



## Review article

# A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise?



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## ABSTRACT

**Objective:** Social support interventions for caregivers of persons with dementia (PwD) are important because informal carers often rely on their social networks for support. This systematic review synthesises findings from research on social support interventions, and examines their methodological quality and effectiveness on caregiver social support and well-being variables.

**Methods:** A systematic literature search utilised five databases. Papers were selected when the primary aim of the intervention was to improve social support. Quality of papers was assessed by the Level of Evidence grade and the criteria list from the Cochrane Back Review Group.

**Results:** 39 papers were identified and classified into 4 social support intervention categories: befriending and peer support, family support and social network interventions, support groups, and remote interventions using the internet or telephone. Content, intensity, uptake, effectiveness and quality of interventions varied widely. In general, the level of evidence was low. Most studies measured effect on well-being variables, while few examined social support outcomes. Multi-component social support interventions were most effective. Evidence suggested, also a caregiver benefit from remote interventions. Generally, results were inconsistent; some papers demonstrated beneficial results, while others demonstrated no improvement on social support and well-being variables. Social support outcomes were more positively evaluated when qualitative outcome measures rather than quantitative measures were used.

**Conclusions:** Although multi-component social support interventions may improve caregiver well-being, there is insufficient evidence to conclude whether a change in social support is the underlying mediating factor. The inclusion, validation and operationalization of caregiver social support measures deserve more attention.

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## 1. Introduction

The on-going developments in dementia care towards early diagnosis [1], rising public health care costs, longer care in the community, and high caregiver burden underscore the importance of investing in programmes to support informal carers of people with dementia (PwD)<sup>1</sup> [2]. Social support interventions are of particular interest because informal caregivers are increasingly asked to draw on their social networks for assistance and support, due to pressure from authorities and other third parties [3]. Evidence suggests social support reduces psychological and non-psychological burden [4], protects against new dementia incidences [5], social isolation and loneliness, and promotes social integration [6,7].

There is a great variety in social support definitions. Some of these emphasize structural (e.g. network size) or functional aspects (type of support—emotional, informational and instrumental), while others use enacted support (support provision) or subjective support experiences of the recipient [8]. Conceptualization of social support is more complicated because it can be initiated by the natural existing social networks, but also by the formal support system. For example, the theory of Cohen et al. [9] defined social support as “the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships” (p. 4).

Previous reviews on psychosocial interventions demonstrated mixed results due to the multi-component nature of the interventions and the variety of outcome measures. Effective studies were often multi-component, showing small to moderate beneficial effects on caregivers’ burden, mood, self-efficacy, quality of life, and subjective well-being [10–13]. Several reviews had a distinct focus on specific treatment modalities, such as support groups [14], befriending schemes [15], or more recently on remote internet- and technological support [16–19]. Moreover, comparability of studies is often problematic due to large variety of treatment aims.

The present review updates, integrates, and adds to the existing knowledge base by applying a specific focus on interventions that explicitly aim to improve social support. Given the variety of social support concepts, the selection of papers was guided by the above-mentioned theory of Cohen [9]. This broad theory is in line with the focus of our review on social support in both formal and informal settings. Furthermore, by using Cohen’s definition we narrowed down the heterogeneous spectrum of psychosocial interventions by selecting solely the interventions including a key component aiming to enhance social support or recruitment of social network members. Considering the variety of existing social support inter-

ventions strategies (e.g. individual vs. group, informal vs. formal, face-to-face vs. remote) we categorized the different interventions into 4 intervention types to create more homogenous groups: peer support and befriending, family support and social network interventions, support groups and remote support interventions. In sum, this systematic review examines the following research questions: (1) How effective are social support interventions on caregiver measures of social support and well-being? (2) What is the methodological quality of the papers included in the present review? (3) How well are the process characteristics of the interventions described? (4) How does the methodological quality of the papers relate to intervention effectiveness across the intervention categories?

## 2. Methods

### 2.1. Search strategy

The following databases were searched for papers written in English between January 1988 and May 2015: PubMed, PsycINFO, CINAHL, Web of Science and the Cochrane Library. We combined free text words with Medical Subject Headings (MESH) and Thesaurus terms, including (dementia or Alzheimer\*) and (social support\* or family meeting\* or mutual sharing or social media or support group\*) and (informal caregiv\*) and (treatment\* or intervention\* or therapy\*). Furthermore, we cross-referenced included papers, relevant reviews, and meta-analyses.

### 2.2. Selection of articles

The following selection criteria were used: (1) Intervention studies targeted informal caregivers of community-dwelling PwD. There were no limits on dementia type or caregiver relationship, but studies using mixed samples containing caregivers of non-demented persons were excluded. (2) Studies had to report on caregiver outcomes, i.e. studies only reporting outcome measures related to the PwD or to intervention cost-effectiveness were not included. (3) Papers had to explicitly specify that the intervention aimed to enhance social support. (4) As we used Cohen et al.’s definition of social support [9], interventions could be facilitated by peers and/or by professionals. (5) There were no set limits for methodological design, thus RCTs,<sup>2</sup> as well as pilot and qualitative studies were included. (6) In case research groups had published several papers using the same caregiver cohort, we selected articles based on their outcome measures and/or content being the most elaborate.

<sup>1</sup> People with dementia.

<sup>2</sup> Randomised controlled trials.

