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Social support interventions for caregivers of older adults with dementia: A scoping review

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Social support interventions for dementia caregivers

Social support interventions for caregivers caring old adults with dementia: A scoping review

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Social support interventions for dementia caregivers

Social support interventions for caregivers of older adults with dementia: A scoping review

Abstract

Background: Many studies have reported interventions to improve social support of caregivers caring older adults with dementia; however, information on the implementation, evaluation, and effects of these interventions is dispersed in the literature, and an up-to-date summary is lacking.

Objectives: To identify and assess the social support interventions provided to caregivers of older adults with dementia, and summarize the outcomes of the interventions.

Methods: The PRISMA Extension for Scoping Reviews was adhered to, and searches were conducted across five databases (PubMed, Web of Science, Embase, Cochrane Library, CINAHL), from their inception through July 2024.

Results: A sum of 29 studies were chosen, and six categories of social support for caregivers of older adults with dementia emerged across various studies, included peer support (n = 7), counselling group intervention (n = 2), health education (n = 2), mindfulness-based stress reduction intervention (n = 1), individual therapy (n = 1), and multicomponent interventions (n = 16). These interventions enhanced the social support of caregivers, and showed positive outcomes in terms of reducing caregivers' caring burden, anxiety, depression, and improving caregivers' coping skills.

Conclusion: This review presents the diversification of interventions that enhance social support for caregivers of older adults with dementia. The findings offer insights for caregivers of older adults with dementia, along with administrators and other stakeholders, to adopt and promote appropriate social support for caregivers.

Registration: A review protocol was registered on the OSF registries, with the following registration doi:

<https://doi.org/10.17605/OSF.IO/D9C53>

Keywords

Dementia Caregivers; Social support interventions; Old adults; Scoping review.

Strengths and limitations of this study : This study only included articles published in English and did not include grey literature or conference literature. Quality evaluations were conducted on the included RCTs, but not on other types of studies.

What is already known

- Better social support can improve the care quality provided by carers and therefore the living standards of those with dementia.
- Research on interventions to reinforce social support for caregivers of

Social support interventions for dementia caregivers

older adults with dementia is gradually increasing.

- Many interventions to enhance social support exist, but some obstacles remain in selecting appropriate interventions.

What this paper adds

- This study summarizes different social support interventions for carers of older adults with dementia, considering different types of caregivers and outcomes.
- This study identifies the advantages and barriers associated with each intervention and provides references on how to choose an appropriate intervention.
- The study summarizes the targeted improvement of different dimensions of social support through different interventions, laying the groundwork for future research on caregivers with diverse needs.

Social support interventions for dementia caregivers

Background

According to World Health Organization(WHO), it is estimated that there are currently more than 55 million people with dementia worldwide and this is expected to increase from 55 million in 2019 to 139 million in 2050 due to an ageing society.¹ Dementia will become the 7th leading cause of mortality globally ². As dementia is accompanied by declines in cognitive function, caring for older adults with dementia is difficult, owing to the behavioral and psychological symptoms ³. Caregivers may be formal or informal; with the latter playing a crucial role in supporting older adults suffering from advanced, terminal illnesses⁴. Approximately 16 million individuals serve as unpaid caregivers, dedicating over 18.6 billion hours to assist older adults with dementia ⁵. Offering assistance and care to those with dementia is a demanding task that requires significant time investment, with caregivers often sacrificing their personal time and resources. The ongoing progression of dementia poses considerable difficulties for family caregivers tending to a loved one⁶. Numerous caregivers experience a dearth of information and community resources, frequently expressing a sense of social isolation and insufficient social support⁷. Recent research indicates that family caregivers of dementia face worse health-related consequences, including increased perceived burden, higher rates of depression, and a reduce quality of life in caregiving, compared with caring for patients with other chronic conditions⁸.

Social support refers to subjective or objective effects on individuals of various social relationships embedded in social networks ⁹, and comes from all aspects of society, including emotional, specific, and informational support ¹⁰, and social support encompasses the exchange of emotional connections(affection, love, admiration, and respect), affirmation (agreement, acknowledgement of the appropriateness of an action, statements, or perspectives), and assistance(provision of resources, financial support,

Social support interventions for dementia caregivers

information, guidance, or favors)¹¹. This concept describes the consistent social engagement between individuals and groups with shared values, serving as a source of mental motivation, feedback, assistance, and material support¹². In theoretical terms, social support framework can be seen as a provider-centric model, where one or more people or network participants offer valuable assistance to the beneficiary¹³. Social support provides a defense against stress, developing psychological resilience and advancing coping strategies^{14–16}. Social support has also been used as a moderating variable between stress and mental and physical well-being^{17,18}.

As an external resource, social support can contribute to enhancing the physical well-being of caregivers^{19,20}. The substantial stress of caregiving responsibilities may exacerbate negative emotions like anxiety and depression among caregivers, adversely affecting their mental and physical well-being and potentially diminishing the quality of care provided²¹. Moreover, the demands of caregiving role may increase loneliness²². Social support is crucial to one’s well-being; however, due to stigma, caregivers are often reluctant to pursue social support, and this isolation can further aggravate their caregiving load²³. Lacking social support, social isolation leads to limited personal activities and decreased caregiver overall life quality²¹. Such factors severely affect the caregivers’ physical and mental well-being, increasing the potential for heart-related diseases²⁴.

It is especially important to provide social support interventions to those caring older adults with dementia, who frequently rely on their social networks for help²⁵. Social support interventions include peer support and counselling, which can be delivered in individual, group, or mixed formats ²⁶. Interventions such as psychological training, therapeutic treatments, and self-care programs have been shown to reduce stress associated with behavioral and emotion issues²⁷. In England, for those caring for advanced dementia, respite care is commonly the top choice²⁸. In terms of delivery of interventions, computer

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Social support interventions for dementia caregivers

networks have been a key methods since the 1990s. As technology becomes more prevalent in caregiving, the delivery of social support through computer has become a natural development²⁹. Caregivers of dementia can use digital and telecommunication platforms to access emotional support, gather essential information, and attain a level of respite from emotional strain²⁶. As social support improves, individuals find it easier to deal with life's challenges. Concurrently, a study has discovered that the satisfaction levels of social support greatly affects Korean American caregivers' attitude towards dementia people³⁰. Despite the availability of numerous social support interventions for dementia caregivers, information on the evaluation and implementation of social support is dispersed in the literature, hampering the substantiation of the effectiveness of social support interventions.

This scoping review aimed to integrate social support research currently applied to caregivers of older adults with dementia. This scoping review 1) summarizes the types of existing research evidence, such as studies on social support and evaluation of research populations; 2) provides an overview of the key points of social support interventions and the significant involvement of caregivers in the development and research processes; and 3) assesses the efficacy of documented interventions of social support for caregivers.

Methods

Research questions

The review targeted the subsequent research questions: (1) What types of support are designed to improve caregivers of older individuals with dementia's social support? (2) What types of tools are utilized to assess social support and what outcomes were evaluated? (3) What effects are observed after utilizing these interventions for caregivers of older adults with dementia?

Search strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Social support interventions for dementia caregivers

extension for Scoping Reviews (PRISMA-ScR) checklist ³¹ served as a framework for presenting the result. This study followed the requirements of Arksey and O'Malley's methodological framework ³², which includes: 1) identifying the research question, 2) searching for relevant studies, 3) selecting studies, 4) charting the data, and 5) collecting, summarizing, and reporting the results. To identify the evidence in this field by mapping out the existing research on this topic, we conducted searches across five key databases: PubMed, Web of Science, Embase, Cochrane Library, and CINAHL. The search strategy aimed to identify studies meeting the inclusion criteria. A preliminary search was performed to locate relevant literature on the topic (see the search strategy section). The keywords "dementia caregivers," "social support," and "intervention" were comprehensively searched to find pertinent evidence from the inception of the databases up to July 2024.

Eligibility criteria

This scoping review encompassed research on social support interventions aimed at for caregivers of older individuals with dementia. Interventions which were designed to target caregivers of older individuals with dementia, at the same time reported social support outcomes. Only original intervention studies with full texts were included. Inclusion was also limited to English language published literatures.

Exclusion criteria

Studies in which the full text was unavailable, vital information was completely lacking, or without an explicit methodology were excluded; studies not published in English were not included in this review.

Types of sources

Consistent with the review questions, this scoping review incorporated intervention studies, including randomized controlled trials (RCTs), nonrandomized controlled trials (NRCTs), and mixed-methods studies.

Study selection

Citations were imported into EndNote X9 citation management software,

Social support interventions for dementia caregivers

and duplicates removed. Two researchers independently conducted the preliminary screening of eligibility based on the titles and abstracts. Following that, they independently reviewed the full texts for further assessment against the predefined inclusion and exclusion criteria, and meticulously documented the rationale for the exclusion of any studies. Exclusion criteria were documented, and there was unanimous consensus on the articles that were incorporated into the review. The search results are presented in the Preferred Reporting Items for Scoping Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1). Discrepancies among the authors were addressed through consultation with an additional reviewer.

Data extraction

A standardized data chart was created in Microsoft Excel based on Arksey and O'Malley's data extraction form ³², after consultation between all authors to extract data from the included records. Two investigators separately collected pertinent information from the eligible studies. A Microsoft Office Excel table was designed, and two reviewers independently extracted details, including information obtained in the studies covering authors' name, country of origin, publication year, study design, characteristics, sample size and assessment tools, intervention strategies (i.e., intervention types, frequency, tools, and outcomes), main findings, and the limitations of the study. Any disagreements were adjudicated by an additional independent reviewer.

