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A systematic meta-review of self-management support for people with dementia

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ABSTRACT

Self-management support for people with dementia is important to help them and their family caregivers to cope with challenges in daily live. Insight into the effects of self-management support interventions on people with dementia is however lacking, despite existing relevant systematic reviews. We therefore conducted a meta-review of relevant systematic reviews, following the PRISMA statement. Systematic literature searches were conducted in PubMed, CINAHL, the Cochrane Library, Embase and PsycINFO. The searches were done in December 2015, and all relevant references until then were taken into consideration. No conclusions about the effects of self-management support interventions on people with dementia could be drawn. Recommendations for future research and practice include that self-management support interventions and effect measurements should be wider in scope than psychological well-being.

INTRODUCTION

Living with dementia presents a huge challenge both to the person with dementia themselves and to their family caregivers. Dementia leads to severe cognitive problems, changes in mood and behavior, and changes in the relationship with the partner and members of their social network (e.g., Milano, Saturnino, & Capasso, 2013; Spalletta et al., 2010). The care is often a considerable burden on persons directly involved, not just physically but also emotionally and because it affects their social lives (e.g., Peña-Longobardo and Oliva-Moreno, 2015; Torrisi et al., 2017). Self-management is therefore important both for the person with dementia and for their family caregivers in dealing with dementia and the consequences for their daily lives. Following the definition of Barlow, Wright, Sheasby, Turner, and Hainsworth (2002), we define self-management as “the individual’s ability to manage symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition.”

However, self-management is far from being a matter of course for people with dementia. They may need support with their self-management, for example, from health care professionals or in the form of eHealth, in the sense of dementia-related information and/or support with the aid of computers or related technologies. Yet up

till now there has not been an overview of the effectiveness of the available interventions for self-management support in people with dementia, despite of existing relevant systematic reviews. We have therefore conducted a meta-review of these existing systematic reviews. However, it became clear during the analysis for the meta-review that it is too soon to draw conclusions on the effects of self-management interventions on people with dementia. Nevertheless, the metareview gives some interesting insights into the kind of interventions being used and provides recommendations for future research and practice. This brief research paper presents the results of the meta-review.

METHODS

We conducted a meta-review, in the sense of a systematic literature study of existing relevant systematic reviews. We followed the PRISMA Statement for systematic reviews (Moher, Liberati, Tetzlaff, & Altman, 2009) wherever possible, as incorporated in a protocol drawn up in advance. The reviews had to deal with self-management support in dementia, in which the effects were measured at the individual patient level. Table 1 summarizes the specific inclusion criteria.

Search strategy and sources

Systematic literature searches were conducted in PubMed, CINAHL, the Cochrane Library, Embase and PsycINFO in December 2015. First, a sensitive search strategy was developed for PubMed/Medline. This was then adapted for use in the other databases. All publications up to December 2015 were taken into consideration, regardless of the publication language.

Study selection

A two-step procedure was used to identify references for inclusion. First, the titles and abstracts of the references that resulted from the database searches were checked to see whether they satisfied the inclusion criteria. One reviewer (JGH) screened all the references. The second reviewer (ALF) then independently screened a 10% random selection. The first reviewer proceeded individually if the level of agreement (Kappa) was ≥ 0.60 . If enough information could not be obtained from the title and abstract, those references were taken to the next step of the selection process. In this second step, the full texts of the references selected in the first step (including the references with insufficient information in the title and abstract) were independently screened by the two reviewers. A third reviewer (RV) was consulted if the first and second reviewer did not agree.

Methodological assessment

After the second selection step (see before), the methodological quality of the reviews was determined with the Quality Assessment Checklist for Reviews developed by Oxman and Guyatt (1991). Reviews with a score of 2 or less were considered to be of "low quality" and were subsequently excluded.

[TABLE 1]

RESULTS

The flow chart in Figure 1 shows the number of studies assessed, excluded, and included at each stage of the selection process.

In the end, seven reviews were found that satisfied all the inclusion criteria (Cooper et al., 2012; Corbett et al., 2012; Orgeta, Qazi, Spector, & Orrell, 2015; Reilly et al., 2015; Spijker et al., 2008; Van't Leven et al., 2013; Zabalequi et al., 2014). One review was identified to have “major flaws,” based on a quality score of 3.0 (Corbett et al., 2012). Three reviews received a quality score of 4.0 (Zabalequi et al., 2014), 5.0 (Cooper et al., 2012), or 6.0 (Van't Leven et al., 2013) reflecting “minor flaws.” Three reviews received a quality score of 7.0 indicating that they met all quality requirements of the Quality Assessment Checklist for Reviews (Orgeta et al., 2015; Reilly et al., 2015; Spijker et al., 2008). Tables 2 and 3 show the key features of these seven reviews.