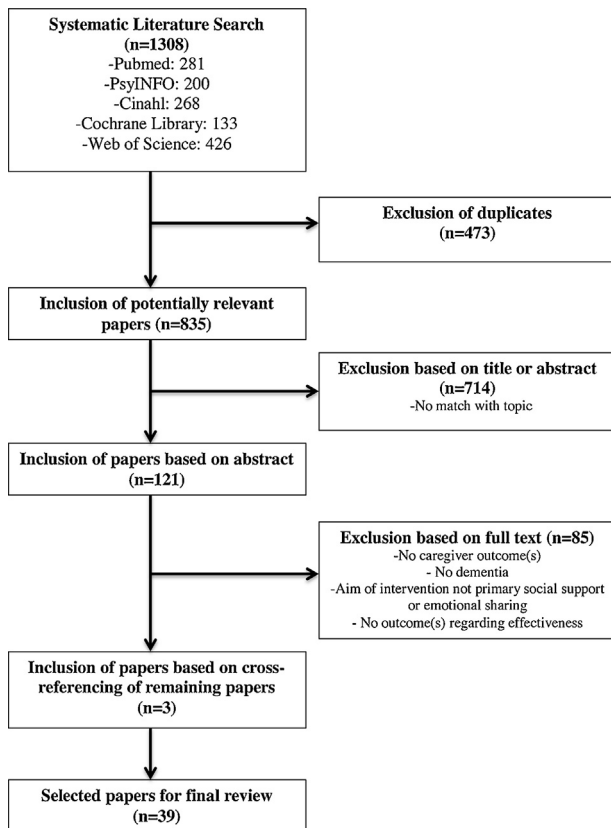


Fig. 1. Flowchart of search strategy.

We applied a consensus procedure of 2 reviewers assessing titles and abstracts (MvB and AD). When the selection of these papers remained inconclusive, full copies of the papers were screened. Any disagreement was resolved in consensus meetings with a third reviewer (MdV). Subsequently, two reviewers conducted all quality assessments (AD, IK). Debatable results were discussed in meetings with a third reviewer (MdV). Papers and key reviews were cross-referenced by AD for other relevant sources (Fig. 1).

### 2.3. Quality assessment

Study characteristics were described using standardised data extraction forms (Appendix A) of the Cochrane Collaboration [20]. To categorise the study designs for level of bias control, we used the Level of Evidence (LOE)<sup>3</sup> grade from the Oxford Centre for Evidence Based Medicine guidelines [21]. The LOE hierarchy yields a score between 1 (systematic review of RCTs) and 5 (expert opinion) by looking at the presence vs. absence of a randomisation procedure, prospective vs. retrospective follow-up and research study vs. expert opinion.

Papers were evaluated for methodological quality using the Cochrane Back Review Group criteria list [22], which applies weights for descriptive, statistical, and internal validity. Because blinding of the therapist is impossible, we instead assessed blinding of the outcome assessor to group assignment. The scores on the Cochrane criteria list (i.e., fulfilled, not fulfilled, or undefined) were summed into a total validity score ranging from 0 to 9. Papers were classified as being of high methodological quality if at least 4 items were scored positively [23] (Appendix B1–4). Finally, we evaluated whether papers provided information on intervention

Table 1  
Scoring overview of methodological quality.

Cochrane back review group criteria	n	(%)
<i>Descriptive items</i>		
Eligibility criteria clearly specified	29	74
Index and control interventions clearly specified	31	79
Description of adverse effects	8	21
Short-term follow-up (measured after intervention)	36	92
Long-term follow-up (measured $\geq 6$ M after intervention)	7	18
<i>Statistical items</i>		
Description of sample size	33	85
Point estimates and measures of variability presented	34	87
<i>Validity items</i>		
Randomization performed	28	72
Was treatment allocation concealed	4	10
Groups similar at baseline (age, sex, outcome)	18	46
Were co-interventions avoided or comparable	7	18
Was compliance acceptable in all groups <sup>a</sup>	9	23
Was the outcome assessor blinded to the intervention?	8	21
Withdrawal/drop-out rate acceptable	22	56
Timing of the outcome assessment in both groups comparable	28	72
Did the analysis an intention-to-treat analysis	13	33

n = the total number of papers that fulfilled a specific Cochrane criteria. For a detailed overview per paper (n = 39) refer to Appendix B in Supplementary information, Table 1–4.

<sup>a</sup> Compliance judgements were often subjective because the required treatment-dose was not always stated in advance.

process characteristics (Supplementary information Appendix B1–4). Scores ranged between 0 and 7 (i.e., reported, or not reported) [24].

## 3. Results

### 3.1. Study characteristics

Thirty-nine papers were selected (Fig. 1). The heterogeneity of intervention strategies and treatment outcomes prohibited pooling of the data in a meta-analysis [25]. Instead, we identified 4 conceptual intervention categories (Appendix A). All of these studies focused on multiple caregiver outcomes, including depression, burden, coping, distress, and self-efficacy. Overall, 22 studies included social support measures such as received support, perceived support and/or social network variables.

### 3.2. Validity and methodology

Papers were scored with an LOE grade of 2 for RCTs (n = 21), 3 for studies with pre-test–post-test or quasi-experimental designs, or 4 for experiments with a historical follow-up (Appendix A, Table 1).

The Cochrane ratings are depicted in Appendix B in Supplementary information (Tables 1–4). Twenty-one out of 39 papers were of sufficient methodological quality (46%; i.e., validity score  $\geq 4$ ). Negative scores were often caused by the absence of a randomisation procedure, control group, or long-term follow-up measurements. Furthermore, concealment of treatment allocation, blinding of outcome assessors, intention-to-treat analysis, adverse effects, and sample size at follow-up time-points were often not clearly specified (Table 1).

### 3.3. Process characteristics

The summated process characteristics scores are presented in Table 2. Individual scores are shown in Appendix B.

<sup>3</sup> Level of Evidence.

