences should have had further exploration in the interviews to find out the real meaning. In total, we identified 27 of the 31 indicators.

The 'Need for activities' theme

The indicator describing the person's with dementia need to maintain activities was present in the needs assessments of 14 dyads. Some people with dementia said quite clearly that they wanted to keep doing what they were used to doing, and some mentioned specific activities, such as household activities or a hobby. A latent need for activity was recognised when a person with dementia said that he or she was bored or missed a daily structure. Other people with dementia said that everything was going fine; they did not know of anything more they could wish for. However, their excitement when talking about past activities might suggest a latent need for current activities. Caregivers had a need for advice about how to help the people with dementia. Some were irritated by the person's with dementia behaviour; for example, about inactivity or a person with dementia gardening for hours without a pause for a meal. These examples may indicate a need for help in learning how to assist the person with dementia in activities, although the case managers did not explore this topic further.

The 'Timing and openness' theme

Several dyads said that they gathered information about dementia, some has already adapted their daily routines, and some said that they took future changes into account. Rejecting domestic help because one prefers to do it one's own way can represent a strong wish to stick to one's current ways.

The 'Lifestyle' theme

The people with dementia and informal caregivers clearly detailed their former lifestyles: how they spent their days, what their usual activities were, and which outings or sports they preferred.

The 'Doing things apart or together' theme

Many informal caregivers clearly stated their need to maintain their own activities. Several dyads also mentioned the need for enjoyable shared activities. Some informal caregivers said they felt a lack of time for shared activities because the person with dementia attended day-care and had other appointments with care services.

The 'Meaning of activities' theme
Several people with dementia and informal caregivers explained clearly what the activities meant to them, and why the activities were important to them. However, the nature of the activities (e.g., social contact, being self-sufficient, or safety) was frequently unclear and difficult to identify from the stories in the needs assessments. One person with dementia said that he did not miss the gardening after he gave up his allotment garden, but when encouraged to tell more, he said he missed the mate he collaborated with. Another person with dementia said he wanted to continue driving; probing questions made it clear that driving a car meant for him that he could keep his role of helping his wife get the groceries.

Some indicators overlapped or were difficult to distinguish from each other. The indicators about the caregiver's need for advice about how to cope with behaviour (Table 1-1.2) and how to assist the person with dementia in activities overlapped (Table 1-1.3). The indicators concerning the meaning of activities for passing time (Table 1-5.1) and engaging physical activity (Table1-5.2) were difficult to distinguish from indicators belonging to the themes of 'Need for activities' (Table 1-1.1) and 'Active lifestyle' (Table 1-3.2).

Discussion

This study shed light on how community–dwelling people with dementia and their informal caregivers expressed their needs and preferences for maintain meaningful activities, and how case managers identified these needs and preferences. Our study confirms that dyads often have needs to maintain activities. However, they need encouragement to express and to explore those needs. We frequently identified activity needs and preferences that were implicit in their stories, which should have been further explored. Preferences related to the theme of 'Lifestyle' were expressed clearly in the needs assessments, but in the other four themes 'Need for activities', 'Timing and openness', 'Apart or together', and 'Meaning of the activity', we identified latent needs and preferences. The set of indicators with guiding questions is useful for searching actively and systematically for activity needs, including latent needs and their meaning.

Influence of the study setting: limitations and strengths

The transcripts of the needs assessments used for this study may not represent usual care. Improving tailored care and multi-disciplinary collaboration were important features in the VitaDem project. As a result, the needs assessment got more emphasis than it would in usual care. The dementia case managers were trained to conduct the needs-assessment interviews with a focus on maintaining daily life and ageing in place.

A strength of this study is the inclusion of needs assessment with people with dementia. Interviewing people with dementia for needs assessment requires a careful approach. Confidence between the person with dementia and the interviewer and the use of short sentences are important in interviewing people with dementia, and questions need to be specific. Questions about needs may be too abstract for them, so prompts and examples were often needed to formulate their experiences, needs, and preferences. Empathy and carefully following their thoughts were essential competencies for the quality of the needs assessments.

Implications for practice

In a person-centred approach, a professional is sensitive to tracing unmet needs, including activity needs [32]. The professionals' expertise in client-centred interview skills is a prerequisite for revealing needs and preferences because people with dementia and their informal caregivers often express only the needs for which they know a solution exists. They need encouragement to explore latent needs.[6,24,25] Our study indicates that explicit training in interview techniques is necessary for professionals in dementia care. However, when unmet needs are made explicit, a higher level of care that adds to health-related quality of life can be achieved.[32] To meet a need adequately, it is also important to explore what that need or wish means to the person. The indicators concerning the 'Meaning of activities' may help identify the goals and objectives of a dyad, such as having a fixed routine in the day, just passing time doing something at hand, being physically active, maintaining social contacts, maintaining independency, addressing safety inside and outside the house, or addressing physical limitations that hinder activities. Knowing the meaning of the activities provides clues to finding alternatives if the preferred activity is no longer possible.

Activating interventions aim to increase a dyad's skills to adapt activities and make changes in the environment or daily routines, and they require readiness.[33] Therefore, the set of indicators include questions about timing and openness for these activating interventions. In an early phase of dementia, people with dementia and their informal caregivers are very aware of social and occupational deficits. Nevertheless, assessment is often limited to medical and personal care domains in usual care.[4] Dementia-care specialists plead for integral needs-based approaches for dementia, which are becoming more and more developed and implemented in clinical practice.[34-36] This needs-based approach is also recommended in care pathways for dementia in several West European countries.[37,38] With regard to activity needs, the potential benefit of activating interventions needs to be taken into account, especially in an early phase of dementia.

Implications for research

The set of indicators can be a starting point for studying implementation in clinical practice and their utility for professionals. Do they have an added value in exploring activity needs, a dyad's being ready for change, and estimating the appropriateness of activating interventions? If so, this approach to developing indicators can be applicable for other needs domains and interventions too.

Conclusions

Needs-based care can contribute to a higher level of care and quality of life for people with dementia and their informal caregivers, but it requires good-quality needs assessment. More attention to exploring needs and preferences seems necessary for professionals in dementia care. The indicators can help professionals assess activity needs so that they can better discuss the appropriateness of activating interventions with a dyad.

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Appendix Indicators in the needs assessments and examples

Indicators	Present in NA (N=20)	Examples and quotes
1. Need for activities		
1** The PWD has a need for a meaningful occupational routine.	**14**	People said that they particularly missed some activities and wanted to continue them. Others needed something to do without mentioning anything specific, but wanted a more satisfying way to spend their time. PWD: *'I sit here so often with idle hands, and that's just not my nature.'*
2* The CG has a need for advice how to cope with the behavior of the PWD.	**9**	Some CGs asked openly for advice. The need for advice was also implicit in statements about expecting too much of the PWDs, asking them to do things they could not do, or blaming them for falling short. CG: *'You* [PWD] *tell me that you liked your meal at the day-care centre. So why can't you remember what it was?'* CM: *'She* [PWD] *is inactive and avoids activities. It's hard for her husband (CG), but he does not know how to activate her.'*
3* The CG has a need for support in how to assist or instruct the PWD to perform activities.	**6**	CGs talked about needing advice for practical things like using a mobile phone or remote control, but also more generally, for how to activate the PWD, how to instruct. CG: 'When I was ill, I sometimes thought it would be so nice if someone brought me a cup of tea and a biscuit… a few of those little things, you know. But I had to do it all myself.' PWD [her husband]: 'Yes, but I did. It isn't that I didn't want to, I just forgot. All those small things I didn't notice.' Other CG: *'She* [PWD] *is fanatic about gardening. She can start at 11 a.m., and last week I had to get her from the garden at 8.30 in the evening and I said, 'Come on, we're going get ourselves something to eat.'* Other CG: *'She* [PWD] *is fanatic about gardening. She can start at 11 a.m., and last week I had to get her from the garden at 8.30 in the evening and I said, 'Come on, we're going get ourselves something to eat.'*
4* The CG has a need for more insight into the capacities of the PWD, what he or she is able to do.	**1**	This indicator was difficult to discern from 1.2. CM: *'He* [PWD] *has a room for himself, for his hobbies, which is a mess. His wife wants him to clean it up, but he doesn't know where to begin.'*
2. Timing and openness for change		
1 The dyad is informed sufficiently about the consequences of dementia for daily life.	**4**	CGs and some PWDs said that they had read about dementia and visited Alzheimer cafés. PWD: *'I feel that I forget things now. I have to watch out not to forget… Yes, I work on it, I write it down.'*
2 The CG has an understanding of the consequences of dementia for the daily activities of the PWD.	**2**	Some CGs recognized the consequences because they had other family members with dementia.
3** The dyad has a pro-active attitude, they want to anticipate themselves on futuresituations.	**7**	Examples were visiting the Alzheimer cafés or meetings for informal caregivers, searching for information (in books, and on internet), and adapting things in the house to minimalise the risk of falling. The dyad took future changes into account. CG: *'We think about what the next step can be. What will be the next thing for her* [PWD] *to hand in? What do we have to know? Where can we get it? Be prepared!'*