[FIGURE 1][TABLE 2][TABLE 3]

Description of the interventions

The term “self-management support” is rarely mentioned explicitly in the seven reviews that were included. However, if the above-mentioned definition based on Barlow et al. (2002) is applied, the selected reviews do indeed consider interventions in which self-management was a central component. Table 3 shows the elements that comprised the self-management support interventions we identified. Self-management support was often aimed at dealing with problems affecting the psychological well-being of the person with dementia. The table also shows that self-management is often combined with cognitive behavioral therapy (CBT) or coping interventions.

Professionals and a focus on managing psychological problems.

The interventions were primarily performed by psychologists, occupational therapists, and psychiatrists. Nursing staff were only explicitly mentioned as professionals providing self-management interventions in two of the seven reviews (Reilly et al., 2015; van't Leven et al., 2013). The interventions focused primarily on managing psychological problems, for example, depression or anxiety. In addition, improvement of quality of life in general and/or postponing admission to a nursing home was often an important aim of the interventions.

Effects.

The seven systematic reviews that were included show effects for a number of outcome variables in the person with dementia, for example, depression (Orgeta et al., 2015) and the time to admission to a nursing home (Reilly et al., 2015). However,

it was not possible to draw conclusions from this about the effects of self-management support on people with dementia. There are two key reasons for this. In the first place, self-management support interventions often include other components as well. A clear example of such a combined intervention can be seen in the study by Burgener, Yang, Gilbert, and Marsh-Yant (2008), included in the systematic review by Orgeta et al. (2015). Burgener et al. studied the effects of a support group in which people with dementia learned how to resolve problems in their day-to-day lives, which can be considered as a self-management intervention. However, this was combined with tai chi exercises and CBT (Burgener et al., 2008). The combination of interventions meant that the individual effects of the self-management components could not be distinguished properly.

The second reason was that four of the seven systematic reviews included studies of selfmanagement support interventions, but did not analyze them separately from studies of other kinds of interventions. The review by Cooper et al. (2012) is one such example. It included a study by Logsdon et al. (2010). Logsdon et al. researched the effects of a selfmanagement support intervention in which discussion groups of people with dementia and their family caregivers talked together about how to deal with how dementia impacts social and family relationships and about making plans for the future. In this review, the effects of this self-management support intervention were analyzed together with those of cognitive stimulation therapies that did not include any self-management support components (Chapman, Weiner, Rackley, Hynan, & Zientz, 2004; Davis, Massman, & Doody, 2001; Spector et al., 2003).

DISCUSSION

Despite the fact that the reviews we examined showed positive effects, it is not possible at this point to draw conclusions about the effectiveness of self-management support interventions on people with dementia. A main reason for this is that the self-management support interventions that were studied were often combined with other kinds of interventions such as CBT.

By excluding reviews with low methodological quality (score of 2 or less), we reduced the risk of biased conclusions. Seven of the eight reviews included received a quality score of 4 or more indicating either minor or no flaws, which is also important for providing unbiased, valid results.

However, a limitation was that the reviews did not label the interventions as “self-management support interventions.” Guided by the explicit inclusion criterion that *“interventions had to explicitly be geared to helping the person with dementia cope with the dementia and its effects on their day-to-day lives and there had to be personal contact between the person with dementia and the healthcare professional,”* we decided whether interventions concerned self-management support. This decision implied subjective judgments.

This meta-review also teaches us that existing self-management support interventions (even if they are not always explicitly denoted as such) focus almost exclusively on the psychological well-being of the person with dementia. Self-management support interventions should however be wider in scope. In addition to psychological well-being, the “relationship with relatives,” “maintaining an active lifestyle,” “techniques to cope with memory change,” and “information” are also important objectives for self-management support interventions (Martin, Turner, Wallace, & Bradbury, 2013). Future interventions should include one or more of these objectives as well in

order to provide the best possible support for self-management by people with dementia and those around them.

Accordingly, different outcome measures linked to the above-mentioned objectives should be used in future research on the effectiveness of self-management support interventions for people with dementia. Examples are outcome measures that indicate “the quality of the relationship with family caregivers,” “the number of social contacts,” or “knowledge about dementia.”