Results

Overview of findings

The initial search identified 2989 relevant citations (Fig.1). After the deduplication process, 1869 articles were selected for inclusion. Following the review of titles and abstracts, 180 studies were chosen for further assessment in full-text review. Among these, 143 articles were ruled out for the following reasons: research designed with protocols (n = 36), participants did not fulfill

Social support interventions for dementia caregivers

the eligibility criteria (n = 24), outcomes that did not include social support (n = 52), not published in English (n = 25), missing full texts (n = 8). Ultimately, 29 studies were incorporated in this scoping review. Figure 1 illustrates the PRISMA flow diagram detailing the screening process. Regarding the article for which the full text cannot be obtained, attempts have been made to contact the author, but no response has been received.

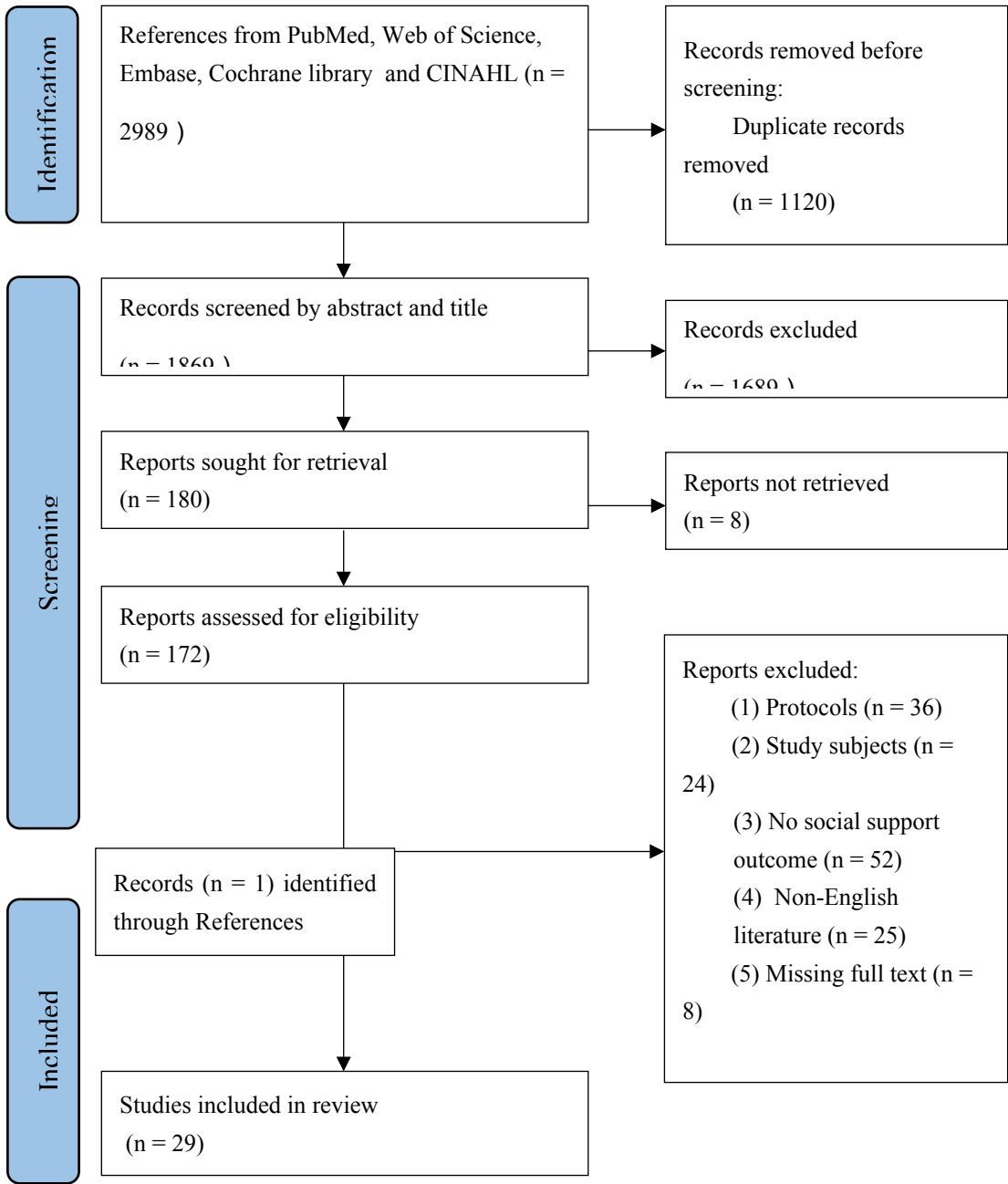


Fig.1 PRISMA flow diagram

Study characteristics

Social support interventions for dementia caregivers

A total of 29 studies were published spanning the period from 1988 and 2024. Among these, 14 studies were RCTs^{22,26,33-44}, eight were NRCTs⁴⁵⁻⁵², and seven were mixed methods studies⁵³⁻⁵⁹. The majority of the studies were carried out in the United States (n = 19), Europe (n = 10), Oceania (n = 1), and Asia (n = 1). Table 1 provides an overview of the of the fundamental details of the included studies. From the perspective of intervention settings, two studies were conducted in long-term care institutions^{22,34}, nine in the community^{26,33,45,48,49,51,53,54,57}, and 18 in older adult's homes^{35-44,46,47,50,52,55,56,58,59}. The total sample size of caregivers was 4213, ranging from 12 to 494, with a median of 85 cases. Most studies focused on family caregivers of older adults with dementia. Regarding the target population, studies were implemented in a multicultural context: three studies specifically examined social support interventions for African American dementia caregivers^{53,55,56}, one focused on caregivers with Turkish and Moroccan backgrounds living in the Netherlands⁴⁴, and one investigated how to enhance social support among Chinese Canadian caregivers⁵⁹. Although some studies were conducted in facilities such as day centers, clinics, hospitals, or communities, the target population was still family caregivers of dementia, and it should be highlighted that one study concentrated on spousal caregivers³⁹.

Quality appraisal

This article conducted a quality appraisal of the included RCT, and more than 60% of the studies that were included were assessed to have a low risk of bias in the subsequent domains: 1) sequence generation; 2) incomplete outcome data; 3) selective reporting. However, less than 50% were rated as low risk for the method of: 1) allocation concealment; 2) blinding of participants and personnel; 3) blinding of outcome assessment; and 4) other potential biases were unclear (Fig. 2).

Social support interventions for dementia caregivers

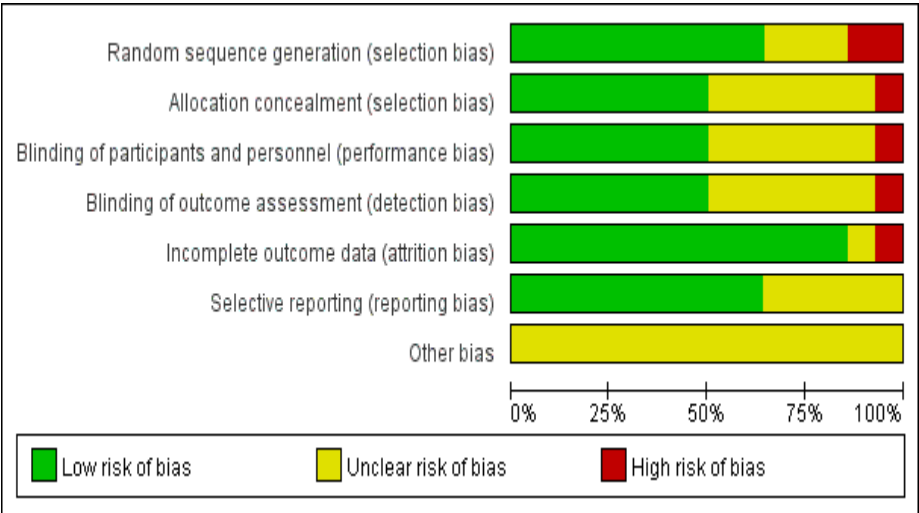


Fig.2 Risk of bias graph.

Table 1 Characteristics of included studies

Author	Year	Country	Design	Setting	Sample
Xu et al.	2023	USA	Mixed methods	Community	20
Blackberry et al.	2023	Australia	Mixed methods	Rural community	113
Glueckauf et	2022	USA	Mixed	Home	12

Social support interventions for dementia caregivers

Author	Year	Country	Design	Setting	Sample
al.			methods		
Berwig et al.	2022	Germany	RCT	Facility	280
Christie et al.	2022	Netherlands	RCT	Home	96
Fields et al.	2021	USA	Mixed methods	Home	16
Szczęśniak et al.	2021	Italy, Poland, UK, Netherlands	Mixed methods	Community	141
Töpfer et al.	2021	Germany	RCT	Home	51
van Wezel	2021	Netherlands	RCT	Home	340
David Gustafson Jr et al.	2019	USA	RCT	Home	26
Czaja et al.	2018	USA	Non-RCTs	Community	146
Wilkerson et al.	2018	USA	Non-RCTs	Home	60
Smith et al.	2018	UK	Mixed methods	Home	16
Tremont et al.	2017	USA	RCT	Home	250
Lykens et al.	2014	USA	Non-RCTs	Community	494
Whitebird et al.	2013	USA	RCT	Home	78
Bass et al.	2013	USA	RCT	Community	486
Czaja, et al.	2013	USA	Non-RCTs	Home	110
Easom et al.	2013	Georgia	Non-RCTs	Rural home	83
Nichols et al.	2011	USA	Non-RCTs	Home	127
Marziali et al.	2011	Canada	Non-RCTs	Community	91
Wai Tong Chien et al.	2011	China	RCT	Home	92
Tompkins et al.	2009	USA	Non-RCTs	Community	367
Chiu et al.	2009	Canada	Mixed methods	Home	35
Bank et al.	2006	USA	RCT	Community	41
Roth et al.	2005	USA	RCT	Home	406
Hébert et al.	2003	Canada	RCT	Home	158

Social support interventions for dementia caregivers

Author	Year	Country	Design	Setting	Sample
Mercedes et al.	2002	Colombia	RCT	Day centers	58
Robinson et al.	1988	USA	RCT	Home	20

Theoretical frameworks utilization research design

Among the 29 studies in this review, eleven were guided by six categories of theories to design their research: the Stress Process Model, Sociocultural Stress and Coping Model, Stress-appraisal Coping and the Crisis Model, Role Transformation Framework, Rural Nursing Theory, Tolsdorf’s Conception of Social Support. Among these, four studies followed the Stress Process Model^{33,45,50,55}, three studies were guided by the Sociocultural Stress and Coping Model^{38,53,56}, one study followed Lazarus and Folkman’s Stress-Appraisal Coping model and the Crisis Model of Moos and Tsu⁵⁷, one study was guided by the Framework of Role Transformation⁵², another implemented the Rural Nursing Theory⁴⁷, and another one was based on Tolsdorf’s Conception of Social Support³⁶. Furthermore, other 18 studies did not mention use of a theoretical framework.