**Table 2**  
Scoring overview of process characteristics.

Process characteristics of the intervention	<i>n</i>	(%)
Characteristics of the facilitator <sup>a</sup>	30	77
Compliance of participants to the intervention	18	46
Drop-out during intervention	34	87
Reasons for drop-out during intervention	20	51
Performance of intervention according to protocol	15	38
Feasibility of the intervention	20	51
Recommendations for improving the intervention <sup>b</sup>	18	46

*n* = the total number of papers that reported on a specific process characteristic. For a detailed overview per paper (*n* = 39) refer to Appendix B in Supplementary information, Table 1–4 (continued).

<sup>a</sup> Degree of education or training.

<sup>b</sup> i.e., Adaption of intensity, use of peer-leader (the majority of studies provided suggestions for methodological improvements, but not always specific recommendations for improving the intervention itself).

### 3.4. Outcomes

In all intervention categories we first report social support outcomes followed by well-being measures.

#### 3.4.1. Befriending and peer support interventions

This intervention category (Appendix A) covered one-to-one peer support by former dementia caregivers or trained volunteer befrienders and contains 3 RCTs and 1 qualitative study. Qualitative social support outcomes demonstrated reduced feelings of social isolation, increased emotional support, and mutual sharing and enjoyment after receiving peer support [26]. Both carers and volunteers gained support and new insights, such as the realisation not to be alone in the caregiving role [26]. In contrast, quantitative social support outcomes showed no improvements on perceived support and loneliness [27].

There were no significant treatment effects on caregiver well-being indicators measuring self-esteem [28], quality of life [27,29], or depressive symptoms [27,28]. However, Pillemer et al. [28] demonstrated a conditional effect, indicating that carers confronted with disruptive behaviour were less prone to depression after the intervention.

#### 3.4.2. Family support and social network interventions

This category included 7 RCTs and 1 pilot study (Appendix A). Firstly, single-component interventions are described, followed by multi-component interventions. A single-component intervention aimed at mobilising caregiver help improved social network variables, such as assistance from the informal social network and satisfaction with social support after nine months [30]. Additionally, several other papers reported multi-component spousal caregiver interventions, offering two individual and four family counselling sessions, adjacent spouse caregiver support groups, and continuous ad-hoc counselling. These intervention demonstrated positive treatment effects on network indicators of social support and increased support satisfaction [31] over a 5-year period [32]. Improvements in support satisfaction were explained by several mediators: having closer network members, seeing family and friends more frequently, and receiving more emotional support [32]. Noteworthy, support satisfaction served as a mediator, explaining the beneficial treatment effects on depression and caregiver appraisal [31].

Results on caregiver well-being were inconsistent. Family meetings neither prevented caregiver depression or anxiety incidences and symptoms [33], nor improved caregiver burden or quality of life [34]. In contrast, multi-component interventions showed short- and long-term beneficial effects on depressive symptoms over a 5-year period [35], appraisal to problem behaviours over a 4-year

period [36], and spousal caregiver physical health over a 3-year period [37].

#### 3.4.3. Support group interventions

This category contained 7 RCTs, 2 quasi-experiments, 2 (pre-) post-test designs, and 1 qualitative study (Appendix A). Firstly, social support outcomes for support groups including the caregiver dyad (i.e. PwD and caregiver) are described, followed by support groups with only caregivers. Regarding support groups with caregiver dyads, beneficial effects were found on qualitative social support measures for social inclusion and isolation [38], but not on quantitative measures for experienced support or loneliness [39]. Similarly, qualitative interview data on support groups for only caregivers demonstrated a sense of relief through sharing problems and new social contacts [40]. However, quantitative findings regarding network variables (e.g. size, frequency of visits) [41,42] and support satisfaction [41–44] showed no significant improvements.

Quantitative indicators of well-being were inconsistent. Support groups including caregiver dyads showed a decrease in psychological and psychosomatic complaints, especially in caregivers experiencing high baseline loneliness [39], improved caregiver social and emotional well-being [38], perceived effectiveness of managing care tasks, preparation activities, care needs [45] and burden, but demonstrated no change in coping and caregiver competence [39]. Additionally, groups with only caregivers demonstrated positive quantitative results for quality of life [41,46,47], depression [48], strain [49], distress [46,47] and burden [41]. However, burden [48] and anxiety [43,44] did not always improve. Qualitative measures on well-being reported improvements on subjective satisfaction [45,46], and reduced feelings of discomfort and embarrassment [46].

#### 3.4.4. Remote interventions

This category contained 11 RCTs, 1 quasi-experiment, and 3 pre-post-test studies on blended remote interventions (Appendix A), allowing social support by online networks [50,51], chat forums [52,53], video-phone [52,54,55], or telephone [56–62], described respectively below.

Considering social support outcomes, internet interventions showed no quantitative improvement on social isolation [51]. However, qualitative findings showed that internet interventions allowed for sharing and companionship [51], and improved social isolation and relationship quality with the PwD [53]. Quantitative results of videoconferencing interventions found enhanced satisfaction with support, whereas received social support or negative support interactions did not improve [54].

For telephone support interventions, no significant quantitative effects were found on received support, number of negative interactions, support satisfaction [56] or on support domain scores (number of supportive persons and social isolation) [63].

Regarding well-being outcomes, internet interventions showed no effect on caregiver depression or anxiety [53]. Although caregiver decision-making confidence improved, decision making-skill did not [51]. Reductions in relationship strain, emotional strain, and activity restrictions were conditional, depending on whether the caregiver was a spouse, experienced high level of informal support, or lived together with the PwD [50].