Hence, future research is needed on the effects of self-management support interventions on patients. At the moment, more information is available regarding the effects on relatives. A previous meta-review (Huis in het Veld, Verkaik, Mistiaen, van Meijel, & Francke, 2015) described effects of self-management support on informal caregivers of people with dementia, for example, an increase of well-being, stress relieve and more quality of life. However, in current health care in which patients themselves are also expected to execute selfmanagement, it is important to further investigate which kinds of self-management support interventions are effective in particularly people with dementia and which are not.

The meta-review also revealed that self-management support is often provided by psychologists, occupational therapists, and other therapists. It is striking that nurses were only mentioned in two of the seven reviews, since self-management support fits with a core competency of nurses, namely acting as an information and education resource for clients seeking to improve life styles, and who have to cope with changes in health and disability and death (ICN, 2008). Nurses are often in closer contact with the person with dementia than psychologists and occupational therapists, for example, and they accordingly see selfmanagement support as part of their job (Verkaik, van Antwerpen-Hoogenraad, de Veer, Francke, & Huis in het Veld, 2016). Nursing professionals can incorporate self-management support in the regular care that they deliver to people with dementia.

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REFERENCES

- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling*, 48, 177–187.
- Burgener, S. C., Yang, Y., Gilbert, R., & Marsh-Yant, S. (2008). The effects of a multimodal intervention on outcomes of persons with early-stage dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 23, 382–394.
- Chapman, S. B., Weiner, M. F., Rackley, A., Hynan, L. S., & Zientz, J. (2004). Effects of cognitivecommunication stimulation for Alzheimer's disease patients treated with donepezil. *Journal of Speech, Language, and Hearing Research*, 47, 1149–1163.
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., ... Livingston, G.; World Federation of Biological Psychiatry – Old Age Taskforce. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24, 856–870.
- Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., ... Ballard, C. (2012). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*, 27, 628–636. DOI: 10.1002/gps.2762.
- Davis, R. N., Massman, P. J., & Doody, R. S. (2001). Cognitive intervention in Alzheimer disease: A randomized placebo-controlled study. *Alzheimer Disease and Associated Disorders*, 15, 1–9.
- Huis in het Veld, J. G., Verkaik, R., Mistiaen, P., van Meijel, B., & Francke, A. L. (2015). The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia: A systematic meta review. *BMC Geriatrics*, 15, 147. doi:10.1186/s12877-015-0145-6 International Council of Nurses (ICN). (2008). Nursing care continuum framework and competencies. ICN Regulation Series. Geneva, Switzerland: ICN.
- Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 65, 691–697.
- Martin, F., Turner, A., Wallace, L. M., & Bradbury, N. (2013). Conceptualisation of self-management intervention for people with early stage dementia. *European Journal of Ageing*, 10, 75–87.
- Milano, W., Saturnino, C., & Capasso, A. (2013). Behavioural and psychological symptoms of dementia: An overview. *Current Neurobiology*, 4, 31–34.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6, e1000097. <https://doi.org/10.1371/journal.pmed.1000097>.
- Orgeta, V., Qazi, A., Spector, A., & Orrell, M. (2015). Psychological treatments for depression and anxiety in dementia and mild cognitive impairment: Systematic review and meta-analysis. *British Journal of Psychiatry*, 207, 293–298. DOI: 10.1192/bjp.bp.114.148130.
- Oxman, A. D., & Guyatt, G. H. (1991). Validation of an index of the quality of review articles. *Journal of Clinical Epidemiology*, 44, 1271–1278.
- Pen~a-Longobardo, L. M., & Oliva-Moreno, J. (2015). Caregiver burden in Alzheimer's disease patients in Spain. *Journal of Alzheimer's Disease*, 43, 1293–1302.
- Reilly, S., Miranda-Castillo, C., Malouf, R., Hoe, J., Toot, S., Challis, D., & Orrell, M. (2015). Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews*, 5, 1CD008345. DOI: 10.1002/14651858.CD008345.pub2.
- Spalletta, G., Musicco, M., Padovani, A., Rozzini, L., Perri, R., Fadda, L., ... Palmer, K. (2010). Neuropsychiatric symptoms and syndromes in a large cohort of newly diagnosed, untreated patients with Alzheimer disease. *American Journal of Geriatric Psychiatry*, 18, 1026–1035.

- Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *British Journal of Psychiatry*, 183, 248–254.
- Spijker, A., Vernooij-Dassen, M., Vasse, E., Adang, E., Wollersheim, H., Grol, R., & Verhey, F. (2008). Effectiveness of nonpharmacological interventions in delaying the institutionalization of patients with dementia: A meta-analysis. *Journal of American Geriatric Society*, 56, 1116–1128. DOI: 10.1111/j.1532-5415.2008.01705.x.
- Torrisi, M., De Cola, M. C., Marra, A., De Luca, R., Bramanti, P., & Calabro, R. S. (2017). Neuropsychiatric symptoms in dementia may predict caregiver burden: A Sicilian exploratory study. *Psychogeriatrics*, 17, 103–107.
- Van't Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review. *International Psychogeriatrics*, 25, 1581–1603. DOI: 10.1017/S10416 10213000860.
- Verkaik, R., van Antwerpen-Hoogenraad, P., de Veer, A., Francke, A., & Huis in het Veld, J. (2016). Self-management-support in dementia care: A mixed methods study among nursing staff. *Dementia (London)*, 16, 1032–1044. DOI:10.1177/1471301216632416.
- Zabalegui, A., Hamers, J. P., Karlsson, S., Leino-Kilpi, H., Renom-Guiteras, A., Saks, K., . . . Cabrera, E. (2014). Best practices interventions to improve quality of care of people with dementia living at home. *Patient Education Counseling*, 95, 175–184. DOI: 10.1016/j.pec.2014.01.009.

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TABLES AND FIGURES

Table 1. Inclusion criteria for the meta-review.

Eligibility criteria

Types of study. Systematic reviews that met the following criteria: (a) the review included a description of search terms, (b) searches were conducted in Medline or PubMed and at least one other international scientific database, and (c) the review included effect studies (RCT, CCT, or quasi experimental designs).

Types of participant. People with dementia, or dyads of primary caregivers and people with dementia, living in the community.

Types of intervention. The systematic reviews had to focus on professional self-management support interventions. These interventions had to explicitly be geared to helping the person with dementia cope with the dementia and its effects on their day-to-day lives. Additionally, there had to be personal contact between the person with dementia and the health care professional. The review had to describe and analyze the effects of self-management support interventions, and to draw an overall conclusion about the interventions' effectiveness. Cognitive training was not deemed a self-management support intervention.

Types of outcome measure. Only systematic reviews discussing effects on persons with dementia were included.

Figure 1. Flow chart of the study selection.