Social support measurements

As shown in Table 2, a total of 21 methods were used to measure social support, the most commonly used was the Medical Outcomes Study (MOS); a total of 5 studies used this scale. MOS is a multidimensional, self-managed, and brief survey developed patients to measure social support⁶². The Multidimensional Scale of Perceived Social Support (MPSS) was utilized in four studies; another four studies extracted 10-21 items ranging from three different broad scales to measure social support. Others were self-developed scales; examples include a 13-item questionnaire consisting of four domains – satisfaction with support, social support network, received support and negative interactions – to understand the situation of social support; the Interpersonal

Social support interventions for dementia caregivers

Support Evaluation List (ISEL); a brief form of the Perceived Social Support Questionnaire (F – SozU), which assesses the extent of social support; experiences of emotional and practical support; social relationships; social support network; social support questionnaire; supporting resources; social support from the perspectives of satisfaction and formal support; social support questionnaire; the Inventory of Socially Supportive Behaviors; and Norbeck's Social Support Questionnaire (NSSQ). Table 2 indicates that the majority of studies failed to report on the reliability and validity of their tools.

Table 2. Social support measurement tool

Name	Scale	Cronbach's alpha
Cerquera et al., 2021;		
Blackberry et al., 2023;		
Gustafson et al., 2019;	Medical Outcomes Study (MOS)	0.736-0.921
Whitebird et al., 2013;		
Wilkerson et al., 2018;		
Chiu et al., 2009;		
Christie et al., 2022;	Multidimensional Scale of Perceived Social Support (MPSS)	NM
Marziali and Garcia, 2011;		

Social support interventions for dementia caregivers

Smith et al., 2018;		
Czaja et al., 2013;		
Easom et al., 2013;	10-21 items from three different broad scales measuring social support	NM
Lykens et al., 2014;		
Nichols et al., 2011;		
Fields et al., 2021;	self-developed scales	NM
van Wezel et al., 2021;		
53;	13-item questionnaire consisting of 4 domains: satisfaction with support, social support network, received support and negative interactions	NM
Glueckauf et al., 2022;	Social support: the Interpersonal Support Evaluation List (ISEL)	0.92
Berwig et al., 2022;	brief form of the Perceived Social Support Questionnaire (F – SozU) to assess the extent of social support	0.90
Szcześniak et al.,2021	experiences of emotional and practical support	NM
Töpfer et al.,2021	social relationships	NM

Social support interventions for dementia caregivers

Roth et al., 2005	social support network	NM
Czaja et al., 2018	social support questionnaire	NM
Bass et al., 2013	supporting resources	NM
Chien and Lee, 2011	social support from the perspectives of satisfaction with social support and formal support	NM
Bank et al., 2006	support questionnaire	NM
Tompkins and Bell, 2009	The Inventory of Socially Supportive Behaviors	NM
Hébert et al., 2003	Norbeck's Social Support Questionnaire (NSSQ)	NM
Robinson, 1988		

NM: Not Mentioned

Social support interventions

As shown in Table 3, six types of social support interventions were used to improve social support: peer support (n = 7), counselling group (n = 2), health education (n = 2), mindfulness-based stress reduction (n = 1), individual therapy (n = 1), and multi-component interventions (n = 16).

Peer support

Peer support refers to the participants receiving intervention courses together with peers or volunteers with caregiving experience. Eight studies used peer-support interventions. Two studies were RCTs, and six were mixed methods. The shortest intervention duration was four hours⁴⁴, while one study lasted 24 weeks, one implemented the intervention in three steps over 32

Social support interventions for dementia caregivers

weeks⁵⁴, and most studies chose six months as the duration of the intervention^{34,53,58}. The intervention time for one study was three months⁵⁶, and that of another study was six weeks⁵². From the included studies, three studies showed an improvement in perceived social support^{34,56,58}, one study showed an improvement in satisfaction with social support⁵³, one study showed an improvement in emotional and informational support⁵², and one study mentioned an increase in support from home care staff, however, the improvement in support from family, friends, neighbors, and advice from doctors was not significant⁴⁴, and one study showed an improvement in overall social support⁵⁴.

Counselling group intervention

The counselling group intervention included caregivers participating in support groups that provided personal and family consultations. Two studies used group counselling interventions, both of which were RCTs. The durations were 12 months³⁹ and 6 months⁴². In those two studies, one mentioned a significant improvement in the utilization of community support services by caregivers, but there was no significant improvement in the utilization of community services and medical resources by the care recipient⁴². Another study mentioned that there were 11 indicators of social support, of which 8 showed significant improvement³⁹.

Health education

This intervention included a social skills program providing health education related to dementia care to improve care skills and confidence, and comprised 12 hours of sessions designed to accomplish diverse goals for caregivers (e.g., developing emotional tolerance, acknowledging the disease, and taking control). Two studies used health education interventions, one of which was an RCT, while the other was a non-RCT study. The intervention duration were 2 months³⁶ and 12 hours⁵¹, respectively. One study reported a significant increase in service usage⁵¹, while the other study reported no

Social support interventions for dementia caregivers

significant increase in social support³⁶.

Mindfulness-based stress reduction

The content encompassed the caregiver receiving guidance on mindfulness principles and engaging in meditation and gentle yoga sessions, all facilitated by an instructor specialized in mindfulness-based stress reduction, on a weekly basis. One RCT reported a mindfulness-based stress reduction intervention. The duration was two months⁴¹, this study reported that the intervention significantly improved caregivers' social support.

Individual therapy

The caregivers participated in an expanded Tele.TAnDem program, consisting of 12 individual therapy sessions (each lasting 50 minutes) conducted via telephone across six months period⁴³. The 12-session program consisted of 10 therapeutic modules. This study reported the 3-year follow-up results, which showed that informal caregivers experienced a notable reduction in caregiver burden, an enhancement in quality of their social relationships, and improved their ability to manage the behavioral issues of the individual with dementia, this intervention significantly improved social relationships, but did not show significant improvement in service usage.

Multi-component interventions

Multi-component interventions integrate psychological education, systematic communication, and physical therapy. Sixteen studies used multi-component interventions, of which six were non-RCTs, seven were RCTs, and three were mixed methods. The shortest intervention duration was two months (Cerquera Córdoba *et al.* 2021), the longest was 18 months²⁶, and the most common intervention duration was six months^{37,40,45,47,48,50,59}. Among the 16 studies mentioned above, a total of nine studies reported a slight increase in social support without statistical significance, but also pointed out that the interventions were in the correct direction^{26,35,37,39,45,47,48,50,59}. One study reported an increase in overall social support³⁶, one mentioned that the intervention improved the perceived social support of caregivers⁵⁵, one

Social support interventions for dementia caregivers

mentioned an increase in emotional support⁵⁷, and another mentioned a significant increase in support resources³³. Meanwhile, one study reported an increase in social support satisfaction⁴⁶, another study proposed that social support were associated with lower stress response to cope with the care recipient's decline in function and cognitive impairment⁴⁹, by the way, one study showed that the intervention group's utilization of family services was significantly decreased⁴⁰.

Intervention outcomes

In addition to improved social support, 9 studies showed that intervention reduced caregiver depression^{33,34,41,45,48,50,51,55,59}, 8 studies reported a reduction in caregiver burden^{36,45,46,48,50,52,52,53,57}, 3 studies reported intervention measures reduced stress^{33,41,52}, 2 studies reported intervention improved caregivers' mental health^{41,49}, 1 study proposed intervention improved caregiver coping skills⁵³, and 1 intervention improved caregiver satisfaction⁵⁷.