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Indicators	Present in NA (N=20)	Examples and quotes
2. Timing and openness for change		
4 The dyad wants to counteract decline actively as much as possible.	**-**	
5** The dyad is not focused on limitations, but on possibilities.	**9**	Dyads adapted their routines to cope with limitations. Examples were adapting activities, taking a course, using services for groceries, domestic help, and ordering articles online. The dyads also mentioned societal arrangements, e.g. for transport and personal alarms. CG: *'I bought an iPad for him. My daughter installed the dementia app and added photos. I have to help him turn it on and find what he wants....'* *PWD adds: 'You just need to ...eh... put your finger on it, and then the photo of one of my boys, or a photo of her is there* [wife and children].'
6** The dyad wants to strongly maintain their current way of living.	**3**	Some dyads did not want to change their routines or could not. They continued their ways as before, despite the consequences of dementia. CM: *'I think she anxiously sticks to this daily program; this is what she can manage.'* CG: *'I cancelled my domestic help. She never does it the way I want, and then I pay her a pile of money, while I do it myself better and quicker.'*
7 The PWD still has the capacity to cut out with routines (e.g. use a memory-aid).	**-**	
8 The CG is able to put energy into coping with a new pproach, is not overburdened.	**1**	Some CGs said they could take decisions; others were overwhelmed and had little energy for starting an intervention. CG: *'I can take decisions firmly and all that.... I hope to continue this for the future. I fear the moment that I have an accident or something. Then it's game over, for him too* [PWD].'
3. Lifestyle		
1** The dyad or one of them (PWD or CG) has or had an active lifestyle.	**8**	The PWDs and CGs talked about their daily activities, now and in the past, painting a picture of an active lifestyle. They mentioned hobbies such as knitting, painting, making music, reading, and physical activity. Others talked about going out '*getting some fresh air every day*', meeting their friends, going to the cinema or theatre. Some dyads would baby-sit their grandchildren, some were volunteers in the church or elsewhere.
2** The PWD and/or CG likes physical activity.	**2**	The PWDs cycled and went for walks. Some mentioned the importance of physical activity for their fitness and for delaying decline; others just liked a walk. Some dyads had in-house rooms for physical fitness
3* The PWD and/or CG likes doing sports, in an institutional (group) setting or as a routine (running, bicycling).	**2**	The participants mentioned regularly going to a fitness centre or a cycling club. They also liked regular swimming, golf, and/or yoga
4* The PWD and/or CG is used to sport.		Some PWDs and CGs mentioned various sports, such as football, tennis, running, triathlons, handball, and skating. It was also evident that others were not accustomed to sports. CG: *'I have never been a sportsman or anything like that.'*

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Indicators	Present in NA (N=20)	Examples and quotes
3. Lifestyle		
5** The PWD and/or CG likes outings like shopping or making a visit.	**9**	The activities mentioned varied: shopping, going to museums, dancing, going out for dinner, and playing bingo or cards. PWD: *'Just sitting around in the house is not my cup of tea.'*
4. Apart or together		
1 The PWD is/is not accustomed to spend time alone.	**-**	
2 The PWD depends a lot/ limited on CG during the day.	**7**	CGs had to manage the PWDs during the day, instruct them, and answer their questions what to do continuously. CGs assisted the PWDs with domestic tasks and, later, personal care as well. CM: *'He* [PWD] *becomes restless if he does not see or hear her.'*
3* The PWD likes to have enjoyable shared activities with CG.	**3**	Only a few mentioned this: CM: *'They are happy with each other. They support each other a lot.'* CG: *'Back in those days most of our activities were separate, but now we do a lot more together. I think my wife needs that because of the illness.'*
4* The CG has a need for enjoyable shared activities with PWD.	**6**	CGs explained what they were accustomed to doing together because of shared interests or practical reasons (domestic tasks). Some missed time to spend together due to appointments. CG: *'Cinema, concerts, taking a walk with you* [PWD]*… the prospect of some nice things that we can do together. I can look forward to that.'*
5** The CG has a strong/limited need for his or her own activities.	**8**	CGs mentioned short activities such as leisurely going to a shop or doing a crossword puzzle – and also their hobbies that take time. CM: *He* [CG] *is a tenor in a choir. He can manage the repetitions in the evening* [leaving his wife alone at home], *but a concert can take a whole day. He foresees that that will be difficult, and he has to make up his mind.'*
6** The CG has a need for more time for his or her own life.	**10**	The CGs said that they did want to let the PWD be alone for a longer time. They felt rushed too often. Some said they simply needed 'peace'. Some CGs cancelled their volunteer work because they could not combine it with caring for their partners. *CG: ' I fly to the shop in a hurry, and I fly back again.'*
5. Meaning of activities		
1 The PWD has a strong/limited need for something to do for passing time.	**14**	See part 2.1
2 The PWD has a strong/limited need for physical activity.	**15**	See parts 3.2 and 3.3
3** The PWD has a strong/limited need for social contacts.	**5**	The PWDs talked about the market, the mall, the sports club, or a club for playing cards because they could meet their friends there and have a chat. PWD: *I used to have mates whom I met regularly at the garden lots.'*

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Indicators	**Present in NA (N=20)**	**Examples and quotes**
5. Meaning of activities		
4** The PWD has a strong/limited need for self-sufficiency.	**7**	The PWDs said that they wanted to do activities by themselves. This was important for their self-esteem. Some PWDs felt it was import for them to be able to do their share in domestic and household activities. PWD: *'I wanted to make the bed, but the sheet… it did not work. It makes me sad. My husband has said it a thousand times: 'I can do it for you', but I don't want that. My answer is: 'I'll do it myself.'*
5 The PWD has a strong/limited need for positive experiences.	**-**	
6** The PWD will benefit from adaptations or assistive devices for physical limitations.	**8**	There were limitations in hand strength, balance, walking, and stairs. Some already had adaptations or assistive devices; others would benefit from them too.
7** The CG has a need for advice about safety at home.	**2**	Some CGs did not want to leave the PWD alone at home, because of things that had happened, but also because they feared there were other dangerous situations. CG: '*Nothing serious has happened – yet. It isn't that he will burn the house down or anything, but suppose something serious did happen to him.'*
8** The CG has a need for advice about safety outside.	**2**	CGs were concerned about PWDs not recognising the route and getting lost, and they worried about risky behaviour in traffic. CG: *'I definitely do not begrudge her* [PWD] *her cycling, but she is not aware of priority rules, for example.'*

PWD: person with dementia; CG: caregiver; CM: case manager; NA: needs assessment
** very good recognizable in the majority of clients, and recommended by expert panel (25)
* fairly good recognizable in the majority of clients, and recommended by expert panel (25)

CHAPTER 7 –

General discussion

This chapter presents the outcomes of our research on dyadic, activating interventions for people with dementia and their informal caregivers, who live together in the community. Dyadic, activating interventions support the maintenance of meaningful activities for people with dementia and their caregivers that dementia may prevent them from participating in. The goal of this thesis was first, to study the impact of these interventions on people with dementia and their caregivers, and second, to explore the appropriateness of criteria for referring them to these interventions. In this final chapter, the main findings of both parts of the thesis are presented, along with a reflection on the findings, methodological considerations, suggestions for future research and implications for practice.