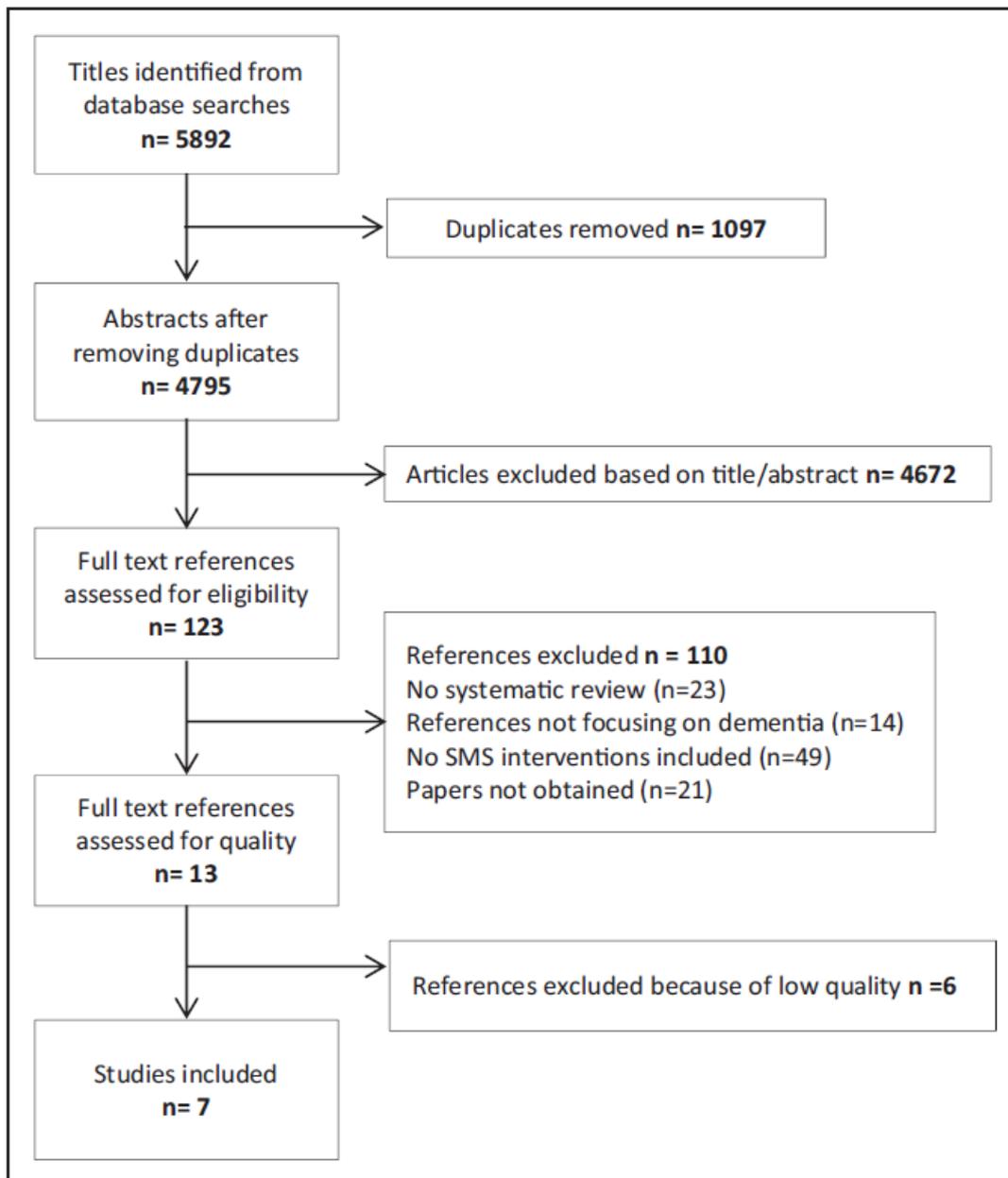


Table 2. General and methodological characteristics of the reviews that were included.

The reviews that were included					Underlying studies in the reviews			
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Cooper et al. (2012) United Kingdom	Systematic review	Give insight into the effectiveness of nonpharmacological interventions on quality of life or well-being of people with dementia.	<p>Inclusion:</p> <ul style="list-style-type: none"> Primary research in people with dementia Evaluating nonpharmacological interventions in randomized controlled trials (RCTs) Which included quality of life or well-being as a quantitative outcome <p>Exclusion:</p> <ul style="list-style-type: none"> Studies not in English Single-case reports, dissertations, meeting abstracts, and studies that only used quality-of-life measure subscales, if reviewers judged that these did not measure overall quality of life 	PubMed, Web of Science, and Cochrane systematic reviews database. Additional searches: searches of included papers and relevant systematic reviews. Asked experts in the field for papers meeting inclusion criteria. Search period: to January 2011.	5	20 studies included (20 RCTs). 3 studies included with self-management interventions including PwD (3 RCTs). Control conditions: usual care; waiting-list controls.	Dyads of persons with dementia and their informal caregivers.	Intervention duration ranged from 5 to 9 weeks. Number of intervention sessions/modules ranged from 6 to 10. Professionals: occupational therapists; volunteer facilitators.
Corbett et al. (2012) United Kingdom	Systematic review with meta-analysis	To determine whether Dementia Adviser services confer significant benefit with respect to quality of life and neuropsychiatric symptoms in people with dementia and level of burden experienced by their carers.	<p>Eligibility criteria:</p> <p>Only randomized controlled trials (RCT) were included in the review. Included studies were those focusing on a service intervention with information provision as a key service component and provided standardized outcome assessments for either people with dementia and their caregivers.</p>	Cochrane, Embase, Medline, and PsycInfo. Search period: Up to November 2009.	3	13 studies included (13 RCTs). 7 studies included with self-management interventions including PwD (7 RCTs)	Persons with dementia or their caregivers.	Reported intervention duration varied between 6 months and 3 years. Reported duration of sessions varied from 30 to 90 minutes. Professionals: not reported.
Orgeta et al. (2015) United Kingdom	Systematic review	To assess the effectiveness of psychological interventions in reducing anxiety and depression in people with dementia or mild cognitive impairment.	<p>Inclusion criteria:</p> <p>Type of study:</p> <ul style="list-style-type: none"> randomized controlled trials including cluster randomized trials including a control group information about study design, results, and number of participants separate data on participants with dementia and MCI <p>Participants:</p> <ul style="list-style-type: none"> diagnosed with dementia or MCI; any settings. <p>Type of intervention:</p>	The Cochrane Dementia and Cognitive Improvement Group (CDCIG) Specialized Register (including MEDLINE, EMBASE, CINAHL, PsychINFO, LILACS). Additional searches: reference lists of identified publications and all review papers. Contacted the corresponding authors of identified trials for	7	6 studies included (6 RCTs). 5 studies included with self-management interventions including PwD (5 RCTs). Control conditions: usual care; attention-control educational program.	Persons with dementia.	Intervention duration ranged from 6 weeks to 12 months. Intensity varied between 30-minute telephone calls, 60-minute therapeutic sessions, and 90-minute group conversations or a combination of these provided weekly or biweekly. Professionals: social workers, psychotherapists, psychologists, master graduate students