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Social support interventions for dementia caregivers

Table 3 Description of social support interventions

Author/Year		Participants Intervention				Outcomes		Results
	sample size	Caregiver type	Type	Duration content	Intervention	Social support	Other outcomes	
Xu/2023	20	African American FCG	Peer support	6 months	The SCP Plus contained a 12 h in-person training with the senior companions.	13 items from four domains.	Burden and/or coping skills; Caregiver appraisal; Coping justifications for caregiving; Caregiver well-being; ZBI; bespoke surveys	KAD, social support satisfaction, coping skills: ↑; Burden: ↓.
Blackberry/2023	113	FCG	Peer support	32 weeks	Verily Connect model	MOS	Severity of CG-identified problems; Depression; Health status; Consequences of caregiving activities	Social support: ↑; ZBI: ↓
Glueckauf/2022	12	African American FCG	Multi-component	12 weeks	12 weekly telephone sessions, 7 one-hour group sessions and 5 one-hour individual goal-setting and implementation sessions.	ISEL	Depression; Health status; Consequences of caregiving activities	Depression: ↓; Perceived social support: ↑; CAI: NS.
Berwig/2022	107 vs 104	FCG	Peer support	6 months	Telephone-based group meeting	FSozU K22	Restrictions; Depressed mood states; general complaints; Quality of life	The mental health domain of quality of life of family carers and perceived social support: ↑ Depression: ↓;

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcome		Results
	sample size	Caregiver type	Type	Duration content		Social support	Other outcomes	
Christie/2022	48 vs 48	Primary CGs	Multi-component	16 weeks	The intervention group had access to Inlife, participants could use Inlife in at their own pace.	MSPSS; Received support; Number of friends and family ties	Utilization of support services; Performance in different areas of life; Sense of competence; Feelings of loneliness; Anxiety and depression; Quality of life; Perceived stress	Received support; MSPSS; Number of friends and family ties: NS; Sense of competence; Feelings of loneliness; Anxiety and depression; Perceived stress: NS.
Fields/2021	16	FCG	Peer support	3 months	Nine in-home psychoeducational sessions covering one topic per week to their paired AD/RD family caregiver over a three-month period were delivered by Each Senior Companion	Self-developed scale	KAD; Coping skills; Caregiver well-being; Burden and/or stress	Received social support: ↑ ; KAD, overall stress/burden levels, well-being of doing activities, coping skills: NS

Social support interventions for dementia caregivers

Author/Year	Participants			Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Szczeniak/2021	45 vs 21 vs 15	FCG	Multi-component	3 months	MCSP for both dementia people and their carers	Experience of emotional and practical support	Satisfaction; Reassurance for participation in the support programme; Burden	Emotionally supports: ↑; Satisfaction: ↑; Burden: ↓.
Töpfer/2021	29 vs 22	FCG	Individual therapy	6 months	The intervention group (IG) received 12 individual therapy sessions (each 50 min) delivered via telephone from Tele.TAnDem intervention.	Social relationships: The German Version of the World Health Organization QoLBREF (WHOQoL-BREF)	Depression; Caregiver burden; Emotional well-being; Utilization of resources;	Changes regarding own illnesses, the living situation with the PwD, the living environment, the employment status, care for any other person than the PwD, and severe illness of any close person in the last 3 years: NS; social relationships: ↑, use of support services: NS
van Wezel/2021	202 vs 184	Turkish or Moroccan background FCG	Peer support	Two hour interventions	Two educational sessions on dementia, each last two hours, with other participants (peers) with the same cultural background (Turkish or Moroccan).	The support received: four self-developed questions	The perceived pressure from informal care; The perceived ability to talk about dementia; KAD;	Support received from family, friends or neighbors, and advice received from a doctor: NS. support received from home-care staff: ↑

Social support interventions for dementia caregivers

Author/Year	sample size	Caregiver type	Participants Intervention Type	Duration content	Intervention	Social support	Other Outcomes	Results
Gustafson Jr/2019	16 vs 15	FCG	Multi-component	6 months	Intervention group receiving D-CHESS. Control group receiving a caregiving book.	MOS	Family conflict; Caregiver burden; Loneliness; Anxiety; Satisfaction with decision; Depression; Coping competence	All findings: NS; Due to small sample size.
Czaja/2018	146	FCG	Multi-component	6 months	12, 60-min individual (6 telephone and 6 face-to-face) educational sessions and skill building and 5 support groups by telephone.	Social Support Questionnaire	Depression; Affective distress; Burden; Caregiving Self-Efficacy; Memory related problems, and disruptive behavior;	Depression, overall burden, overall bother: ↓; Social support, positive aspects of caregiving or obtaining respite services: NS.

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcome		Results	
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes		
Wilkerson/2018	60	Informal CGs	Peer support	6 weeks	Participants were allotted to two private Facebook groups receiving the intervention over the course of six weeks.	MOS	Burden; Frequency of emotional problems; Learned activities	Burden; ↓; Perceived stress: ↓; Emotional and informational supports: ↑	
Smith/2018	16	FCG	Peer support	6 months	Carers receiving one-to-one peer support or befriending from volunteers at least a weekly basis.	MSPSS	Depression and anxiety; Loneliness	Perceived social support: ↑; Depression, anxiety and loneliness: NS.	
Tremont/2017	105 vs 94	Informal CGs	Counseling group	6 months	Trained therapists contacted caregivers 16 times use telephone for 6 months, providing recommendations for resources, information about dementia, and emotional support.	Community support services used times, healthcare resource use	Burden; Depression; Behavior problems	Caregivers who received the FITT-C used community support services significantly more than those receiving TS; FITT-C caregivers had a significantly lower rate of ED visits and hospital stays; Care recipient use of community or medical resources did not differ according to group.	

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration content	Intervention	Social support	Other outcomes	
Lykens/2014	494	FCG	Multi-component	6 months	Certified interventionists deliver the intervention included 12 sessions [9 in-home, and 3 telephone sessions], five structured telephone support group sessions	10 item Risk Assessment of feeling isolated, availability of someone to talk to or assist with caregiving	Caregiver Burden; Depression; Self-efficacy	Caregiver burden and Depression: ↓, Social support and self-care: a slight but not statistically significant increase after the service, which is in the correct direction.
Whitebird/2013	38 vs 40	Primary CGs	MBSR	8 weeks	8 weekly 2.5-hr in-person group sessions.	MOS	Stress, Mental Health, Burden	MBSR was more effective at reducing stress, decreasing depression, and improving overall mental health than CCES. Both interventions improved caregiver mental health and were similarly effective at improving anxiety, social support, and burden.

Social support interventions for dementia caregivers

Author/Year	Participants Intervention				Outcomes		Results	
	sample size	Caregiver type	Type	Duration content	Intervention	Social support		Other Outcomes
Bass/2013	299 vs 187	FCG	Multi-component	12 months	Partners in Dementia Care: initial assessment; action plan; Ongoing Monitoring and Reassessment	Support resource:1) number of informal helpers; 2) use of caregiver support services	Unmet needs; Caregiver strains; Depression	Three types of caregiver strains, depression, unmet needs: ↓ , and two support resources: ↑
Czaja,/2013	36 vs 63	FCG	Multi-component	5 months	A technology based multi-component psychosocial intervention was delivered in-home and via videophone technology over 5 months.	10 items assessing three domains of support: (a) received support(b) satisfaction with support(c) negative interaction s/ supports	Burden; Depression; Positive aspects of caregiving	Caregiver burden: ↓; satisfaction with social support: ↑; appreciation of the positive aspects of caregiving: ↑;

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention		Outcomes			Results
	sample size	Caregiver type	Type	Duration content	Intervention	Social support	Other outcomes	
Easom/2013	85	FCG	Multi-component	6 months	Nine face-to-face (in the home) and three telephone sessions, tailored education and support.	A Risk Appraisal Assessment: three questions of social support	A Risk Appraisal Assessment: five questions addressing caregiver safety and health behaviors, three questions targeting stressors on behavioral frustrations caregiving risk areas of advanced care planning, education, safety, health and healthy behaviors, and caregiving frustrations.	The scores for Self-Care and Social Support increased slightly post-service were not statistically significant, which is in the correct direction.
Nichols/2011	127	FCG	Multi-component	6 months	The intervention included education, support, and skills training to address 5 caregiving risk areas: safety, social support, problem behaviors, depression, and caregiver health.	The 21-question risk appraisal, adapted from REACH II		Depression, burden, impact of depression on daily lives, and caregiving frustrations: ↓; Social support: NS.

Social support interventions for dementia caregivers

Author/Year	Participants Intervention					Outcomes		Results
	sample size	Caregiver type	Type	Duration content	Intervention	Social support	Other outcomes	
Marziali/2011	91	FCG	Multi-component	10 weeks	Online Chat Group Intervention: the Chat Group was provided with access to the CFO website for 6 months; Online Video Conferencing Support Group Intervention: 10 weekly sessions in mutual self-help mode with 1 of the group members manipulating the technical aspects of the video-conferencing meetings.	MSPSS	Caregiver health; Depression; Coping; Cognitive function	The Video Group demonstrated greater improvement in mental health status. For the Video Group, improvements in neuroticism, self-efficacy, and social support were associated with lower stress response to coping with the care recipient's decline in function and cognitive impairment.
Chien/2011	46 vs 46	FCG	Multi-component	6 months	DFCP	satisfaction with social support available: SSQ6; Formal support services: FSSI	Burdin; QOL	Intervention group's utilization of family services was significantly decreased at the 18-month follow-up, the routine care group's service utilization had a slight increase.
Tompkins and Bell/2009	367	FCG	Health educated	12h	12h training	SCP usage questionnaire.	Overall satisfaction; Depression; Overall services used	Depression: ↓; Overall services used: ↑;

Author/Year		Participants			Intervention			Outcomes		Results
		sample size	Caregiver type	Type	Duration content			Social support	Other outcomes	
Chiu/2009		35	FCG	Multi-component	6 months	The ICSS supported two Internet-based communication tools: (a) a caregiver information handbook, and (b) personalized e-mail communication between client and clinician.		MSPSS	Family burden Caregiver's ability Depression; Perceived overall health; PAC were recipients, functioning level.	Burden, social support and health behavior: NS; depression: ↓.
Bank/2006		41	FCG	Multi-component	18 months	Professional provides telephone support group		Support Group Questionnaire	NO	Support group attendance : NS; Intervention Improved relationships among family members, and telephone support groups made them more willing to participate in community support groups

Social support interventions for dementia caregivers

Author/Year	Participants Intervention					Outcomes		Results
	sample size	Caregiver type	Type	Duration content	Intervention	Social support	Other outcomes	
Roth/2005	163 vs 149	Spouse CGs	Counselling group	12 months	Counseling and support	Social support network: caregiver's Satisfaction: methods of Stokes; caregivers' reports of the frequency at which they received information or assistance from support persons.	Stress appraisals of caregiver's behavior; Decision	Intervention group achieved significant increases after 1 year on 8 of the 11 indicators, which were total size of social network, number of close family members, general satisfaction, satisfaction with assistance, satisfaction with emotional support, telephone calls (no. per month), personal visits (no. per month), sitting with patient (no. per month).
Hébert/2003	60 vs 56	Primary CGs	Multi-component	16 weeks	Participants in the study group had fifteen 2-hr weekly sessions focusing on stress appraisal and coping	The Inventory of Socially Supportive Behaviors	Frequency of behavioral and memory problems; Desire to institutionalize; Subjective load	Institutionalization: ↓;personal efficacy: ↑;other outcomes:NS.