Main findings of the thesis

Part I Impact of dyadic, activating interventions for people with dementia and their informal caregivers

Our systematic review of the impact of dyadic, psychosocial interventions showed significant positive effects on the mood, behavior, daily activities and quality of life of people with dementia, as well as on the mood, sense of burden, competence and quality of life of caregivers (Chapter 2). We found particularly promising results when reviewing components of interventions closely related to the targeted functional domains. Components designed to increase the practice of meaningful activities did improve levels of activity and functional dependence. Components designed to increase the caregiver's supporting skills improved their sense of competence. And components designed to improve sleep at night had a positive impact on sleep. Despite these positive and obvious associations, the results across all studies were heterogeneous. Interventions proven effective in one trial were often not replicated in other studies studying similar interventions. The needs of people with dementia and their caregivers were not considered as part of the inclusion process by any of the studies. Scientific studies are frequently based on a 'one size fits all' approach. We therefore hypothesized, that one of the reasons for the heterogeneity of effects may be a poor match between intervention components and personal needs, characteristics and preferences of people with dementia and their caregivers.

In our next two studies, we investigated the potential of tailored support through dyadic, activating interventions (Chapters 3 and 4). We included three interventions that can be considered as ‘dyadic, activating interventions’. Dyadic, activating interventions aim to increase the skills of people with dementia and their informal caregivers in both maintaining daily activities and coping with a decline in general functioning due to the illness. The Pleasant Events Program focused on maintaining enjoyable activities, the Exercise and Support Intervention on maintaining physical fitness and enjoyable activities, and Occupational Therapy (Community Ocupational Therapy in Dementia – COTiD) on maintaining independence in meaningful activities.[1-4]

We studied each intervention’s fit with the needs, characteristics and preferences of participating dyads (Chapter 3). Interviews with participants and their coaches revealed five factors that described the most important needs, characteristics and preferences that lead to a better match with the intervention. Four factors describe actual needs, characteristics and preferences of dyads, whereas the fifth factor explores the meaning of the activities for a dyad:

1 Timing and openness to change: dyads who were aware of the impact dementia had on their daily life and who were open to making changes in their routine perceived the interventions as appropriate. Often, this occurred in an early stage of dementia.
2 Need for activity: dyads who experienced a lack of daily activities, but expressed a desire to maintain these activities perceived the interventions as appropriate.
3 Lifestyle: dyads with an active lifestyle and a preference for physical activity perceived the interventions as appropriate.
4 Doing activities apart-or-together: dyads having a need for joint activities and shared experiences felt supported by the interventions.
5 Meaning of the activity: before any appropriate matches can be made, it seemed highly relevant to explore the reason why the people with dementia and their caregivers participated in that particular activity. A need for activity can stem from the loss of daily pastimes, but also from experiencing pleasure or satisfaction or enjoying independence or social contacts while performing certain activities. For example, the ability to make coffee can mean a variety of things for different people: independence, daily routine, caring for or sharing with their partner, friends and family.

Next, we studied the working mechanisms of the interventions as perceived by participating dyads and professionals (Chapter 4). Three working mechanisms were identified, each with several components. Interventions were perceived as positive, when the coach:

1 Enabled participation in activities for the person with dementia and the caregiver without providing false hope. Components:
   - Focusing on the dyad staying active.
   - Emphasizing their abilities, while not ignoring any limitations.
   - Attuning to their motivation.
   - Focusing on opportunities to learn new habits or adapt their routines.
2 Explored the most important personal activity needs of the person with dementia and the caregiver. Components:
   - Paying attention to the needs of both the person with dementia and the caregiver.
   - Being competent in the field of dementia.
   - Observing dyads practicing activities to explore capacities and limitations.
   - Setting attainable goals and choosing doable activities.
3 Utilized a solution-focused approach to adapt, test, and practice activities. Components:
   - Piloting ideas, tips and solutions.
   - Stimulating dyads' persistence and repetition of activities.
   - Creatively adapting activities.
   - Practicing activities together.
   - Using coaching communication.

The core theme was empowerment. The interventions seemed to work when they empowered people with dementia and their caregivers by increasing their self-confidence, competence and hope which enabled them to maintain activities.

Part II The Appropriateness of criteria for referral to dyadic, activating interventions

Part II of this thesis was directed at applying the findings of Part I to assist clinical professionals when referring people with dementia and their caregivers to dyadic, activating interventions taking into account their needs, characteristics and preferences. The five factors identified in chapter 3 were operationalized into draft-criteria. According to an expert panel of referring professionals, the presence or absence of just over half the criteria (18 of 31) could be recognized in the large majority of their clients (Chapter 5). In the panel discussion, experts repeatedly mentioned the complexity of conducting a comprehensive needs assessment, especially when trying to identify people's latent needs. Some reported a lack of attention to a dyad's need for social contact or their preference for physical exercise. They also shared that they were used to limiting their assessments to services they knew were readily available.

The draft-criteria were regularly identified in real-life needs assessments conducted by dementia case managers, but they were usually not expressed in an explicit manner (Chapter 6). Most dyads expressed the need to maintain activities. However, the importance of and the meaning of the activity was not frequently discussed. The dyads clearly needed encouragement to share and explore those needs, but no further exploration took place. Similar to the previous study, we found that case managers often limited their exploration of needs to those catered for by standard care services. A service-oriented focus instead of a person-centered approach seemed to be common practice.

Reflection on the findings

Within person-centered care, it is important to address meaningful activities.[5-9] Dyadic, activating interventions can support dyads to maintain activities. Neurological or physical impairment, as well as personal, social, and environmental contexts can influence activity and participation.[10] The dyadic, activating interventions that we studied, are focused on enablement, taking impairment, activity and participation into account.[11] This enabling approach is oriented to the optimal use of remaining capacities and person-centered, a core recommendation in the Global Action Plan on the Public Health Response to Dementia of the World Health Organisation.[12] In this thesis we developed criteria that may help referring professionals in estimating the appropriateness of dyadic, activating interventions for a dyad. The criteria that are recognizable, as demonstrated in chapters 5 and 6, can be used as a conversation tool to both assess the activity needs of a dyad and evaluate the appropriateness of the interventions. Our research revealed two barriers for the use of these criteria: the suboptimal quality of the needs assessments (Chapters 3, 5, 6), and a limited awareness of activating interventions to support dyads (Chapters 4, 5). We will discuss these barriers in more detail below.

Quality of needs assessment

Our studies identified several limitations in current needs assessments (Chapter 3, 5, 6). The needs, characteristics and preferences of people with dementia and informal caregivers are not systematically checked, and the assessment is often limited to medical and personal care domains. We also noticed a lack of in-depth exploration of needs and their meaning for that specific dyad. Previous research shows that dyads only mention needs when they know a service exists.[13] They are hesitant to mention needs and preferences when they are unsure if there is a potential intervention.[14] A comprehensive needs assessment can explore personal needs in more detail. Our research showed that questions about preferences and wishes encourage people with dementia and their caregivers to talk about their daily life and how they cope with limitations (Chapters 3, 4, 6). By doing so, latent needs might emerge, particularly those related to their daily functioning. In addition, exploring needs stimulated people with dementia and caregivers to come up with solutions themselves. It can be challenging to talk about practical topics in detail, because the stories of people with dementia and their caregivers are often focused on loss and grief.[15] However, people with dementia and caregivers in our research mentioned that a professionals' acknowledgement of their needs and feelings was important to them, even without a direct solution (Chapter 4).