(continued)

Table 2. Continued

The reviews that were included				Underlying studies in the reviews				
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
			<ul style="list-style-type: none"> to reduce anxiety and depression or improve adaptive functioning or both based on psychological theory, structured interaction between facilitator and participant. Exclusion of treatments involving medication, exercise, reminiscence therapy, music therapy, art and drama therapy, befriending, or bibliotherapy <p>Type of outcome:</p> <ul style="list-style-type: none"> outcome measure of depression or anxiety 	<p>additional references and unpublished data.</p> <p>Search period: to February 2013.</p>				
Reilly et al. (2015) United Kingdom	Systematic review with meta-analysis	To evaluate the effectiveness of case management approaches in home support for people with dementia from the perspective of the different people involved (patients, carers, and staff).	<p>Inclusion criteria:</p> <p>Types of studies: randomized controlled trials (RCTs) and economic evaluations conducted alongside the RCTs. RCTs were sufficient in number and had enough participants to allow meta-analysis.</p> <p>Types of participants:</p> <p>People with dementia of any type who live in the community and their carers. Studies that focused exclusively on carers were excluded.</p> <p>Types of interventions: Any case management intervention delivered in the community that predominantly focused on the planning and co-ordination of care required to meet the identified needs of the person with dementia. This may or may not have been part of multi-component interventions.</p>	<p>ALOIS, Specialized Register of the Cochrane Dementia and Cognitive Improvement Group, The Cochrane Library, MEDLINE, EMBASE, PsycINFO, CINAHL, LILACS, Web of Science (including Science Citation Index Expanded (SCI-EXPANDED) and Social Science Citation Index), Campbell Collaboration/SORO database and the Specialized Register of the Cochrane Effective Practice and Organization of Care Group.</p> <p>Search period: up to 31 December 2013.</p>	7	<p>13 studies included (13 RCTs).13 studies included with self-management interventions including PwD (13 RCTs).Control conditions: Waiting list control; usual care; augmented usual care.</p>	<p>Persons with dementia.</p>	<p>Duration of the intervention ranged from 4 months to 2 years.</p> <p>Frequency of contacts with case managers ranged from one contact per month to two or more contacts per month.</p> <p>Professionals: registered nurses, district nurses, advanced practice nurses, social workers, occupational therapists and social workers, a psychiatrist, health care advisors without a professional qualification.</p>
Spijker et al. (2008) The Netherlands	Systematic review with meta-analysis	To estimate the overall effectiveness of nonpharmacological support programs for caregivers and patients	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> A study population of patients with dementia and their informal caregivers 	<p>PubMed (including Medline), Web of Knowledge, and PsycInfo.</p> <p>Additional searches: searches of included papers</p>	7	<p>13 studies included (10 RCTs, 2 pretest/post-test, 1 quasi-experimental design). 13 studies included with self-</p>	<p>Dyads of persons with dementia and their informal caregivers.</p>	<p>Intervention duration ranged from 3 months to 8.5 years.</p> <p>Professionals: counselors, case managers, unknown.</p>

(continued)