Social support interventions for dementia caregivers

Author/Year	sample size		Caregiver type	Participants Intervention		Duration content	Intervention	Social support	Outcomes		Results
				Type					Other outcomes		
Mercedes/2002	19	vs 19	vs	FCG	Multi-component	8 weeks	1.multicomponent + respite group; 2. respite group; 3. control group	MOS	Burden		The control group social support: ↓; the multicomponent plus respite group social support: ↑ after10-month follow-up.
Robinson/1988	11	vs 9		FCG	Health education	8 weeks	Social skill training program	NSSQ	Self-esteem; Social skills; Caregiving burden		Objective and subjective burden: ↓; the treatment group and control group of social support: NS.

FCG: Family caregivers; NR: not reported; SSRS: Social Support Scale; CAI: Caregiver Appraisal Inventory; CBI: Caregiver Burden Inventory; SCSO: Simplified Coping Style Questionnaire; GSES: General Self-Efficacy Scale; ↑ : significant improvement; NS: No Significant difference; ↓ : significant reduction; MSPSS: Multidimensional Scale of Perceived Social Support; PAC: Positive Aspects of Caregiving; CGs: Caregivers; MOS: Medical Outcomes Study; KAD: Knowledge of Alzheimer’s disease/dementia; NSSQ: Norbeck’s Social Support Questionnaire; ISEL: Interpersonal Support Evaluation List; MCSP : Dutch Meeting Centers Support Programme; DFCP: Dementia Family Care Programme; SSQ6: Six-item Social Support Questionnaire; FSSI: Family Support Services Index; MBSR: Mindfulness-Based Stress Reduction; SCP Plus: Senior Companion Program Plus; PwD: people with dementia; ZBI: Zarit Burden Interview

Social support interventions for dementia caregivers

Discussion

Studies have reported interventions to improve social support of caregivers caring older adults with dementia, nevertheless, evidence on the categories of intervention, implementation, evaluation, and effects of these interventions is dispersed in the literature, and an up-to-date summary is lacking. This scoping review comprehensively summarizes existing intervention trials for enhancing social support for dementia caregivers. Six effective interventions, including peer support, group counseling, health education, mindfulness-based stress reduction, individual therapy, and multi-component interventions, were found in this study, which differed in terms of content, duration, acceptance, and effectiveness.

Characteristics of the participants

The individuals involved were the main caregivers who undertook the main caregiving tasks for older individuals with dementia. Although caregivers can also be recruited from facilities such as day care centers, almost all research has focused on improving social support for informal caregivers. Among the included studies, family caregivers consisted of spouses, children, other relatives, neighbors, and friends; only one study mainly focused on spousal caregivers, while the remaining studies included all kinds of caregivers³⁹. Individuals with dementia are mostly looked after by informal caregivers, with special focus on spouses who are considered to be at a higher risk of social isolation⁶¹, which shows that spouses and other caregivers exhibit different responses to social support that alleviates caregivers' pain⁶². Meanwhile, social support among African Americans has gradually received more attention, with three studies investigating social support interventions for African Americans^{53,55,56}. On average, caregivers dedicate about 14 hours daily to caregiving, with 29% providing care around the clock³⁴. The lengthy care time and heavy burden of care weigh on caregivers, which takes a toll on their well-

Social support interventions for dementia caregivers

being. Therefore, through interventions, enhancing caregivers' knowledge of dementia, care skills, and providing respite services can alleviate these difficulties. Interventions tailored to individuals of different races and cultural backgrounds should be developed to effectively enhance social support and coping skills.

Social support measures

A total of 21 different assessment tools were utilized to measure the effect of the interventions: 18 studies used validated scales for evaluation, used self-developed scales, 4 studies used partial items from other scales, and different tools emphasized different aspects. For example, the MSPSS mainly measures perceived social support, and one study evaluated the level of social support based on social networks and the presence or absence of individuals seeking help ⁵⁶. Only three types of tools were described in terms of their reliability and validity. Since social support is a multidimensional concept, different interventions aim to improve different dimensions. While subjective social support is difficult to measure by quantitative methods, more methods focus on objective social support and consider only some aspects of social support, such as restrictions in social participation ³⁴, measuring supported resources ³³, perceived support from significant others, family, and friends ^{35,59}, social networks and the four dimensions of functional social support ²², or satisfaction with support ⁴⁵. Most of the tools measure satisfaction with support, aspects of support received, and positive aspects. Because of the multidimensional nature of the concept of social support, the measurement results can only reflect part of the situation. Therefore, more precise measurement tools need to be developed.

Social support interventions

Six types of interventions to improve social support exist, including peer support, group counselling, health education, mindfulness-based stress reduction, individual therapy, and multi-component interventions. Apparently, support from others is crucial; caregivers of older adults with dementia need

Social support interventions for dementia caregivers

this support initially, and eventually turn to seeking help and support. Caregivers from various regions possess distinct requirements regarding the methods and types of support they need. The findings from the included studies indicate that multi-component interventions enhance social support for caregivers across different domains, such as emotional, practical, and informational support. Multi-component interventions fit the concept of multidimensional social support, and involve integrating multiple intervention measures in the fields of health education, care skills, coping strategies, and social support for dementia caregivers, these have been demonstrated to effectively alleviate the burden on caregivers, decrease depressive symptoms, and increase their perceived satisfaction. The intervention content includes mental health-related educational programs, supportive services, respite care or adult daycare, psychotherapy, caregiver competence, and can be delivered on an individual or group basis²⁶, which can be intervened in from all aspects to improve the overall social support of caregivers. Peer support has demonstrated advantages for individuals with various requirements, including alleviating depressive symptoms⁶³, enhancing coping strategies⁶⁴, and reducing feelings of isolation and loneliness. Qualitative research indicates that caregivers value opportunities to discuss challenging experiences and obtain guidance from volunteers⁶⁵. Because peer support primarily enhances caregiver social support from an emotional perspective, there is a significant need for emotional and informational support⁵²; people who have the same experience can better provide emotional support to each other, thus reducing the emotional burden. Health education can enhance caregivers' care skills and confidence through a series of sessions^{36,51}. Health education has better effects in improving depression and self-reported health; however, its single intervention method can be covered by multi-component intervention. Interventions such as consultation groups, mindfulness-based stress reduction, and individualized treatment, have good outcomes in improving social support.

Social support interventions for dementia caregivers

However, the angle of improvement is relatively one-dimensional, which can be used as a part of multi-component intervention, so as to achieve multidimensional improvement. Delivery intervention methods include face-to-face, telephone-based and Internet-based intervention, as well as online and offline combinations. Since most caregivers are also older adults who cannot use electronic devices smoothly, they are more willing to accept face-to-face intervention; at the same time, face-to-face feedback can be more prompt, although it is not always feasible, given that it is challenging for caregivers to leave older individuals with dementia unattended at home or due to their residence in remote locations where face-to-face support is in accessible ³⁴. Therefore, telephone- and internet-based interventions are increasingly being applied to social support interventions. Another study indicates that technology-assisted interventions help alleviate caregiver burden and enhance support, similar to face-to-face support ⁶⁶. Considering that online and offline interventions have their own characteristics and shortcomings, the combination of the two can effectively reduce inconvenience and provide better and more comprehensive application of intervention measures to caregivers, to ensure they can receive more effective support to reduce their burden, ultimately enhancing the well-being of older individuals with dementia.

Interventions outcomes

Drawing from the studies that were included, improvement of social support can lay a good foundation for reducing the care burden, depression and stress and eventually enhancing the well-being of caregivers, and multi-component interventions can improve multiple dimensions of social support. In the implementation of interventions in the future, smarter and easier-to-operate intervention equipment can be developed for caregivers, such as voice control or AI equipment, so that their operation can be more easily mastered, and the distance between people can be narrowed. Simultaneously, it is crucial to consider the unique requirements of caregivers with diverse backgrounds in

Social support interventions for dementia caregivers

order to amplify the benefits of ongoing support initiatives. In the future It is also possible to develop interventions that simultaneously contain the essence of six categories, leverage their respective characteristics, integrate their advantages into one intervention, and maximize their effectiveness.

Limitations

Due to language barriers, this review only included English language literature and did not include gray literature, which might have overlooked some information. In addition, we included only primary studies and excluded reviews, which may have resulted in missing on significant findings.

Conclusion

This scoping review presents an extensive examination of the landscape of social support interventions implemented in the field of dementia care; however, in the process of caring older adults with dementia, problems remain related to seeking support and in delivering interventions. We suggest that combining online and offline interventions with caregivers probably can achieve the results with the effort. Future research can integrate existing technologies and utilize them to provide comprehensive interventions to caregivers. Meanwhile, it is necessary to conduct research with larger sample sizes and different cultures, and identify interventions suitable for different people. At the same time, interventions with more durable effects need to be explored.

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Social support interventions for dementia caregivers

Declaration of Competing Interests

The authors declare that they have no competing interests.