Finally, identifying the meaning of an activity for people with dementia and caregivers is important as part of a comprehensive needs assessment, as it helps professionals to both better understand the dyad's needs and find an appropriate intervention (Chapters 3, 4, 5, 6). Riding a bicycle can be meaningful as a mode of transportation, but also as a need for a healthy lifestyle, recreation, or social contact. An appropriate intervention should match the meaning of the activity for that individual. As a result, different interventions might be suggested to people with, superficially, a similar activity need.

Awareness and knowledge of activating interventions and their impact
Our research showed that referring professionals were neither sufficiently aware of nor informed about activating interventions for people with dementia and their caregivers. Hence, they did not inform people with dementia sufficiently about the possible positive outcomes of training and an enabling physical and social environment, which might compensate for declines in functioning. As a result, people with dementia often thought that nothing more could be done, further increasing their feeling of helplessness following a diagnosis that is often devastating in itself (Chapter 3).

People with dementia and their caregivers can feel more positive when they are aware of small steps and changes that can help them cope.[16] For example, one person with dementia in our study, mentioned that the intervention had encouraged him to stay active and to push himself to maintain his daily activities. A caregiver shared that she learned to motivate her partner in a gentler way, rather than using a phrase that frustrated him ('you have to'). Other studies also emphasize the importance of positive feelings as a coping mechanism for people with dementia.[17-20] When referring professionals are more aware of dyadic, activating interventions, they can discuss an enabling and capacity-building approach and its possible benefits with a dyad.

Methodological considerations

Evidence for impact of interventions

Our systematic review and other reviews showed evidence for the beneficial impact of dyadic, activating interventions.[21-24] These reviews also point to inconsistency in evidence for individual interventions. This is also the case for the three interventions central to this thesis. Some scientific evidence supported them when this study began, but the positive findings of the 'Exercise and Support Intervention' and 'COTiD' were not replicated in later studies.[25-33] Looking back, this may be because the studied interventions did not specifically match the needs, characteristics and preferences of the participants involved.[14,34-36] There is still a gap in knowledge, especially regarding which intervention works best for whom and when.[22,37] This research addresses some of those issues.

Criteria and indicators

In Part II of this thesis, criteria for the assessment of activity needs were developed using the RAND Appropriateness Method (Chapter 5). The RAND methodology requires an extensive literature review on the effectiveness of the relevant intervention as a basis for developing indicators.[38] However, there was a limited amount of evidence available supporting our research. We still choose to use the RAND methodology as it offered a structured and objective procedure for evaluating the recognizability of the draft-criteria. We formulated the draft-criteria following the findings of our qualitative study (Chapter 3). The RAND expert panel then rated them for recognizability in their daily practice. RAND normally uses the term 'indicators,' but because the underlying evidence for our study was less rigorous, the term 'criteria' was more adequate.

Triangulation in data collection and analysis

Input from several stakeholders is a strength in research. We interviewed people with dementia, their caregivers and the coaches involved in the studies described in chapters 3, 4 and 6. For the studies described in chapters 5 and 6 we included referring professionals, like case managers, geriatricians and general practitioners. This enabled us to incorporate a variety of perspectives. The unit of analysis in our studies was a case, where each case consisted of a person with dementia, their informal caregivers and any supporting professionals.[39] In each case, the narratives of the person with dementia, the caregiver and the coach complemented each other, resulting in 'rich data'.[39] The inclusion of multiple sources of information contributed to increased validity, credibility and trustworthiness of our findings.[40,41]

Roles of the primary investigator

In qualitative research, the researcher's expectations and assumptions may influence the validity of the findings.[41] The professional experience of the primary investigator as an occupational therapist working with people with dementia and their caregivers played a significant role in this thesis. It contributed to both building a confidential relationship ('rapport') with respondents and acknowledging the perspectives of both dyads and coaches (role-taking).[42] However, the primary investigator's experience as an occupational therapist in the field of dementia also poses a potential bias, as personal expectations and assumptions may have influenced the data interpretation process.[40] Reflexive objectivity can improve the validity of a study's outcomes.[43] In our studies, we strived for 'reflexive objectivity' through collaboration with researchers from several backgrounds, including nursing, psychology, medicine, and public health sciences.[41,43]

Recommendations for research

In this thesis, we developed a set of criteria to match dyadic, activating interventions with the needs, characteristics and preferences of people with dementia and their caregivers. The criteria can be used as a tool for both assessing activity needs of a dyad and evaluating the appropriateness of dyadic, activating interventions. Research regarding the validity of the criteria as a referring tool in clinical practice is needed. Furthermore, future research could focus on different dyadic, activating interventions, and add diversity of participants for example different cultural backgrounds.

With regard to the design of future studies on dyadic, activating interventions for people with dementia and their caregivers, we recommend to explore a dyad's needs and preferences before including them in the study. Furthermore, specific outcome measures should be included related to the target areas of the intervention in addition to generic outcomes. For example, if an intervention is focused on physical fitness, one of the outcome measures should be directly related to physical fitness. If an intervention is focused on an increase in activities or social contacts, then the outcomes should at least include the measurement of those domains. We also recommend the inclusion of a measure regarding empowerment, like 'competence' or 'self-confidence', since this may help explain any impact that could be found. In addition to the usual outcome measures, like mood, behavioral changes and sense of burden, these outcome measures can give more comprehensive insight into the impact of dyadic, activating interventions and their working mechanisms.[44-46]

Implications for practice

The implications for practice provide suggestions for referring professionals, providers of dyadic, activating interventions, and teachers who focus on dementia care.

Referring professionals

Quality of the needs-assessment

Referring professionals, like clinicians and case managers, may benefit from learning additional skills to perform comprehensive needs assessments. In the Netherlands, geriatricians, general practitioners and dementia case managers hold a central position for referral to care and support after the initial dementia diagnosis. A comprehensive assessment would include all domains of daily life, like cognitive and physical impairment, activity, the social and environmental context and participation. Client-centered interview techniques and sensitivity to unmet needs and preferences in coping with declines in capacities and functioning are important. Questions like, 'What activities do you prefer?', or, 'What activities do you like to do together', followed by questions about the meaning and limitations the dyad experiences may help identify activity needs, preferences and latent needs. Such a needs assessment may assist the dyad in coming up with their own solutions.

Awareness and knowledge of dyadic, activating interventions
Referring professionals should become more aware of dyadic, activating interventions' positive impact in that they can make a big difference to people with dementia and their caregivers. For example, they may better cope with daily problems, even if they only made minor changes at first. Next, they should actively search the available dyadic, activating interventions and strength-based approaches in their region.[47]

Providers and professionals of dyadic, activating interventions

Availability of dyadic, activating interventions
Service providers in the field of dementia care should increase the amount of dyadic, activating interventions offered, preferably evidence-based and focusing on different domains like physical activity, pleasant activities, music, social contacts and ADL-activities. This will make it easier to refer people with dementia and their caregivers to interventions that fit their needs. Wider availability will also add increased public awareness of the remaining capacities and interests of people with dementia. Professionals who provide dyadic, activating interventions should actively inform referring professionals about the goals and impacts of their intervention.

Competencies of professionals guiding the interventions
Professionals guiding dyadic, activating interventions must be able to set realistic goals with a dyad. For every dyad, they should explore where adaptations are needed. For an enabling approach using strength-based interventions, a professional must focus on clients' abilities while respecting their limitations. A professional will also benefit from extensive knowledge of cognitive and behavioral processes that accompany dementia to recognize capacities and limitations.[48] A rehabilitative approach is central to the paramedical health disciplines. Along with the other disciplines, they can shape this enabling approach in dementia care services. Finally, a creative and open mind will help professionals brainstorm solutions tailored to the people with dementia and the caregivers.

Education on dementia care

The following recommendations concern both undergraduate study programs and professional education in dementia-care.