Videoconferencing interventions, showed beneficial quantitative results on well-being indicators of mental health, self-efficacy [52], reduced burden [54], distress [52] and depression [55]. Well-being findings for telephone interventions were mixed. Quality of life [56], burden [57,62,63], caregiver symptomatology [62] and depressive symptoms [56,57,59,62,63] improved. However, there were exceptions for distress [60,61] and burden [59–61]. Effects on depression were conditional, i.e. larger in case of high baseline

depression level [57,64], older age [59] or depending on ethnicity [55]. Similarly, larger improvements in burden and stress were found in case of high baseline stress and/or burden [64].

#### 4. Discussion

This review synthesized findings of social support interventions for dementia caregivers, and examined their level of evidence and effectiveness on quantitative and qualitative social support and well-being outcomes. We identified 39 papers covering 4 intervention categories (Appendix A). A wide variation in content, duration, uptake and effectiveness of the interventions was demonstrated. Remarkably, 44% of the intervention studies aiming to improve social support actually did not include formal measures of social support. Heterogeneity of outcome measures prevented pooling the data into a meta-analysis. Instead, we strengthened the comparability and reliability of our results by using standardised data extraction forms of the Cochrane Collaboration [20] and developing distinct intervention categories. Due to the multi-modality of interventions there inevitably is some overlap in these categories.

##### 4.1. Social support findings and methodological limitations

Studies with a lower level of evidence demonstrated more positive results on social support variables. Compared to quantitative studies, all qualitative studies found beneficial results on social support outcomes [19,26,38,40]. There is insufficient evidence to draw strong conclusions about which type of intervention works best in improving particular social support outcome(s). Concurrent with earlier research [15] befriending and peer support interventions showed improvements on qualitative measures of social isolation and emotional support [26], whereas no quantitative benefits were identified. Similarly, support groups did not quantitatively improve support satisfaction or objective network characteristics, whereas qualitative improvements on social inclusion and new social contacts were demonstrated [38,40]. In contrast, family interventions found broader beneficial effects on both quantitatively measured support satisfaction [30–32,37] and objective network variables [30,32]. This might be explained by the fact that these interventions recruit additional network members. Also, remote interventions had positive but inconsistent effects on subjective [52–54] and objective support measures [57,60,61]. Despite the promising quantitative findings of both family and remote interventions more independent replications are needed.

The observed trends should be interpreted with great caution due to both conceptual and methodological reasons. Regardless of intervention type, studies often did not measure the entire concept, but only some aspects of social support; i.e., only subjective parameters (e.g. perceived social support [27,39,52,53], support satisfaction [31,32,41,43,44,54], social isolation [26,38,51]), or objective network measures [30,32,42,60,61]. Interpretations of social support findings are complicated since many different social support instruments were applied that conceivably differ in their sensitivity to change. Overall, methodological quality was suboptimal (46%: Cochrane score  $\geq 4$ ). Although qualitative findings might be more sensitive to capture the subjective experience of social support they are flawed by methodological shortcomings due to the lower level of evidence. The absence of a randomisation, control group, and the risk for a social desirability bias in qualitative studies potentially cause erroneous conclusions about intervention effectiveness.

##### 4.2. Well-being findings and methodological limitations

Regardless of intervention category, positive but inconsistent effects were found with respect to caregiver well-being, most

frequently measured by depression [27,28,33,35,54–58], burden [41,54,57,58], and quality of life [27,41,46,47,56]. Inconsistent well-being findings might be due to the large variety of intervention strategies and outcome measures, moderating factors (e.g. effects depended on high baseline complaints [28,39,44,57,64,65]), or small sample sizes causing power problems. Concurrent with earlier reviews [16,66], multicomponent interventions [32,35], were more effective than single social support interventions [27,28,33]. The multi-component nature of interventions limits investigation of the mediation role of social support [67]. However, a rigorous study with sufficient quality and a large sample suggested changes in social support variables are potential mechanisms of action [31,32,37].

##### 4.3. Future directions

This review highlights that the outcome measures used within social support studies often not match the goals addressed by the intervention [68], since many studies did not measure social support outcomes. This lack of operationalization was not due to a paucity of available social support instruments. Since social support is a multi-dimensional concept consisting of structural, functional and evaluative aspects, we recommend integrating objective (e.g. network size, function, contact frequency) and subjective social support measures (e.g. perceived satisfaction). Currently, there is little consensus which social support measures are most applicable [69]. Therefore, social support measures should be customized and validated for specific contexts and target groups. This is highly needed to reach more homogeneity in outcome measures, and to investigate the causal mechanisms of action in social support interventions.

Additionally, to optimize methodological quality we recommend applying randomized-controlled study designs with larger sample sizes and longer follow-up periods of at least 6 months after the intervention [22]. Information on process characteristics, such as protocol implementation checks was often lacking [16,70,71]. We suggest development of transparent theoretical-based treatment protocols to prevent implementation error caused by a lack of treatment fidelity by the therapists [72].

Finally, future studies should investigate the potential of remote interventions and/or social media to increase access to social support regardless of time, distance, or mobility constraints. This may offer new cost-effective possibilities not only important for affected caregivers but also on a societal level, as family and friends are increasingly involved in informal dementia care.

#### Conflicts of interests

All involved authors declare no conflicts of interest.

#### Author Contributions

The original proposal for this review was developed by AD, MdV, MvB and FV. AD performed the search strategy, extracted data and wrote the manuscript. IK extracted data. MdV and MvB assisted in the data-extraction process. MdV, MvB, IK and FV provided valuable feedback to the manuscript.

#### Funding

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#### Appendix A.

