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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.

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