Table 2. Continued

The reviews that were included					Underlying studies in the reviews			
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
		with dementia that are intended to delay institutionalization.	<ul style="list-style-type: none"> Community-dwelling patients with dementia and informal caregivers An outcome measure of institutionalization A single-study design (not a review or a meta-analysis) A controlled clinical study A nonpharmacological study A study written in English 	Search period: from 1990 to March 2006.		management interventions including PwD (10 RCTs, 2 pretest/post-test, 1 quasi-experimental design). Control conditions: memory training for persons with dementia, respite care for caregivers; psychogeriatric day care; usual care; informal support upon request.		
Van't Leven et al. (2013) The Netherlands	Systematic review	To 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 of the programs.	<p>Inclusion criteria:</p> <p>Types of studies:</p> <ul style="list-style-type: none"> Randomized controlled trials <p>Types of participants:</p> <ul style="list-style-type: none"> People with dementia (≥ 65 years) and their informal caregivers living in the community <p>Types of interventions:</p> <ul style="list-style-type: none"> Dyadic psychosocial interventions Combined interventions Involving face-to-face contact between a care professional, the person with dementia and the caregiver Targeting improvement of mental health or well-being <p>Exclusion criteria:</p> <ul style="list-style-type: none"> The reviewers 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 	PsychInfo, Embase, Medline, Cinahl, Cochrane Library for systematic reviews. Additional searches: reference lists of identified systematic reviews. Search period: 1991 to January 2012.	6	23 studies included (23 RCTs). 16 studies included with self-management interventions including PwD (16 RCTs).	Dyads of persons with dementia and their informal caregivers.	Intervention duration ranged from 5 weeks to 3 years. Duration of sessions varied from 30 minutes to 2 hours. Number of sessions varied from 5 to 75. Professionals: occupational therapists; multi-disciplinary teams; nurses; case managers; home care advisors; psychiatrists; primary care physicians; nurse practitioners; psychologists.

(continued)

Table 2. Continued

The reviews that were included					Underlying studies in the reviews			
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Zabalegui et al. (2014) Spain	Systematic review	To identify effective interventions which improve quality of care for people with dementia living at home.	<ul style="list-style-type: none"> Excluded: pooled data from combination of intervention studies Inclusion criteria: <ul style="list-style-type: none"> Randomized controlled trial design Articles in English published between 1990 and 2012 in peer review journals Interventions that addressed people with dementia living at home and their caregivers PwD in the trial were older than 65 years. Exclusion criteria: <ul style="list-style-type: none"> Articles that focused only on pharmacological treatment of dementia 	MEDLINE (PubMed), CINAHL, PsycINFO, and ISI Web of Science. Search period: 1990 to 2012	4	23 studies included (23 RCTs). 17 studies included with self-management interventions including PwD (17 RCTs)	Persons with dementia.	Intervention duration varied from 3 weeks to 2 years. Duration of sessions varied from 30 minutes to 3 hours. Number of sessions varied from 2 to 10. Professionals: not reported.

PwD: person(s) with dementia; RCTs: randomized controlled trials; MCI: mild cognitive impairment.

Table 3. Outcome and effects of the reviews that were included.

Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Cooper et al. (2012) United Kingdom	Interventions for dyads of people with dementia living in the community. <ul style="list-style-type: none"> • Combined interventions: programs containing activity and coping interventions • Discussion groups 	<ul style="list-style-type: none"> • QoL 	<p>Combined interventions: In the two high-quality studies, quality of life was higher in the groups receiving the combined activity and coping intervention than in the comparison groups</p> <p>Discussion groups: In the lower-quality study, there was conflicting evidence about whether a discussion-based group program for people with dementia and their family carers improved quality of life. There were no significant differences on the SF-36 or on the patient-rated quality of life scores between groups post-intervention.</p>	No effects for participant and intervention characteristics were reported.	No specific conclusions were drawn in relation to the interventions in which self-management was supported.
Corbett et al. (2012) United Kingdom	Interventions for people with dementia or care givers of people with dementia living in the community Combined intervention programs containing, e.g.: <ul style="list-style-type: none"> • Education on communications skills • Caregiver coping skills • Exercises and video for patient • Caregiver handbook • Education on behavior management • Maintaining residual functional abilities 	<ul style="list-style-type: none"> • QoL • Neuropsychiatric symptoms • Caregiver burden 	The results cannot be related to the 7 self-management interventions including PwD.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which the PwD was included can be drawn.