- Professionals must be trained in a dyadic approach to both people with dementia and informal caregivers, taking their personal needs, characteristics and preferences into account when considering psychosocial interventions.[5,49]
- The relationship between meaningful activities and well-being requires more attention in professional education. It should be emphasized that meaningful activities may be small activities such as daily habits and self-care or bigger activities and hobbies.[50]
- The working mechanisms for an enabling and activating approach can be part of training programs, such as a focus on capacities, motivation, attainable goals, practicing activities and strength-based strategies for people with dementia and their caregivers.[16,49]
- Finally, for a person-centered approach, interprofessional collaboration is needed, a challenge for all professionals involved in dementia care. This requires a professional to be empathetic and have knowledge of the services offered by other care providers. To date, both referring professionals and those guiding the interventions are still too focused on how the client can benefit from what they themselves do, rather than focusing on what is best for that particular dyad. It is important that students from different study programs collaborate on projects that come from 'real-life' clinical practice. They should be familiar with other disciplines from the start of their education and learn how to collaborate and complement each other.

Conclusion

Based on the identified factors for determining a fit and the perceived working mechanisms, criteria have been developed to guide clinicians and case managers in assessing activity needs and evaluating the potential match of an activating intervention with a dyad's needs, characteristics and preferences. A more comprehensive assessment of activity needs and greater awareness of the potential of dyadic, activating interventions may help people with dementia and their caregivers. This will contribute to more attention for continuing activities and feelings of self-confidence, competence and hope.

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Summary

Chapter 1 describes the introduction of this thesis' topic. People with dementia have trouble maintaining their usual, daily life. A lack of daytime activities at home and outdoors and the need for company is frequently reported. Informal caregivers report difficulties supporting the person affected by dementia with his or her activities and engaging in shared activities. Maintaining their own activities is also difficult, as care work consumes much time and energy. Dyadic, activating interventions place emphasis on maintaining meaningful activities and using the remaining capacities of the affected person to support both people with dementia and their caregivers. Three of those dyadic, activating interventions are central in our studies: the 'Pleasant Events Program', the 'Exercise and Support Intervention' and 'Occupational Therapy'(according to the Community Occupational Therapy in Dementia-guideline – COTiD). Past scientific effect-studies for these interventions have shown positive results in mood, daily activities and the general health of people with dementia, as well as on the mood and competence of their caregivers, and the quality of life of both parties.

Despite the difficulties encountered by people with dementia and their caregivers in daily activities, dyadic, activating interventions are scarcely offered. In current dementia care, the needs assessment is often limited to medical and personal care domains, while social and occupational domains are not systematically checked. More knowledge of dyadic, activating interventions and how to match them with person-specific needs, characteristics and preferences is needed. Criteria for evaluating the appropriateness of dyadic, activating interventions might help referring professionals in the referral process. The overall aim of this thesis has been (1) to study the impact of dyadic, activating interventions on people with dementia and their caregivers, and (2) to develop and evaluate criteria for referring a dyad to these interventions.

Part I The impact of dyadic, activating interventions for people with dementia and their informal caregivers

Chapter 2 reports the evidence of dyadic, psychosocial interventions for people with dementia and their family caregivers and the relationship with treatment components. A systematic review included 23 randomized controlled trials of moderate to high quality. These trials concerned 20 different dyadic psychosocial programs for people with dementia and caregivers between January 2005 and January 2012. 19 of these programs found significant positive effects on mood, behavior, daily activities and the quality of life of people with dementia, and on the mood, sense of burden, competence and quality of life of caregivers. We found promising results for interventions with treatment components that were closely related to the targeted functional domains. Components designed to increase the practice of meaningful activities did improve levels of activity and functional dependence. Components designed to increase the caregiver's supporting skills improved their sense of competence. And components designed to improve sleep at night had a positive impact on sleep. However, while some of these interventions were proven effective in one trial, studies on similar interventions in other settings found no effect. We hypothesized that more attention must be devoted to matching targeted functional domains and the treatment components of an intervention with the needs of the person with dementia and the informal caregiver.

Chapter 3 describes a qualitative study to explore factors that participants perceive to be important for the match of dyadic, activating interventions. To improve knowledge about which intervention best suits specific needs, characteristics and preferences, we conducted semi-structured interviews with people with dementia (27), their caregivers (34) and coaches (19) after their participation in one of the following interventions: the 'Pleasant Events Program', the 'Exercise and Support Intervention' or 'COTiD'. Five factors were identified influencing the intervention's appropriateness with the needs, characteristics and preferences of a dyad.

1 Timing and openness to change: dyads who were aware of the impact of dementia on their daily life and who were open to making daily routine changes, perceived the interventions as appropriate. Often, they were in an early stage of dementia.
2 Need for activity: dyads who experienced a lack of daily activities, but expressed a desire to maintain these activities, felt supported by the interventions.
3 Lifestyle: dyads with an active lifestyle and a preference for physical activity perceived the interventions as appropriate.
4 Doing activities apart-or-together: dyads having a need for joint activities and shared experiences felt supported by the interventions.
5 Meaning of the activity: the interventions had to match the reason why the people with dementia and their caregivers participated in that activity. Their need for activity can stem from the loss of daily pastimes, pleasure or satisfaction with certain activities, independence, or social contacts. For example, the ability to make coffee can mean different things for different people:

independence, daily structure, caring for and sharing with their partner, friends and family.

Attention to these five factors when choosing an intervention can contribute to a more person-centered approach, allowing the intervention to better fit the personal needs, characteristics and preferences of people with dementia and their caregivers.

Chapter 4 comprises a qualitative study about the working mechanisms of the three dyadic, activating interventions, as perceived by people with dementia, their caregivers and coaches. More knowledge of the working mechanisms of activating interventions might help to increase their impact. We analyzed the semi-structured interviews with dyads and coaches to find out what the working mechanisms had been for them. Three working mechanisms were identified, each with several components. Interventions were perceived as positive, when the coach:

1. Enabled the person with dementia and the caregiver without providing false hope. Components:
    - Focusing on the dyad staying active.
    - Emphasizing their abilities, while not ignoring any limitations.
    - Attuning to their motivation.
    - Focusing on opportunities to learn new habits or adapt their routines.
2. Explored the most important personal activity needs of the person with dementia and the caregiver. Components:
    - Paying attention to the needs of both the person with dementia and the caregiver.
    - Being competent in the field of dementia as a coach.
    - Observing dyads practicing activities to explore capacities and limitations.
    - Setting attainable goals and choosing doable activities.
3. Utilized a solution-focused approach to adapt, test, and practice activities. Components:
    - Piloting ideas, tips and solutions.
    - Stimulating dyads' persistence and repetition of activities.
    - Showing creativity to adapt activities.
    - Training activities.
    - Using coaching communication

Empowerment emerged as a core theme. Participants appreciated the focus on finding remaining capacities and strengths to compensate for limitations. They perceived that an individualized, strength-based approach contributed to positive changes, like more attention for continuing activities and feelings of confidence, competence, and hope. Dyads were able to take control of their situation and find out what worked for them. Coaches needed to be skilled in assessing a dyad's needs, capacities and limitations for taking part in activities, in communicating about activities, and in teaching dyads a solution-focused approach.

Part II The appropriateness of criteria for referral to dyadic, activating interventions

The five factors described in chapter 3 may help referrers match an intervention with the needs, characteristics and preferences of dyads. To make this knowledge more accessible and useful in clinical practice, we operationalized these factors into 31 draft-criteria, based on the qualitative descriptions in the interviews. Each criterion described a need, characteristic or preference of the person with dementia or the caregiver.

Chapter 5 presents a study about the recognizability of these draft-criteria for referring professionals. A panel of 12 physicians and case managers, all experts in dementia care, rated how recognizable these criteria were in their clinical practice, using the 'RAND Appropriateness Method'. The panelists scored 18 criteria as recognizable in most of their clients. For criteria about a preference for physical and social activities, a consensus was lacking, because referrers were not accustomed to assessing those criteria. Panelists also reported difficulty with making the latent needs of a dyad explicit, and the habit to limit their assessment to services within their region. The 18 recognizable criteria offer guidance to referrers to assess activity needs and discuss the appropriateness of an activating intervention with a dyad.