References:

1. World Alzheimer Report 2023 | Alzheimer’s Disease International (ADI). Accessed August 7, 2024. <https://www.alzint.org/resource/world-alzheimer-report-2023/>

2. 2021 Alzheimer’s disease facts and figures. *Alzheimers Dement*. 2021;17(3):327-406. doi:10.1002/alz.12328

3. Huisman C, Huisman E, Kort H. Technological Applications Contributing to Relieve Care Burden or to Sleep of Caregivers and People With Dementia: A Scoping Review From the Perspective of Social Isolation. *Front Public Health*. 2022;10:797176. doi:10.3389/fpubh.2022.797176

4. Theißen T, Ullrich A, Oechsle K, Wikert J, Bokemeyer C, Schieferdecker A. “Being an informal caregiver - strengthening resources”: mixed methods evaluation of a psychoeducational intervention supporting informal caregivers in palliative care. *BMC Palliat Care*. 2024;23(1):95. doi:10.1186/s12904-024-01428-0

5. 2020 Alzheimer’s disease facts and figures. *Alzheimers Dement*. Published online March 10, 2020. doi:10.1002/alz.12068

6. Davies N, Iliffe S, Hopwood J, et al. The key aspects of online support that older family carers of people with dementia want at the end of life: A qualitative study. *Aging Ment*

Social support interventions for dementia caregivers

- Health*. 2020;24(10):1654-1661. doi:10.1080/13607863.2019.1642299
7. Stoltz P, Udén G, Willman A. Support for family carers who care for an elderly person at home - a systematic literature review. *Scand J Caring Sci*. 2004;18(2):111-119. doi:10.1111/j.1471-6712.2004.00269.x
 8. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatr*. 2018;18(1):189. doi:10.1186/s12877-018-0885-1
 9. Kerres Malecki C, Kilpatrick Demary M. Measuring perceived social support: Development of the child and adolescent social support scale (CASSS). *Psychology in the Schools*. 2002;39(1):1-18. doi:10.1002/pits.10004
 10. Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Soc Sci Med*. 2006;63(4):957-967. doi:10.1016/j.socscimed.2006.02.020
 11. Antonucci T. Social Supports, and Social Relationships. In; 1990. Accessed November 9, 2023. <https://www.semanticscholar.org/paper/Social-Supports%2C-and-Social-Relationships-Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2>
 12. Caplan G, Killilea M, Abrahams RB, eds. *Support Systems and Mutual Help*.

Social support interventions for dementia caregivers

Multidisciplinary Explorations. Grune & Stratton; 1976.

13. Hupcey JE. Clarifying the social support theory-research linkage. *J Adv Nurs*. 1998;27(6):1231-1241. doi:10.1046/j.1365-2648.1998.01231.x

14. Cheng Y, Li X, Lou C, et al. The association between social support and mental health among vulnerable adolescents in five cities: findings from the study of the well-being of adolescents in vulnerable environments. *J Adolesc Health*. 2014;55(6 Suppl):S31-38. doi:10.1016/j.jadohealth.2014.08.020

15. Uchino BN. Understanding the Links Between Social Support and Physical Health: A Life-Span Perspective With Emphasis on the Separability of Perceived and Received Support. *Perspect Psychol Sci*. 2009;4(3):236-255. doi:10.1111/j.1745-6924.2009.01122.x

16. Barrera M, Fleming CF, Khan FS. The role of emotional social support in the psychological adjustment of siblings of children with cancer. *Child Care Health Dev*. 2004;30(2):103-111. doi:10.1111/j.1365-2214.2003.00396.x

17. Cobb S. Presidential Address-1976. Social support as a moderator of life stress. *Psychosom Med*. 1976;38(5):300-314. doi:10.1097/00006842-197609000-00003

18. Kaplan BH, Cassel JC, Gore S. Social support and health. *Med Care*. 1977;15(5 SUPPL):47-58. doi:10.1097/00005650-197705001-00006

19. Cohen S. Social relationships and health. *Am Psychol*. 2004;59(8):676-684.

Social support interventions for dementia caregivers

doi:10.1037/0003-066X.59.8.676

20. Sw W, Cs W, S Z, J M, D D, Pd S. Emotional and physical health of informal caregivers of residents at the end of life: the role of social support. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2008;63(3). doi:10.1093/geronb/63.3.s171
21. Feldstein AC, Nichols GA, Elmer PJ, Smith DH, Aickin M, Herson M. Older women with fractures: patients falling through the cracks of guideline-recommended osteoporosis screening and treatment. *J Bone Joint Surg Am*. 2003;85(12):2294-2302.
22. Cerquera Córdoba, A. M., Tiga-Loza, D. C., Álvarez Anaya, W. A., Dugarte Peña, E., Jaimes Espíndola, L. R., & Plata Osma, L. J. (2021). Ensayo controlado aleatorizado de un programa multicomponente para cuidadores informales de pacientes con Alzheimer. *Revista Cuidarte*, 12(2), e2002.
23. Chen L, Zhao Y, Tang J, et al. The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: a qualitative study. *BMC Psychiatry*. 2019;19(1):75. doi:10.1186/s12888-019-2052-4
24. Elovainio M, Komulainen K, Sipilä PN, et al. Association of social isolation and loneliness with risk of incident hospital-treated infections: an analysis of data from the UK Biobank and Finnish Health and Social Support studies. *Lancet Public Health*. 2023;8(2):e109-e118. doi:10.1016/S2468-2667(22)00253-5
25. Dam AEH, de Vugt ME, Klinkenberg IPM, Verhey FRJ, van Boxtel MPJ. A systematic

Social support interventions for dementia caregivers

review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*. 2016;85:117-130. doi:10.1016/j.maturitas.2015.12.008

26. Bank AL, Argüelles S, Rubert M, Eisdorfer C, Czaja SJ. The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist*. 2006;46(1):134-138. doi:10.1093/geront/46.1.134
27. Cheng ST, Zhang F. A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. *BMC Geriatr*. 2020;20(1):137. doi:10.1186/s12877-020-01547-2
28. Kampanellou E, Chester H, Davies L, et al. Carer preferences for home support services in later stage dementia. *Aging Ment Health*. 2019;23(1):60-68. doi:10.1080/13607863.2017.1394441
29. Brennan PF, Moore SM, Smyth KA. Alzheimer's disease caregivers' uses of a computer network. *West J Nurs Res*. 1992;14(5):662-673. doi:10.1177/019394599201400508
30. Lee Y, Choi S. Korean American dementia caregivers' attitudes toward caregiving: the role of social network versus satisfaction with social support. *J Appl Gerontol*. 2013;32(4):422-442. doi:10.1177/0733464811431163
31. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169(7):467-473.

Social support interventions for dementia caregivers

doi:10.7326/M18-0850

32. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*. 2005;8(1):19-32. doi:10.1080/1364557032000119616
33. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc*. 2013;61(8):1377-1386. doi:10.1111/jgs.12362
34. Berwig M, Lessing S, Deck R. Telephone-based aftercare groups for family carers of people with dementia - results of the effect evaluation of a randomised controlled trial. *BMC Health Serv Res*. 2022;22(1):177. doi:10.1186/s12913-022-07490-9
35. Christie HL, Dam AEH, van Boxtel M, Köhler S, Verhey F, de Vugt ME. Lessons Learned From an Effectiveness Evaluation of Inlife, a Web-Based Social Support Intervention for Caregivers of People With Dementia: Randomized Controlled Trial. *JMIR Aging*. 2022;5(4):e38656. doi:10.2196/38656
36. Robinson KM. A social skills training program for adult caregivers. *ANS Adv Nurs Sci*. 1988;10(2):59-72. doi:10.1097/00012272-198801000-00010
37. Gustafson DH, Gustafson DH, Cody OJ, Chih MY, Johnston DC, Asthana S. Pilot Test of a Computer-Based System to Help Family Caregivers of Dementia Patients. *J Alzheimers Dis*. 2019;70(2):541-552. doi:10.3233/JAD-190052

Social support interventions for dementia caregivers

38. Hébert R, Lévesque L, Vézina J, et al. Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. *J Gerontol B Psychol Sci Soc Sci*. 2003;58(1):S58-67. doi:10.1093/geronb/58.1.s58

39. Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging*. 2005;20(4):634-644. doi:10.1037/0882-7974.20.4.634

40. Chien WT, Lee IYM. Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *J Adv Nurs*. 2011;67(4):774-787. doi:10.1111/j.1365-2648.2010.05537.x

41. Whitebird RR, Kreitzer M, Crain AL, Lewis BA, Hanson LR, Enstad CJ. Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *Gerontologist*. 2013;53(4):676-686. doi:10.1093/geront/gns126

42. Tremont G, Davis JD, Ott BR, et al. Randomized Trial of the Family Intervention: Telephone Tracking-Caregiver for Dementia Caregivers: Use of Community and Healthcare Resources. *J Am Geriatr Soc*. 2017;65(5):924-930. doi:10.1111/jgs.14684

43. Töpfer NF, Sittler MC, Lechner-Meichsner F, Theurer C, Wilz G. Long-term effects of telephone-based cognitive-behavioral intervention for family caregivers of people with dementia: Findings at 3-year follow-up. *J Consult Clin Psychol*. 2021;89(4):341-349. doi:10.1037/ccp0000640