See [Table A1](#)

**Table A1**  
Characteristics, measures and outcomes of social support interventions for dementia caregivers.

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
<b>Befriending and peer support interventions (n=4)</b>										
Charlesworth et al., 2008 Wilson et al., 2009	Multi-site, single blind RCT with 24 M FU	Community settings in East Anglia & London	Family carers of PwDs (n=236)	CAU (n=120)	6 M weekly contact with facilitator, offer of match with befriender (n=116)	MSPSS, loneliness (2008)	HADS, PANAS, and EuroQol	Depression: ns, anxiety: ns, positive affect: ns, loneliness: ns, perceived support: ns (2008), quality of life: ns (2009)	2	
Greenwood et al., 2013	Qualitative interview study	Community setting in South London	Carers of PwD (n=9)	No CGR	One-to-one peer support by former PwD carers 1 h weekly for 6 W (n=9)	Semi-structured qualitative interviews	Semi-structured qualitative interviews	Feelings of isolation ↓ <sup>96</sup> , emotional support ↑ <sup>96</sup> , release ↑ <sup>96</sup> , enjoyment ↑ <sup>96</sup> , support managing the situation ↑ <sup>96</sup> , positive perspective ↑ <sup>96</sup> , doubts impact of IV	3	See paper for IV effects for peers
Pillemer & Suito, 2002	Pretest-posttest RCT with 6 M FU	Community setting in New York	Primary carers of people with AD (n=147 at baseline, n=115 at FU)	CAU (n=61)	One-to-one peer support by former AD carers 2 h weekly for 8 W (n=54)	None	CES-D, RSS, satisfaction with IV	Depression (in case of disruptive behaviour) ↓, self-esteem: ns, satisfied with IV	2	
<b>Family support and social network interventions (n=8)</b>										
Cohen et al., 1998	Pilot of 7 case studies with 9 M FU	Re-habilitation agency in Toronto	Spousal carers of PwD (n=7)	No CGR	Social network therapy: increase help for carers from informal social network and improve service connection (n=7)	SSQ, descriptive network measures	Formal service use rated on a 6-point scale, qualitative data on coping style	After 5M: 3 of 7 cases informal net-work size ↑#, additional carers →# After 9M: frequency of assistance ↑#, size formal network ↑#, formal service use ↑#, support satisfaction ↑#, coping styles changed	3	
Joling et al., 2012; 2013	Multi-centre RCT with 12 M FU	Community setting in the Netherlands	Primary carers of PwD (n=219)	CAU (n=96)	2-S individually and 4 family meetings once every 2 to 3 M. Ad hoc telephone counseling available (n=96)	None	MINI, CES-D, HADS-A, CRA, SF-12	Depression/anxiety incidence and symptoms: ns, burden: ns, health-related quality of life: ns (2012; 2013)	2	

Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Mittelman et al., 2004a; 2004b; 2007; Drentea et al., 2006 Roth et al., 2005	RCT with 1Y (2005) 3Y (2007) 4Y (2004b), or 5Y (2004a; 2006) FU	Community setting in New York	Spousal carers of PwD ( $n = 406$ ) Recruited over 9,5Y: in the 1st phase ( $n = 206$ ) and 2nd phase ( $n = 200$ )	CAU ( $n =$ dependent on FU)	(1)2-S individual and 4-S tailored family counseling (2) weekly support groups (3) continuous ad hoc telephone counseling ( $n =$ dependent on FU)	SSNL, satisfaction with social network on 6-point Likert-scale (2005; 2006; 2007)	GDS, MBPC, adapted OARS, service use	Depression ↓ sustained 1Y up to 5Y (2004a), negative appraisal ↓ over 4Y FU (2004b), self-rated health ↑ up to 2Y FU (mediated by improvement in support satisfaction, 2007), satisfaction with social support networks ↑, partly mediated by more emotional support, closer network members and seeing people more often over 5Y FU (2006), key social support measures ↑ (assistance, size, satisfaction), effects on depression and appraisal mediated by support satisfaction over 1Y FU (2005)	2	
<b>Support group interventions (<math>n = 12</math>)</b>										
Andren, & Elmstahl, 2008	Quasi-experimental design with 6 M and 12 M FU	2 districts of a municipality in South Sweden	Family carers of PwD ( $n = 308$ )	Resource information, telephone contact every 3M ( $n = 155$ )	5 weekly 2 h-S on coping strategies, mobilizing help, reducing social isolation and 3M conversation group ( $n = 153$ )	None	CBS, CASI, NHPS	After 6M: strain ↓, disappointment ↓, satisfaction regarding purpose ↑, trend remained after 12M, stronger effects for mild dementia or carers in impaired health	3	
Chu et al., 2013	RCT with 1 M FU	Outpatient clinic of a medical centre in Northern Taiwan	Carers of PwD ( $n = 85$ )	CAU ( $n = 42$ )	12W support group: discussion of emotions, communication problems, information on managing reactions, self-care, community resources ( $n = 43$ )	None	BDI-II, CBI	Post-intervention and at 1 M FU: depression ↓, burden: ns	2	
Diehl et al., 2003	Pilot study with post-intervention and 6 M FU	Outpatient unit for cognitive disorders in Germany	Female spousal carers of individuals with FTD ( $n = 8$ )	No CGR	7 weekly 90 m-S support group: mutual support, sharing, information and coping. Followed by monthly self-help meetings	Qualitative Questionnaire	Qualitative Questionnaire about satisfaction at post-intervention and coping questionnaire at 6 M FU	Carers felt relieved ↑ <sup>96</sup> , learned from each other ↑ <sup>96</sup> , developed social contacts ↑ <sup>96</sup> , shared coping strategies	3	small qualitative study

Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Dow et al., 2011	Qualitative evaluation study	Alzheimer Australia in Victoria ( <i>n</i> = 402)	PwD and their carers, family, friends, staff of café and service providers	No CGR	Vic Memory Lane Cafés every 4 to 8 W: social inclusion, communication, sharing, information, forum for informal advise and peer support, including speakers and entertainment	Focus groups	3 focus groups ( <i>n</i> = 37) with PwDs and their carers, surveys ( <i>n</i> = 139), staff consultation ( <i>n</i> = 8), service provider interview ( <i>n</i> = 24), researcher observations ( <i>n</i> = 3)	Social inclusion ↑ <sup>96</sup> , isolation ↓ <sup>96</sup> , social and emotional well-being ↑ <sup>96</sup> , intended aims of intervention but not all needs of attendees were met	3	
Dröes et al., 2006	Quasi-experimental design, matched groups with FU at 3 M and 7 M	8 meeting centres and PDC in 3 nursing homes in Amsterdam	Carer-patient dyads ( <i>n</i> = 128)	Historical CGR, regular day care ( <i>n</i> = 34)	MCSP: (1) social club for PwD with social and recreational activities. (2) therapeutic, informative and discussion meetings for carers	SSL, LS	GHQ-28, single burden item, SCS, JCS, aUoS, LS, NPI	Competence: ns, coping: ns, experienced informal and formal support: ns, loneliness: ns, psychological and psychosomatic symptoms ↓ (when high baseline loneliness), support from other services ↑, burden ↓ (3 to 7M)	4	Matched groups; historical control, see p. 114
Fung et al., 2002	RCT with pre-test and 1 M post-test	2 day-care centres in Hong Kong	Family carers ( <i>n</i> = 52; 50% spouses)	CAU ( <i>n</i> = 26)	Peer-led mutual support group ( <i>n</i> = 26): 12-S, 1h weekly: discussion, sharing, psychological support, establishing support, education & problem solving	None	NPI-D, WHOQOL-BREF(HK)	Distress ↓, quality of life ↑ (especially in social and psychological domain)	2	
Gallagher-Thompson et al., 2003 Rabinowitz et al., 2006	RCT with pre- and post-test at 3 M	Community setting in the US	Female Anglo and Latino carers of PwD ( <i>n</i> = 213)	No CGR	10-S, 2 h weekly: (1) CWC: learning cognitive behavioral skills ( <i>n</i> = 105) (2) ESG: reciprocal peer support, guided discussion, empathic listening ( <i>n</i> = 108)	ISSB (2003; 2006)	CES-D, RWCCCL, RMBPC (2003) STAIS-A.D., RWCCCL, SE (SE: OR, SE: CT, SE: DB) (2006)	CWC opposed to ESG: depression ↓ (2003) (greater when low baseline SE:OR, 2006), negative coping ↓ (2003), negative interaction ↓ (2003), positive coping ↑ (2003), Both ESG and CW: carer bother ↓, anxiety: ns, support satisfaction: ns (2003)	2	
Gaugler et al., 2011	Single group pre- post-test evaluation	3 memory club sites in Minnesota	People with early dementia/memory loss and their family care partners ( <i>n</i> = 63)	No CGR	Memory Club: 10 to 13-S weekly joined support group: (1) joined interaction period (2) separate group session (3) wrapping up	None	GDS, distress, effectiveness of care, preparation checklist	Perceived effectiveness ↑, preparation activities ↑, preparation for care needs ↑, high satisfaction with IV	3	



Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Wang et al., 2011	RCT with pre- and post-test after 1 W	Community recruited from 4 dementia care centres in Hong Kong	Chinese family carers of PwD (n = 80)	CAU (n = 40)	6 M 8-S bi-weekly FMSP-DC: developing extended social network relations, self-care, community support, skills (n = 40)	SSQ	FCBI, WHOQOL-BREF	Burden ↓, quality of life ↑, number of support persons: ns, satisfaction: ns	2	
Wang et al., 2012	RCT with pre- and post-test after 1 M	Community recruited from 2 centres in mainland China	Chinese family carers of PwD (n = 78)	CAU (n = 39)	24 W 12-S biweekly, 1.5 h: use group support system, establish support outside group & relationships, self-care, skills (n = 39)	None	NPI-D, WHOQOL-BREF (HK), FSSI	Distress ↓, quality of life ↑, service utilization ↑, discomfort ↓ <sup>96</sup> , embarrassment ↓ <sup>96</sup>	2	
Zarit et al., 1987	Quasi-randomized controlled comparison study with 1Y FU	Community recruited 2 sites in US.	Primary carers of PwD (n = 184)	Waiting-list control group (n = 39)	7 W, 8-S IFC (n = 36) or SG (n = 44): information, problem-solving skills, sharing and help to identify formal and informal support	social support on Likert-scale	BI, BSI, MBPC, caregiver situation and perception of IV on Likert-scale, CCI	Treatment effects: ns IFC compared to SG felt more supported during IV period: assistance ↑, perceived support ↑, number of household visits ↓, Both IFC and SG: positive subjective ratings	2	
<b>Remote social support interventions (n = 15)</b>										
Bass et al., 1998 Brennan et al., 1995	RCT with 12 M FU	In-home web-based support in US	Carers of people with AD (n = 102)	Single in-formation session on caregiving and AD (n = 51)	Access to Computer Link; a computer support network including communication functions (e-mail, peer forum, nurse Q/A) and solitary components (information on caregiving, AD, local services) (n = 51)	IESS (1995)	DCS (adapted version), ICS, CES-D, service use, pre- and post-test interview measuring 4 types of caregiver strain	Decision making confidence ↑, decision making skills: ns, social isolation: ns (1995), emotional strain ↓ (in case of high informal support), relationship strain ↓ (greater for spouse), activity restriction ↓ (greater for caregivers not living alone and with high informal support), interactions for communication and solitary functions on strain (1998)	2	

Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Belle et al., 2006; Hatch et al., 2014	RCT with 6 M FU	Controlled clinical settings in 5 American cities	Hispanic, Caucasian or African-American carers of individuals with AD or related dementias ( <i>n</i> = 642)	Telephone calls at 3 M and 5 M and education materials ( <i>n</i> = 319)	9-S in-home, 3-S individually by telephone, and 5-S telephone support groups over 6M ( <i>n</i> = 323)	Social support composite score of: received support, satisfaction and negative interaction (2006)	CES-D, ZBI, self-care, RMBPC, quality of life	Quality of Life ↑ (dependent on ethnicity, 2006), clinical depression ↓ (when high baseline depression, 2014), RMBPC stress ↓ (when high stress and/or home health aide at baseline, 2014), burden ↓ (when high burden and/or high RMBPC stress at baseline, 2014), composite social support score: ns (but clinical meaningful improvement, 2006)	2	
Czaja et al., 2013	RCT with 5 M FU	Community setting in Miami	Hispanic or African-American carers of PwD ( <i>n</i> = 110)	(1) attention-CGR ( <i>n</i> = 36) (2) information-only-CGR ( <i>n</i> = 36)	5-S videophone support group and 6-S, monthly, 1h education on caregiving and social support, plus notebook ( <i>n</i> = 38)	Questionnaires on social support and positive caregiving	CES-D, RMBPC,	Burden ↓, satisfaction with social support ↑, negative support interactions: ns, received social support: ns, positive perceptions of caregiving ↑, depression: ns, caregiving skills ↑*, technology easy to use	2	
Eisdorfer et al., 2003	RCT with 6 and 18 M FU	Community setting in Miami	Caucasian or Cuban carers of PwD ( <i>n</i> = 225)	(3) MSC condition: regular telephone calls for 12 M ( <i>n</i> = 73)	(1) SET condition: 12 M 1.5h family psychotherapy ( <i>n</i> = 75) (2) SET + CSTIS condition: 18 M family psychotherapy and telephone-based support ( <i>n</i> = 77)	None	CES-D, RMBPC,	SET+CSTIS group: depression ↓, (greater for Cuban husband and daughter caregivers)	2	Stratified random-ization
Finkel et al. 2007	RCT with 6 M FU	Community setting in Miami	Family carers of PwD ( <i>n</i> = 46)	Education materials, check-in calls 3 M and 5 M, invitation workshop 6 M ( <i>n</i> = 23)	2-S in-home and 12-S CTIS 8-S education and 6-S support group on dementia, services, safety, communication, self-care, social support, behavioural management ( <i>n</i> = 23)	ISSB (social support scale revised)	CES-D, RMBPC, CHHBS	Burden ↓, depression ↓ (in case of high baseline depression), smaller expected reduction in support ↓ (in case of high levels of baseline support)	2	

Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Goodman et al., 1990a; 1990b	Cross-over design with stratified random-ization with 3 M (1990b) and 6 M FU (1990a)	In-home web-based support in US	Carers of individuals with AD ( $n=81$ ; $n=40$ , 1990a vs. $n=66$ , 1990 had complete data for analysis)	No CGR	Telephone peer network component (NC): a 3 M telephone peer network of 12 weekly calls ( $n=22$ , 1990a vs. $n=31$ , 1990b) telephone lecture component (LC): 3 M 12 weekly telephone-based lecture series on 12 different topics ( $n=18$ , 1990a vs. $n=35$ , 1990b)	PSSC, social support measures (1990a; 1990b)	MBPC, ZBI, GI-38, knowledge on AD), CERS	NC followed by LC: informal contacts ↓ (time × group effect; 1990a; 1990b), increase social support satisfaction: ns (group × time interaction; 1990b) LC followed by NC: information gain ↑, informal contacts for emotional support ↑ (group × time interaction 1990a; 1990b), burden: ns, distress: ns, quality of relationship: ns independent of group sequence: perceived social supports ↑ support satisfaction ↑ informal emotional support ↑ (time effect; 1990a; 1990b)	2	
Lykens et al., 2014	Single group pre-post-test study	Community setting in North Texas	494 carers of individuals with AD	No CGR	9-S in-home, 3-S by telephone, and 5-S tele-phone support groups over 6 M on 5 targets: social support self-care, problem behaviours, depression, burden self-care	Social support (one domain on a 16-item risk assessment instrument)	Assessment of four domains: burden, depression, self-care and social support by a 16-item risk assessment instrument developed for REACH II	Domain scores for depression and burden ↓, social support: ns, self-care: ns	3	
Martindale-Adams et al., 2013	RCT with 6 M and 12 M FU	Community setting of veterans in the US	Carers of veterans with dementia ( $n=154$ )	Pamphlets on dementia safety, in-formation on service, notebook, workshop ( $n=77$ )	1Y telephone support group: 2 M bi-weekly, 10 M monthly, total of 14 1h sessions ( $n=77$ )	None	SF-36, self-care, ZBI, CES-D, GWS, RMBPC	No significant findings	2	Veteran caregivers

Table A1 (Continued)