Chapter 6 focuses on the usefulness of the criteria for needs assessment and referral to dyadic, activating interventions. As well as recognizability, we wanted to explore the practicality of the criteria for assessing the activity needs of a person with dementia and their caregiver in clinical practice. We performed secondary analyses of interviews for needs assessments with 20 dyads by a dementia case manager. Most people with dementia and caregivers reported activity needs. We frequently identified activity-needs, characteristics and preferences that were implicit in the stories of dyads. Preferences related to lifestyle were always expressed explicitly, but preferences for the other factors were often implicit. These needs should have been explored more profoundly in the assessment, to investigate the appropriateness of activating interventions.

Chapter 7 contains the general discussion. The criteria developed in this thesis may help referrers to assess activity needs, characteristics and preferences of dyads, and estimate the appropriateness of a dyadic, activating intervention, in line with a person-centered approach. The criteria are recognizable for referrers in their clinical practice and are present in most real-life needs assessments. Our studies reveal two barriers to using the criteria for selecting the most appropriate dyadic, activating intervention: the quality of the needs assessment and limited knowledge of activating interventions. We notice a lack of in-depth exploration of personal needs, and, where activity needs are identified, the exploration of the meaning of those activities for a dyad is often insufficient.
Our studies demonstrate that a service-oriented focus is most prevalent in needs assessments rather than a person-centered approach. Furthermore, referring professionals have limited knowledge about and are not sufficiently aware of the impact of dyadic, activating interventions.

The criteria developed in this thesis can be used as a conversation tool for assessing activity needs of a dyad, and evaluating the appropriateness of dyadic, activating interventions. We propose the following recommendations for research and practice:

- Research regarding the validity of the criteria as a referring tool in clinical practice is needed.
- Future studies exploring dyadic, activating interventions, should explore a dyad's needs and preferences before including them in a study. Possible effects are contingent on whether they fulfil the needs and preferences of the participants. They should also include outcome measures directly related to the target areas of the activating intervention and empowerment.
- Referring professionals, like clinicians and case managers, should move from a service-oriented focus to a person-centered approach. A detailed assessment of a dyad's personal needs includes their activity needs and exploring what the various activities mean to them. Greater awareness is needed of the impact of

strength-based and enabling approaches, such as dyadic, activating interventions.

- Dementia care providers should include more dyadic, activating interventions in their services.
- Professionals need to be trained in a person-centered, dyadic approach. Education for referring professionals should both address needs assessment and convey the relation between daily activities for people with dementia and their caregivers and their well-being.
- Education in dementia care should teach the skills for implementing an activating approach for people with dementia and their caregivers, instead of taking over activities in caregiving.
- Teaching creative thinking techniques will help brainstorm tailored solutions for the person with dementia and the caregiver.
- Interprofessional education should support interprofessional collaboration, an important condition for implementing a person-centered approach.

Samenvatting – Summary in Dutch

Hoofdstuk 1 beschrijft de aanleiding voor dit proefschrift. Mensen met dementie hebben moeite om hun dagelijks leven en hun bezigheden voort te zetten zoals ze gewend waren. Zij hebben zowel binnenshuis als buitenshuis vaak weinig om handen en kunnen een gebrek aan sociale contacten ervaren. Tegelijkertijd ervaren mantelzorgers regelmatig problemen bij het ondersteunen van de persoon met dementie in activiteiten, en bij het ondernemen van gezamenlijke activiteiten. Ook vinden zij het vaak moeilijk om hun eigen activiteiten voort te zetten, omdat de zorg veel tijd en energie vraagt. Activerende interventies, gericht op hen als koppel, zijn van belang om zowel de persoon met dementie als de mantelzorger te ondersteunen bij het continueren van betekenisvolle activiteiten, en het benutten van de nog aanwezige capaciteiten van de persoon met dementie.

Drie van dergelijke op koppels gerichte, activerende interventies staan centraal in onze studies: de ‘Plezierige Activiteiten Methode’, de ‘Thuisinterventie met Beweging en Ondersteuning’ en ‘Ergotherapie (Ergotherapie voor mensen met Dementie en hun Mantelzorgers aan Huis (Edomah)- programma)’. Effectstudies naar deze interventies lieten positieve resultaten zien voor mensen met dementie op hun stemming, algemene gezondheid en het uitvoeren van dagelijkse activiteiten, en voor mantelzorgers op hun stemming en gevoel van competentie, en voor beiden op de kwaliteit van leven.

Ondanks deze positieve effecten worden deze op koppels gerichte, activerende interventies nog maar beperkt aangeboden. Ook ontbreekt kennis over wie het beste is gebaat bij welke interventie. Vanuit een persoonsgerichte benadering is het belangrijk dat interventies aansluiten op persoonlijke behoeften, voorkeuren en kenmerken van de persoon met dementie en de mantelzorger. In de huidige dementiezorg worden vooral medische en zorgbehoeften geïnventariseerd. Het sociale domein, waar in een vroeg stadium van dementie veel behoeften aan het behouden van betekenisvolle activiteiten kunnen liggen, wordt niet systematisch in de behoefte inventarisatie meegenomen. Criteria om behoeften, voorkeuren en kenmerken gericht op betekenisvolle activiteiten te inventariseren ontbreken, terwijl professionals (artsen en casemanagers) juist kunnen helpen door te verwijzen naar geschikte activerende interventies voor mensen met dementie en hun mantelzorgers. Het doel van deze thesis was (1) de impact van activerende interventies voor mensen met dementie en hun mantelzorgers te bestuderen, en (2) criteria om naar op koppels gerichte, activerende interventies te verwijzen te ontwikkelen en te evalueren.

Deel I Activerende interventies voor mensen met dementie en mantelzorgers

Hoofdstuk 2 beschrijft de effectiviteit van activerende interventies voor mensen met dementie en mantelzorgers, en de relatie met de behandelcomponenten van de interventies. In een systematische review zijn 23 studies van gemiddelde tot hoge kwaliteit over 20 op koppels gerichte, psychosociale interventies voor mensen met dementie en mantelzorgers opgenomen. De studies zijn tussen januari 2005 en januari 2012 gepubliceerd. Voor 19 interventies werden significante, positieve effecten gevonden op een of meerdere van de volgende uitkomstmaten: stemming, gedrag, dagelijkse activiteiten en kwaliteit van leven voor mensen met dementie, evenals voor stemming, zorglast, competentie en kwaliteit van leven van mantelzorgers. Soms was een interventie effectief in één studie, maar kon een andere studie geen effect aantonen. Het wetenschappelijk bewijs voor de effectiviteit van verschillende op koppels gerichte, psychosociale interventies is daarom heterogeen. Uit de literatuurreview kwam ook naar voren dat interventies met behandelcomponenten die betekenisvolle activiteiten ondersteunen veelbelovend zijn voor effecten op het domein 'uitvoeren van activiteiten'. Dat gold ook voor interventies met behandelcomponenten waarbij de mantelzorger praktische vaardigheden oefende voor het omgaan met de persoon met dementie voor effecten op competenties van de mantelzorger.

Hoofdstuk 3 beschrijft een kwalitatieve studie naar factoren die volgens de deelnemers van belang waren voor de aansluiting van de drie op koppels gerichte, activerende interventies op hun individuele behoeften, kenmerken en voorkeuren. We hebben semigestructureerde interviews gehouden met mensen met dementie (27), hun mantelzorgers (34) en de begeleidende coaches (19) na deelname aan een van de interventies: de 'Plezierige Activiteiten Methode', de 'Thuisinterventie met Beweging en Ondersteuning' en 'Ergotherapie (Edomah)'. De analyse leidde tot vijf factoren, die de aansluiting van de interventies op behoeften, kenmerken en voorkeuren, beïnvloedden.

1. Tijdigheid en openstaan voor verandering. Mensen met dementie en mantelzorgers die zich bewust waren van de consequenties van de dementie in hun dagelijks leven, en ervoor openstonden om hun dagelijkse routines aan te passen, vonden de interventies geschikt. Vaak waren zij in een beginnend stadium van dementie. Mensen met dementie en mantelzorgers die hun routines niet konden of wilden aanpassen op dat moment, hadden de interventies niet als geschikt ervaren.