Social support interventions for dementia caregivers

44. van Wezel N, van der Heide I, Devillé WL, et al. Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: A cluster randomised controlled trial. *Patient Educ Couns*. 2021;104(7):1726-1735. doi:10.1016/j.pec.2020.11.008
45. Czaja SJ, Lee CC, Perdomo D, et al. Community REACH: An Implementation of an Evidence-Based Caregiver Program. Meeks S, ed. *The Gerontologist*. 2018;58(2):e130-e137. doi:10.1093/geront/gny001
46. Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial intervention for dementia caregivers. *Am J Geriatr Psychiatry*. 2013;21(11):1071-1081. doi:10.1016/j.jagp.2013.02.019
47. Easom LR, Alston G, Coleman R. A Rural Community Translation of a Dementia Caregiving Intervention. *Online Journal of Rural Nursing and Health Care*. 2013;13(1):66-91. doi:10.14574/ojrnhc.v13i1.248
48. Lykens K, Moayad N, Biswas S, Reyes-Ortiz C, Singh KP. Impact of a community based implementation of REACH II program for caregivers of Alzheimer's patients. *PLoS One*. 2014;9(2):e89290. doi:10.1371/journal.pone.0089290
49. Marziali E, Garcia LJ. Dementia caregivers' responses to Internet-based intervention programs. *Am J Alzheimers Dis Other Dement*. 2011;26(1):36-43. doi:10.1177/1533317510387586
50. Nichols LO, Martindale-Adams J, Burns R, Graney MJ, Zuber J. Translation of a

Social support interventions for dementia caregivers

Dementia Caregiver Support Program in a Health Care System—REACH VA. *Arch Intern Med.* 2011;171(4). doi:10.1001/archinternmed.2010.548

51. Tompkins SA, Bell PA. Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer’s caregiver. *J Gerontol Soc Work.* 2009;52(2):89-104. doi:10.1080/01634370802561877

52. Wilkerson DA, Brady E, Yi EH, Bateman DR. Friendsourcing Peer Support for Alzheimer’s Caregivers Using Facebook Social Media. *Journal of Technology in Human Services.* 2018;36(2-3):105-124. doi:10.1080/15228835.2018.1449709

53. Xu L, Fields NL, Williams IC, et al. The Senior Companion Program Plus (SCP Plus): Examining the Preliminary Effectiveness of a Lay Provider Program to Support African American Alzheimer’s Disease and Related Dementias (ADRD) Caregivers. *Int J Environ Res Public Health.* 2023;20(7):5380. doi:10.3390/ijerph20075380

54. Blackberry I, Rasekaba T, Morgan D, et al. Virtual Dementia-Friendly Communities (Verily Connect) Stepped-Wedge Cluster-Randomised Controlled Trial: Improving Dementia Caregiver Wellbeing in Rural Australia. *Geriatrics (Basel).* 2023;8(5):85. doi:10.3390/geriatrics8050085

55. Glueckauf RL, Kazmer MM, Nowakowski ACH, et al. African American Alzheimer’s Caregiver Training and Support Project 2 (ACTS2) pilot study: Outcomes analysis. *Rehabil Psychol.* 2022;67(4):437-448. doi:10.1037/rep0000470

Social support interventions for dementia caregivers

56. Fields NL, Xu L, Richardson VE, Parekh R, Ivey D, Calhoun M. Utilizing the Senior Companion Program as a platform for a culturally informed caregiver intervention: Results from a mixed methods pilot study. *Dementia (London)*. 2021;20(1):161-187. doi:10.1177/1471301219871192
57. Szcześniak D, Rymaszewska J, Saibene FL, et al. Meeting centres support programme highly appreciated by people with dementia and carers: a European cross-country evaluation. *Aging Ment Health*. 2021;25(1):149-159. doi:10.1080/13607863.2019.1683814
58. Smith R, Drennan V, Mackenzie A, Greenwood N. The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Arch Gerontol Geriatr*. 2018;76:188-195. doi:10.1016/j.archger.2018.03.005
59. Chiu T, Marziali E, Colantonio A, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with Alzheimer disease and related dementia. *Can J Aging*. 2009;28(4):323-336. doi:10.1017/S0714980809990158
60. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32(6):705-714. doi:10.1016/0277-9536(91)90150-b
61. Zhu X, Chen S, He M, et al. Life experience and identity of spousal caregivers of people with dementia: A qualitative systematic review. *Int J Nurs Stud*. 2024;154:104757. doi:10.1016/j.ijnurstu.2024.104757
62. Burgio L, Stevens A, Guy D, Roth DL, Haley WE. Impact of two psychosocial

Social support interventions for dementia caregivers

interventions on white and African American family caregivers of individuals with dementia. *Gerontologist*. 2003;43(4):568-579. doi:10.1093/geront/43.4.568

63. Mead N, Lester H, Chew-Graham C, Gask L, Bower P. Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis. *Br J Psychiatry*. 2010;196(2):96-101. doi:10.1192/bjp.bp.109.064089

64. Bjorck JP, Klewicki LL. The effects of stressor type on projected coping. *J Trauma Stress*. 1997;10(3):481-497. doi:10.1023/a:1024849522973

65. Greenwood N, Habibi R, Mackenzie A, Drennan V, Easton N. Peer support for carers: a qualitative investigation of the experiences of carers and peer volunteers. *Am J Alzheimers Dis Other Dement*. 2013;28(6):617-626. doi:10.1177/1533317513494449

66. Lee E. Do Technology-Based Support Groups Reduce Care Burden Among Dementia Caregivers? A Review. *J Evid Inf Soc Work*. 2015;12(5):474-487. doi:10.1080/15433714.2014.930362

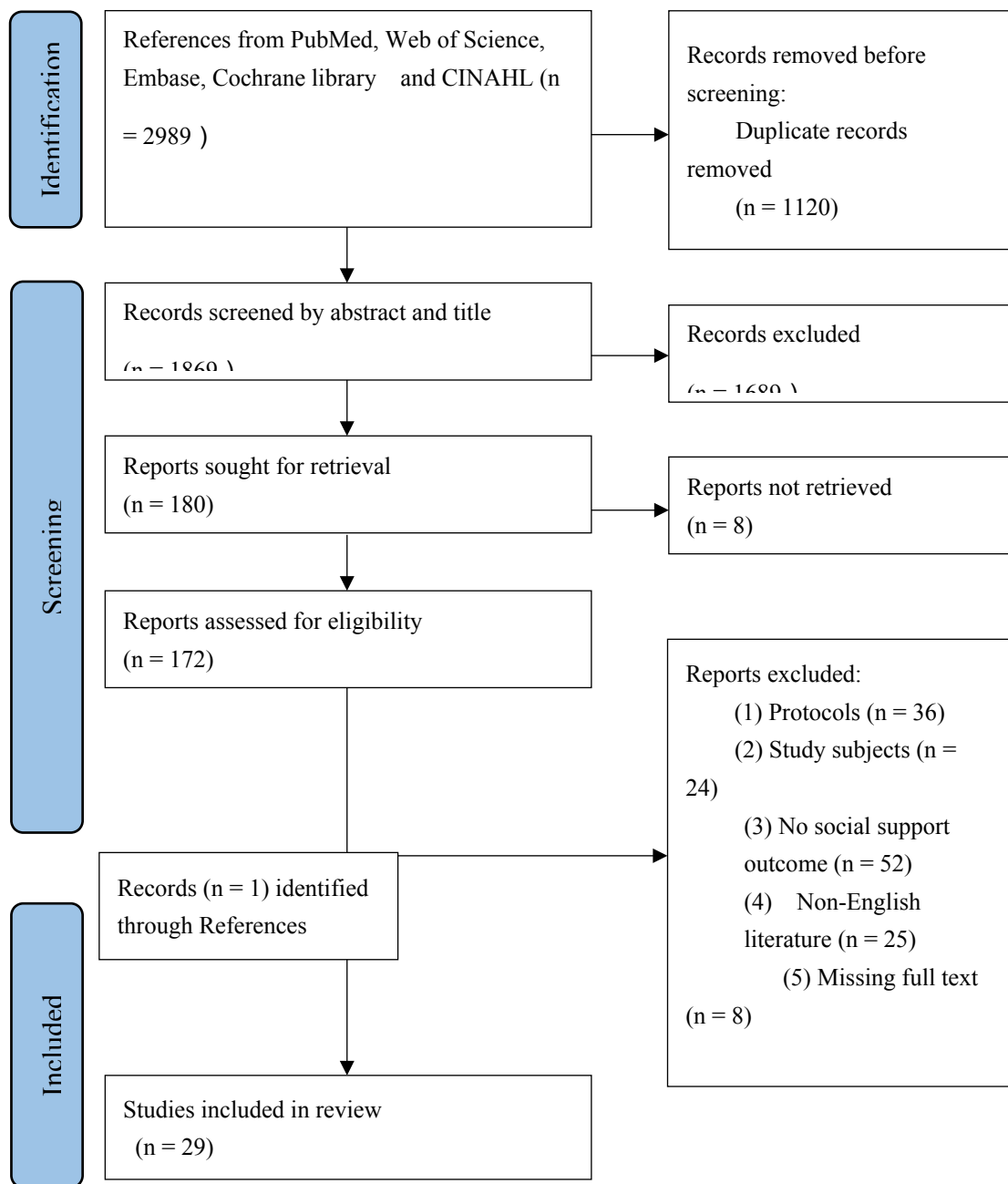
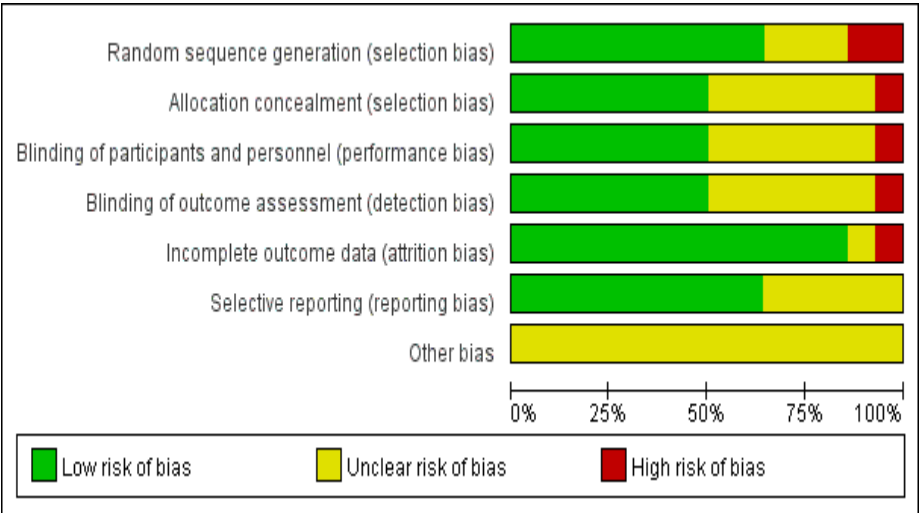