Author/year	Design	Setting	Sample	CGR	Intervention	Social support measures	Well-being measures	Results	LOE	Comment
Marzialli et al., 2011	Quasi-experimental study with 6 M FU	Community setting in 3 Canadian cities (French/English)	Carers of PwD (n=91)	No CGR	(1) 6 M internet-based chat forum support group, information handbook, and 6 educational videos (CSG condition; n=40) (2) 10 W video conferencing support group followed by 10 W self-help group, and information handbook (VSG condition; n=51)	MSPSS	EPO-R, CSES-R, SMAF-D, HSQ 12, CES-D, current service utilization	Both CSG & VSG: self-efficacy ↑ VSG compared to CSG: mental health ↑, distress related to deterioration ↓ CSG: distress related to IADL ↓ VSG: neuroticism ↑, self-efficacy ↑, social support ↑ (all mediated by lower stress responses to mental deterioration and ADL activities)	3	
McKechnie et al., 2014	Mixed-method design with pre-post-test, 3 M FU	In-home web-based forum in the UK	Carers of PwD who were new forum users (n=61)	No CGR	Talking Point, a 3 M online peer support forum (n=61)	Qualitative interviews	GAD-7, PHQ-9, SQCRC (n=61), qualitative interviews on experiences using the forum (n=8)	Quality of relationship ↑, anxiety and depression: ns, positive and limited negative experiences from forum usage	3	
Strawn et al., 1998	Pre-post-test cross-over design with 6 W, 12 W and 14 W FU	In-home telephone intervention in the US	Carers of PwD (n=14)	No CGR	Telecare, 3 M weekly telephone contact with a caring caller	None	BSI, BI	Symptomatology ↓, perceived burden ↓	3	Small sample anecdotal
Winter et al., 2006	RCT with 6 M FU	Community setting in the US	Female family carers of PwD (n=103)	CAU (n=45)	6 M 1 h weekly telephone-based support group, 5 carers per group (n=58)	None	ZBS, CES-D, GTGIS	Depression ↓ (for older carers), burden: ns, personal gains: ns	2	

Quantitative outcomes: ↓ = significant reduction; ↑ = significant improvement; ns = non-significant difference, ↓# = descriptive reduction; ↑# = descriptive improvement; →# = no change. Qualitative outcomes: ↓# = reduction; ↑# = improvement; →# = no change. Multiple papers in one row refer to the same study cohort. If CGR, then reported results refer to difference between CGR and IG. If no CGR, then reported results refer to difference between baseline and FU. AD: Alzheimer's disease; aUoS: adapted Use of Services checklist; BDI-II: Beck Depression Inventory-II; BI: Burden Interview; BSI: Brief Symptom Inventory; CAU: care as usual; CASI: The Carers' Assessment of Satisfaction Index; CBI: Caregiver Burden Inventory; CBS: Caregiver Burden Scale; CCI: Caregiver Change Interview; CERS: Caregiver-Elder Relationship Scale; CES-D: Center for Epidemiologic Studies Depression Scale; CGR: control group; CHHS: Caregiver Health and Health Behaviours Scale; CRA: Caregiver Reaction Assessment; CSG: Chat Support Group; CSES-R: Caregiver Self-efficacy Scale-revised; CSTIS: Computer-Telephone Integrated System; CWC: Coping With Caregiving; DCS: Decision Confidence Scale; EPO-R: Eysenck Personality Questionnaire Revised; ESG: Enhanced Support Group; EuroQoL5: measurement of health-related quality of life; FCBI: Family Caregiving Burden Inventory; FMSP-DC: Family Mutual Support Programme in Dementia Care; FSSI: Family Support Services Index; FU: follow-up; GAD-7: 7-item Generalized Anxiety Disorder Scale; GDS: Geriatric Depression Scale; GHQ-28: General Health Questionnaire; GI-38: Global 38-item Index; GTGIS: Gain Through Group Involvement Scale; GWS: General Well-Being Scale; h: hour(s); HADS: Hospital Anxiety and Depression Scale (refers to HADS-A and HADS-D); HSQ 12: Health Status Questionnaire; ICS: Impact of Caregiving Scale; IFC: individual and family counselling; IG: intervention group; IESS: Instrumental and Expressive Social Support Scale; ISSB: Inventory of Socially Supportive Behaviours; IV: intervention; JCS: Jalowiec Coping Scale; LOE: Level of Evidence; LS: Loneliness Scale; M: month(s); MBPC: Memory and Behaviour Problems Checklist; MCSP: Meeting Centres Support Program; MINI: Mini International Neuropsychiatric Interview; MSC: minimal support control; MSPSS: multidimensional scale of perceived social support; NHPS: Nottingham Health Profile scale; NPI: Neuropsychiatric Inventory; NPI-D: Neuropsychiatric Inventory-Caregiver Distress Scale; OARS: Older Americans Recourses and Services Multidimensional Assessment Questionnaire; PANAS: Positive and Negative Affectivity Scale; PHQ-9: 9-item Patient Health Questionnaire; PSSC: Perceived Social Support for Caregiving and Social Conflict; PwD: persons with dementia; RCT: randomized controlled trial; RMBPC: Revised Memory and Behaviour Problems Checklist; RSS: Rosenberg Self-Esteem Scale; RWCC: Revised Ways of Coping Checklist; -S: session(s); SCS: Sense of Competence Scale; SE: Self-Efficacy (OR: obtaining respite CT: controlling upsetting thoughts, DB: responding to disruptive behaviours); SET: Structural Ecosystems Therapy; SF-12/-36: Short Form Health Survey 12-item/36-item questionnaire; SG: support groups; SMAF-D: Functional Autonomy Measurement System-Distress; SSL: Social Support list; SSNL: Stokes Social Network List; SSQ: Social Support Questionnaire; STAIS-A.D: modified State Trait Anxiety Inventory; SQCRC: Scale for Quality of Current Relationship in Caregiving; VSG: video support group; W: week(s); WHOQOL-BREF(HK): The World Health Organization Quality of Life Measure-Brief Version; ZBI: Zarit Burden Interview; ZBS: Zarit Burden Scale; Q/A: Question and Answer.

## Appendix B. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.maturitas.2015.12.008>

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