2 Behoefte aan activiteiten. Mensen met dementie en mantelzorgers die hun dagelijkse bezigheden wilden behouden, en daarbij problemen tegenkwamen, vonden de interventies positief en ondersteunend. De interventies sloten niet aan bij mensen met dementie en mantelzorgers voor wie andere onderwerpen dan activiteiten op dat moment het belangrijkst waren.
3 Leefstijl. Mensen met dementie en mantelzorgers met een actieve leefstijl en een voorkeur voor fysieke inspanning vonden deze interventies geschikt.
4 Het samen of juist apart doen van activiteiten. Mensen met dementie en mantelzorgers bij wie de interventies aansloten bij de behoefte aan gezamenlijke activiteiten en gedeelde ervaringen voelden zich ondersteund.
5 Betekenis van de activiteit. De interventies werden als geschikt ervaren als zij aansloten bij de betekenis van de activiteit voor de persoon met dementie en de mantelzorger. Die betekenis kon zijn: iets te doen hebben, plezier in bepaalde bezigheden hebben, ervaren van zelfredzaamheid of het onderhouden van sociale contacten. Koffiezetten kan bijvoorbeeld verschillende betekenissen hebben voor verschillende mensen: het behouden zelfstandigheid of dagelijkse structuur, het verzorgen van een kopje koffie voor de ander, of het ontvangen van visite. Naast betekenis werden bij deze factor ook fysieke beperkingen als belemmeringen genoemd.

Aandacht voor deze vijf factoren bij het kiezen van een interventie kan bijdragen aan een meer persoonsgerichte benadering, waarbij de interventie zo goed mogelijk aansluit op persoonlijke behoeften, kenmerken en voorkeuren van mensen met dementie en mantelzorgers.

Hoofdstuk 4 bevat een kwalitatieve studie naar de werkzame mechanismen van de drie op koppels gerichte, activerende interventies, volgens de deelnemers en de begeleiders. Meer inzicht in de werkzame mechanismen kan helpen om de impact van de interventies te vergroten. In de semigestructureerde interviews met mensen met dementie, mantelzorgers en de coaches vroegen wij hen wat volgens hen werkzame mechanismen van de interventies waren. De analyse hiervan leidde tot drie werkzame mechanismen, elk bestaand uit meerdere componenten.

De interventies werden als positief ervaren als de coach:

1 de persoon met dementie en de mantelzorger ondersteunde en stimuleerde actief te blijven, zonder valse hoop te wekken.
Componenten van dit mechanisme waren:

- Focussen op ‘actief blijven’;
- Benadrukken van de aanwezige capaciteiten, maar ook de beperkingen erkennen;
- Aansluiten bij hun motivatie;
- Focussen op mogelijkheden voor mensen met dementie en mantelzorgers om nieuwe gewoonten te leren of hun routines aan te passen.

2 de meest belangrijke individuele behoeften aan activiteiten van de persoon met dementie en mantelzorger onderzocht. Componenten van dit mechanisme waren:
  - Aandacht schenken aan de behoeften van zowel de persoon met dementie als de mantelzorger;
  - Competent zijn als coach op dementiegebied;
  - Het observeren van de koppels bij het uitvoeren van activiteiten en het in kaart brengen van capaciteiten en beperkingen;
  - Haalbare doelen stellen en het kiezen van haalbare activiteiten.

3 een oplossingsgerichte benadering toepaste om activiteiten aan te passen en te oefenen. Componenten van dit mechanisme waren:
  - Ideeën, tips en oplossingen uitproberen;
  - Het stimuleren van het doorzettingsvermogen van koppels en van het herhalen van activiteiten;
  - Creativiteit gebruiken om activiteiten aan te passen;
  - Activiteiten gezamenlijk oefenen;
  - Coachende communicatie gebruiken.

Empowerment was het centrale thema. De deelnemers waardeerden de focus op de nog aanwezige capaciteiten en hun sterke kanten om hun beperkingen te compenseren. Ze vonden dat de individueel aangepaste, op sterke kanten gebaseerde benadering had bijgedragen aan positieve veranderingen, zoals meer aandacht voor het blijven doen van activiteiten, meer zelfvertrouwen, een groter gevoel van competentie, en hoop. Mensen met dementie en mantelzorgers ervoeren meer grip op hun situatie, en leerden uit te zoeken wat voor hen werkte. De coaches moesten vaardig zijn in het inventariseren van behoeften, capaciteiten en beperkingen van mensen met dementie en mantelzorgers voor het uitvoeren van activiteiten, daar helder over kunnen communiceren, en in staat zijn om hen een oplossingsgerichte aanpak te leren.

Deel II Criteria om naar op koppels gerichte, activerende interventies te verwijzen

De vijf factoren, die in hoofdstuk 3 zijn beschreven, kunnen verwijzers helpen bij het kiezen van een interventie die aansluit op behoeften, kenmerken en voorkeuren van mensen met dementie en mantelzorgers. Om deze kennis meer toegankelijk te maken en bruikbaar in de klinische praktijk, hebben we deze factoren geoperationaliseerd in 31 concept-criteria, gebaseerd op de omschrijvingen in de interviews. Ieder criterium beschrijft een behoefte, een kenmerk of een voorkeur van de persoon met dementie of de mantelzorger.

Hoofdstuk 5 beschrijft een studie naar de herkenbaarheid van deze concept-criteria voor verwijzende professionals. Een panel van 12 artsen en casemanagers, allemaal experts in de zorg voor mensen met dementie, scoorden de mate waarin deze criteria voor hen herkenbaar waren in hun klinische praktijk. We gebruikten de ‘RAND Appropriateness Method’. De panelleden scoorden een groot deel van de criteria (18) als herkenbaar bij de meeste van hun cliënten. Consensus ontbrak voor de criteria over een voorkeur voor lichamelijke en sociale activiteiten, omdat de verwijzers niet gewend waren om deze voorkeuren te inventariseren. De panelleden bespraken ook de moeite die ze hadden om latente behoeften expliciet te maken, en hun gewoonte om de behoefte inventarisatie te beperken tot de beschikbare mogelijkheden in hun regio. De 18 herkenbare criteria bieden verwijzers richting om behoeften aan activiteiten van de persoon met dementie en de mantelzorger te inventariseren en de geschiktheid van een activerende interventie met beiden te bespreken.

Hoofdstuk 6 richt zich vervolgens op de praktische toepassing/bruikbaarheid van de criteria voor een behoefte inventarisatie en de verwijzing naar op koppels gerichte, activerende interventies. We voerden een secundaire analyse uit op interviews van casemanagers gericht op de inventarisatie van de behoeften van 20 cliëntparen. De meerderheid van de mensen met dementie en mantelzorgers noemde behoeften op het gebied van activiteiten. Voorkeuren met betrekking tot de factor Leefstijl waren altijd expliciet terug te vinden, maar de criteria behorend bij de andere factoren (Tijdigheid en openstaan voor verandering, Behoefte aan activiteiten, Activiteiten samen of juist apart en Betekenis van de activiteit) bleven vaak impliciet. Deze behoeften zouden uitgebreider geïnventariseerd moeten worden, om de geschiktheid van op koppels gerichte, activerende interventies te kunnen inschatten.

Hoofdstuk 7 bevat de algemene discussie. De ontwikkelde herkenbare criteria kunnen verwijzers helpen om behoeften, kenmerken en voorkeuren van mensen met dementie en van hun mantelzorgers met betrekking tot activiteiten te inventariseren, en vervolgens de geschiktheid van een activerende interventie in te schatten, passend bij een persoonsgerichte benadering. Onze studies tonen twee belemmeringen voor het gebruik van de criteria: de kwaliteit van de behoefte inventarisatie en de beperkte kennis over deze interventies bij verwijzers. We constateren dat behoefte inventarisaties niet erg diepgaand zijn. Als behoeften omtrent activiteiten werden aangegeven, werd de betekenis ervan voor de persoon met dementie en de mantelzorger vaak niet (genoeg) nagevraagd. Onze studies tonen aan dat behoefte inventarisaties eerder aanbodgericht dan persoonsgericht waren. Daarnaast hebben verwijzers beperkte kennis van op koppels gerichte, activerende interventies, en zijn ze onvoldoende op de hoogte van de impact ervan.