(continued)

Table 3. Continued

Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Orgeta et al. (2015) United Kingdom	<p>Interventions for people with dementia living in the community:</p> <ul style="list-style-type: none"> • Combined interventions: programs containing, e.g., CBT, information, activity and coping interventions, and telephone support • Psychotherapy 	<ul style="list-style-type: none"> • Depression • Anxiety • QoL • ADL • Neuropsychiatric symptoms • Cognition 	<ul style="list-style-type: none"> • Depression: improvement (remark: also a nonself-management study was included). • Anxiety: clinician-rated anxiety = improvement; self-rated anxiety = no effect. • Patient self-rated QoL = no effect. • Carer rated QoL = no effect. • ADL = no effect. • Neuropsychiatric symptoms = no effect. • Cognition = no effect. • Other: behavioral problems: not reported. 	<p>No effects for participant and intervention characteristics were reported based on an analysis. The review did not identify any trials of psychological treatment aimed at people with MCI that met the inclusion criteria.</p>	<p>Self-management interventions delivered in the form of psychological treatments reduce depressive symptoms in people with dementia. No effects were found on any of the secondary outcomes, activities of daily living, self-rated and carer-rated patient quality of life (QoL), neuropsychiatric symptoms, cognition.</p>
Reilly et al. (2015) United Kingdom	<p>Interventions for people with dementia living in the community.</p> <p>Combined intervention programs (case management) containing, e.g.:</p> <ul style="list-style-type: none"> • Participant information and education • Participant advocacy • Medications review • Financial assistance • Emotional support • Counseling • Carer education 	<p>Primary:</p> <ul style="list-style-type: none"> • Time to institutionalization • Number of institutionalizations • Number of hospital admissions • Mean number of days in nursing home / hospital • Number of deaths • Costs <p>Secondary:</p> <p>Behavioral measures:</p> <ul style="list-style-type: none"> • Depression • QoL • ADL • Neuropsychiatric symptoms • Cognition 	<ul style="list-style-type: none"> • Number of institutionalizations: improvements at follow-up at 6 and 12 months. • Short nursing-home stays / hospital admissions: improvements at follow-up at 6 and 12 months. • Costs: improvements at follow-up at 12 months. • Use of services: increased use of services. • Neuropsychiatric symptoms: improvements at follow-up at 18 months. 	<p>No effects for participant and intervention characteristics were reported based on an analysis.</p>	<p>There is some evidence that self-management support delivered in the form of case management is beneficial in improving some outcomes at certain time points, in the person with dementia.</p> <p>There was some evidence from good-quality studies to suggest that admissions to care homes and overall health care costs are reduced in the medium term; however, the results at follow-up after longer intervals were uncertain. There was not enough evidence to clearly assess whether case management could delay institutionalization in care homes. There were uncertain results in patient depression, functional abilities and cognition.</p>

(continued)

Table 3. Continued

Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Spijker et al. (2008) The Netherlands	Interventions for dyads of people with dementia living in the community. Combined intervention programs containing, e.g.: <ul style="list-style-type: none"> • Psychoeducation • CBT • Respite care • Environmental modifications • Skills training/problem solving • Case management • Memory training 	<ul style="list-style-type: none"> • The odds of institutionalization • Time to institutionalization 	<ul style="list-style-type: none"> • Patients involved in experimental interventions were significantly less likely to be institutionalized than patients in control groups • The mean change in mean time to institutionalization from baseline to follow-up was significantly greater in patients involved in the experimental interventions than in the control groups 	Effective support programs include counseling and personal assistance with problem solving, and they offer caregivers a choice of various support strategies and support services. The caregiver and the patient with dementia are actively involved in seeking solutions together and can try out and choose the support strategies or services that are best tailored to their individual needs.	Support programs can significantly decrease the odds of institutionalization and significantly increase the time to institutionalization.
van't Leven (2013) The Netherlands	Interventions for dyads of people with dementia living in the community. Combined intervention programs containing, e.g.: <p>PwD:</p> <ul style="list-style-type: none"> • Information • ADL training • Walking or exercise • Environmental adaptations <p>CG:</p> <ul style="list-style-type: none"> • Information • Psycho-education • Skills training • Coping strategies 	<ul style="list-style-type: none"> • Behavioral problems • Cognitive functioning • Mood • Independence in daily activities • Sleep • QoL 	The results cannot be related to the 16 self-management interventions.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which self-management was supported can be drawn.

(continued)

Table 3. Continued

Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Zabalegui et al. (2014) Spain	Interventions for people with dementia or dyads of people with dementia living in the community. Combined intervention programs containing, e.g.: <ul style="list-style-type: none">• Cognitive rehabilitation• Physiotherapy• Education• Individual support• Counseling• Training• Neurologist advice• Support group• Occupational therapy• CBT• Respite care• Psychoeducational interventions	<ul style="list-style-type: none">• QoL	The results cannot be related to the 17 self-management interventions including PwD.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which the PwD was included can be drawn.

PwD: person(s) with dementia; RCTs: randomized controlled trials; MCI: mild cognitive impairment; QoL: quality of life; ADL: activities of daily living.