We hebben de volgende aanbevelingen voor verder onderzoek, en voor de praktijk:
- Voor het verder ontwikkelen van een verwijsinstrument voor de klinische praktijk, is verder onderzoek naar de validiteit van de criteria nodig.
- Toekomstige studies naar op koppels gerichte, activerende interventies zouden de behoeften en voorkeuren van mogelijke deelnemers en de aansluiting van specifieke interventies daarop moeten inventariseren, alvorens hen te includeren in de studie. Mogelijke effecten zijn immers afhankelijk van het al dan niet aansluiten bij die behoeften van de deelnemers. Ook zouden studies naar de effectiviteit van deze interventies uitkomstmaten moeten opnemen die empowerment en de domeinen waarop de interventie zich richt meten.
- De behoefte inventarisatie van verwijzende professionals, zoals artsen en casemanagers, zou moeten bewegen van aanbod-georiënteerd naar persoonsgericht. Een gedetailleerde inventarisatie van de persoonlijke behoeften van mensen met dementie en hun mantelzorgers moet ook behoeften aan activiteiten en de betekenis ervan bevatten. Verwijzers moeten zich meer bewust zijn van de impact van benaderingen die uitgaan van mogelijkheden van mensen met dementie, zoals deze activerende interventies.
- Aanbieders van zorg voor mensen met dementie zouden hun diensten moeten uitbreiden met meer op koppels gerichte, activerende interventies.
- Verwijzende professionals moeten worden getraind in een persoonsgerichte, op koppels gerichte benadering. Daarin moet aandacht zijn voor de kwaliteit van de behoefte inventarisatie en voor de relatie tussen (dagelijkse) activiteiten voor mensen met dementie en hun mantelzorgers en hun welbevinden.

- Vaardigheden voor een activerende benadering zouden in het onderwijs voor uitvoerende professionals meer aandacht moeten krijgen, om te snel overnemen van activiteiten te voorkomen.
- Technieken voor creatief denken in het onderwijs kunnen bijdragen aan het vinden van oplossingen-op-maat voor de persoon met dementie en mantelzorger.
- Ten slotte zou in het onderwijs aandacht moeten zijn voor interprofessionele samenwerking bij dementie, om verder te kunnen kijken dan het aanbod van de eigen discipline, een belangrijke voorwaarde voor een persoonsgerichte benadering.

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Ouderen en mensen met dementie zijn altijd de rode draad in mijn werk gebleven,

als docent aan de Opleiding Ergotherapie, als onderzoeker bij het Kenniscentrum Zorginnovatie van de Hogeschool Rotterdam, en als ergotherapeut in een vrijgevestigde praktijk. De focus was op hoe hun dagelijkse activiteiten en gewoonten bij kunnen dragen aan het behouden van een betekenisvol leven. Het geeft dan ook veel voldoening dat ik juist op dit onderwerp onderzoek kon doen en kon promoveren. Ik ben Jacomine, Anne Margriet en Eva dankbaar dat zij dit onderwerp met mij deelden. Ik bedank de Hogeschool Rotterdam, en dan met name de Opleiding Ergotherapie en het Kenniscentrum Zorginnovatie, dat zij mij hierin wilden faciliteren.

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Over de auteur – About the author in Dutch

Netta van 't Leven, geboren op 16 mei 1959, groeide op in Den Haag, en volgde de middelbare school aan het Christelijk Lyceum Delft. Na een tussenjaar, heeft ze van 1978-1982 Ergotherapie gestudeerd aan de Revalidatie Academie Hoensbroeck (nu Zuyd Hogeschool). Zij volgde van 1999-2001 de European Masters Study of Science in Occupational Therapy, een gezamenlijk initiatief van Karolinska University Stockholm, School of Occupational Therapy and Physiotherapy, Naestved, Hogeschool van Amsterdam, en University of Brighton.

Na de studie Ergotherapie ging ze als ergotherapeut tijdelijk aan het werk in het Nederlands Zeehospitium Kijkduin (nu Basalt). Daarna werkte zij zes jaar bij Psychogeriatrisch verpleeghuis Dorestad, onderdeel van Psychiatrisch Centrum Bloemendaal, in Den Haag (nu Parnassia), waar zij voor het eerst met mensen met dementie te maken kreeg. Later verbreedde zij haar werkervaring bij Stichting Verpleeghuis De Bieslandhof in Delft (nu Pieter van Foreest).

Vanaf 1994 werkt zij als docent Ergotherapie aan de Hogeschool Rotterdam.
Na het afronden van haar masterstudie combineerde zij de functie van hogeschooldocent met die van onderzoeker bij projecten van het Kenniscentrum Zorginnovatie van Hogeschool Rotterdam, onder andere Academische Werkplaats Dementie en VitaDem, en bij de afdeling IQ healthcare van het Radboudumc.
Van 2008 tot 2015 was zij praktijkhouder van een vrijgevestigde ergotherapiepraktijk 'Ergotherapie voor Ouderen', te Schiedam, waar zij ongeveer een dag per week als praktiserend ergotherapeut werkte.

In 2010 startte zij dit (part-time) promotietraject m.b.v. een promotievoucher van de Hogeschool Rotterdam. De studies voor deze thesis werden uitgevoerd bij het Kenniscentrum Zorginnovatie van Hogeschool Rotterdam, in samenwerking met de afdeling Klinische, neuro- en ontwikkelingspsychologie van de Vrije Universiteit, Amsterdam.

Publications and presentations

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- Presentatie: Doing and being in the atmosphere of the doing: Environmental influences on occupational performance in a nursing home". Van't Leven N, Jonsson H. World Congress for Occupational Therapy, Stockholm, 2002.

This thesis focuses on the needs of people living with dementia and their informal caregivers for activating interventions. We studied the impact of dyadic, activating interventions for people with dementia and their caregivers. The interventions were aimed at maintaining meaningful activities and using the affected person's remaining capacities to support both people with dementia and their caregivers. Professionals such as physicians and case managers see a lot of people with dementia who may profit from these activating interventions. However, knowledge about matching dyadic, activating interventions to person-specific needs and preferences is needed. We therefore developed criteria for the assessment of activity needs that might help referring professionals estimate the appropriateness of dyadic, activating interventions, and evaluated them on recognizability and usefulness in clinical practice. Referring professionals can use these criteria to improve the assessment of activity needs of people with dementia and caregivers.
Still, greater awareness of the impact of strength-based and enabling approaches, such as dyadic, activating interventions is needed.

Dit proefschrift gaat over de behoeften van mensen met dementie en hun mantelzorgers aan activerende interventies. We onderzochten de impact van deze activerende interventies voor mensen met dementie en hun mantelzorgers als koppel. De interventies benutten de nog aanwezige capaciteiten van de persoon met dementie om hen beiden ondersteuning te bieden bij het behouden van betekenisvolle activiteiten. Professionals zoals artsen en casemanagers zien veel mensen met dementie, die gebaat kunnen zijn bij de activerende interventies. Maar er is meer kennis nodig over de aansluiting van deze interventies op de individuele behoeften en voorkeuren van de persoon met dementie en mantelzorger. Daarom ontwikkelden wij criteria om behoeften en voorkeuren gericht op betekenisvolle activiteiten te inventariseren. We toetsten deze criteria op herkenbaarheid en bruikbaarheid in de klinische praktijk. Deze criteria kunnen professionals helpen bij het verwijzen naar passende activerende interventies voor mensen met dementie en hun mantelzorgers.
Daarnaast is meer aandacht nodig voor benaderingen die uitgaan van mogelijkheden van mensen met dementie, zoals deze activerende interventies.

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