Fig.1 PRISMA flow diagram



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Adam L. Bank et al. 2006	Low	Unclear	Unclear	Unclear	Low	Low	Unclear
Cerquera Mercedes et al. 2002	Low	Low	Low	Low	Low	Low	Unclear
DavidH. Gustafson Jr et al. 2019	Unclear	Unclear	Unclear	Unclear	Low	Low	Unclear
David L. Roth et al. 2005	Low	Low	High	High	High	Unclear	Unclear
David M. Bass et al. 2013	Low	Low	Low	Low	Low	Unclear	Unclear
Geoffrey Tremont et al. 2017	Low	Low	Low	Low	Low	Low	Unclear
Hannah Liane Christie et al. 2022	Low	Low	Low	Low	Low	Low	Unclear
KarenMeier Robinson et al. 1988	High	High	Unclear	Unclear	Unclear	Unclear	Unclear
Martin Berwig et al. 2022	Low	Low	Unclear	Unclear	Low	Low	Unclear
Nienke van Wezel 2021	Low	Low	Low	Low	Low	Unclear	Unclear
Nils F. Töpfer et al. 2021	Unclear	Unclear	Unclear	Unclear	Low	Low	Unclear
Réjean Hébert et al. 2003	Unclear	Unclear	Low	Low	Low	Unclear	Unclear
Robin R. Whitebird et al. 2013	Low	Unclear	Low	Low	Low	Low	Unclear
Wai Tong Chien et al. 2011	Low	Unclear	Unclear	Unclear	Low	Low	Unclear

Fig.2 Risk of bias graph.

Database	Search strategy
PubMed	<ol style="list-style-type: none"> 1. ("Dementia"[Mesh]) 2. Amentia [Title/Abstract] 3. Senile Dementia [Title/Abstract] 4. Familial Dementia [Title/Abstract] 5. "Alzheimer Disease"[Mesh] 6. Alzheimer Dementias [Title/Abstract] 7. Presenile Alzheimer Dementia [Title/Abstract] 8. (Presenile Alzheimer Dementia [Title/Abstract]) 9. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 10. "Caregivers"[Mesh] 11. Carers [Title/Abstract] 12. 10 OR 11 13. "Social Support"[Mesh] 14. Social care [Title/Abstract] 15. Perceived social Support [Title/Abstract] 16. 13 OR 14 OR 15 17. Interventions [Title/Abstract] 18. program*[Title/Abstract] 19. 17 OR 18 20. 9 AND 12 AND 16 AND 19
Web of Science	<ol style="list-style-type: none"> 1. TS= (dement* OR ament* OR Lewy Body Disease OR

	<p>Alzheimer* OR Alzheimer disease OR senile dementia)</p> <p>2. TS= (caregiver* OR carer*)</p> <p>3. TS= ("social support")</p> <p>4. TS=(intervention*)</p> <p>5. (1 AND 2 AND 3 AND 4)</p>
Cinahl	<p>S1. (MH "Dementia") OR (MH "Dementia, Vascular") OR (MH "Dementia, Senile) OR (MH "Dementia, Presenile) OR (MH "Alzheimer's Disease")</p> <p>S2. AB dement* OR Alzheimers OR cognitive impairment OR memory loss OR amenti*</p> <p>S3. S1 OR S2</p> <p>S4. AB caregiver* OR carer*</p> <p>S5. AB social support OR social network</p> <p>S6. AB interventions OR strategies OR best practices</p> <p>S7. S3 AND S4 AND S5 AND S6</p>
Cochrane	<p>#1. MeSH descriptor: [Dementia] explode all trees</p> <p>#2. MeSH descriptor: [Alzheimer Disease] explode all trees</p> <p>#3. (Amenti* OR Dementi* OR Alheimer* disease): ti,ab,kw</p> <p>#4. #1 OR #2 OR #3</p> <p>#5. MeSH descriptor: [Caregivers] explode all trees</p> <p>#6. (Caregiver* OR Carer*): ti, ab, kw</p> <p>#7. #5 OR #6</p>

	<p>#8. MeSH descriptor:[Social support] explode all trees</p> <p>#9. (social support OR social network): ti, ab, kw</p> <p>#10. #8 OR #9</p> <p>#11. (intervention*): ti, ab, kw</p> <p>#12. #4 AND #7 AND #10 AND #11</p>
EMBASE	<p>#1. 'dementia'/exp</p> <p>#2. amenti*:ti,ab,kw OR dementi*:ti,ab,kw</p> <p>#3. 'alzheimer disease'/exp</p> <p>#4. 'alzheimer disease':ti,ab,kw OR 'alzheimer dementia':ti,ab,kw OR alzheimer*:ti,ab,kw OR 'senile dementia':ti,ab,kw</p> <p>#5. #1 OR #2 OR #3 OR #4</p> <p>#6. 'caregiver'/exp</p> <p>#7. caregiver*:ti,ab,kw OR carer*:ti,ab,kw</p> <p>#8. #6 OR #7</p> <p>#9. 'social support'/exp</p> <p>#10. 'social support':ti,ab,kw</p> <p>#11. #9 OR #10</p> <p>#12. intervention*:ti,ab,kw</p> <p>#13. #5 AND #8 AND #11 AND #12</p>

Social support interventions for caregivers of older adults with dementia: A scoping review

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Primary Subject Heading:	Nursing
Secondary Subject Heading:	Mental health
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Social support interventions for dementia caregivers

Social support interventions for caregivers caring old adults with dementia: A scoping review

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Social support interventions for dementia caregivers

Social support interventions for caregivers of older adults with dementia: A scoping review

Abstract

Objectives To identify and assess the social support interventions provided to caregivers of older adults with dementia, and summarize the outcomes of the interventions.

Design A scoping review.

Data sources The PRISMA Extension for Scoping Reviews was adhered to, and searches were conducted across five databases (PubMed, Web of Science, Embase, Cochrane Library, CINAHL) from their inception through February 2025.

Eligibility criteria for selecting studies We included original intervention studies published in English that examined social support interventions for caregivers of older adults with dementia, focusing on outcomes reporting social support.

Data extraction and synthesis Data extraction was conducted using a standardized Microsoft Excel chart based on Arksey and O'Malley's method. Two reviewers independently collected information on study characteristics (authors, country, publication year, design, sample size, assessment tools, interventions, and outcomes). Disagreements were resolved by a third independent reviewer.

Results A sum of 31 studies were chosen, and six categories of social support for caregivers of older adults with dementia emerged across various studies, included peer support (n = 7), counselling group intervention (n = 2), health education (n = 2), mindfulness-based stress reduction intervention (n = 1), individual therapy (n = 1), and multicomponent interventions (n = 18). These interventions enhanced the social support of caregivers, and showed positive outcomes in terms of reducing caregivers' caring burden, anxiety, depression, and improving caregivers' coping skills.

Conclusion This review presents the diversification of interventions that enhance social support for caregivers of older adults with dementia. The findings offer insights for caregivers of older adults with dementia, along with administrators and other stakeholders, to adopt and promote appropriate social support for caregivers.

Registration: A review protocol was registered on the OSF registries, with the following registration doi:

Social support interventions for dementia caregivers

<https://doi.org/10.17605/OSF.IO/D9C53>

Strengths and limitations of this study:

- This scoping review used a comprehensive search for articles included interventions which were designed to target caregivers of older individuals with dementia.
- We conducted a quality evaluation on the included Rcts, but not on other types of studies.
- This study only included articles published in English and did not include grey literature or conference literature.

Background

According to World Health Organization(WHO) 2023 Report, dementia affects over 55 million people, globally, with projections indicating a rise to 139 million by 2050, driven by global population ageing¹. Dementia will become the 7th leading cause of mortality globally ². Caring for older adults with dementia presents significant challenges due to the progressive cognitive decline and neuropsychiatric manifestations associated with the condition, including behavioural and psychological symptoms of dementia (BPSD)³. Caregivers caring people with dementia may be formal or informal; with the latter playing a crucial role in supporting older adults suffering from advanced, terminal illnesses⁴. Informal caregivers typically refer to family members, friends, or relatives who voluntarily provide daily care and support for people with dementia, but always unpaid⁵. Formal caregivers refer to professionally trained nursing staff, such as nurses, nursing assistants, rehabilitation therapists, etc., who provide professional nursing services to people with dementia and usually receive compensation⁶. Approximately 16 million individuals serve as unpaid caregivers, dedicating over 18.6 billion hours to assist older adults with dementia ⁷. Caregiving for individuals with dementia is a time-intensive role, often requiring substantial personal and temporal commitments. The progressive nature of dementia exacerbates challenges for family caregivers, particularly in managing neuropsychiatric symptoms and functional decline⁸.

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Social support interventions for dementia caregivers

Numerous caregivers often feel isolated and helpless due to a lack of emotional support, informational support, and practical assistance⁹. Evidence suggests that family caregivers of individuals with dementia experience elevated caregiver burden, depressive symptoms, and reduced quality of life relative to caregivers of patients with non-dementia chronic conditions¹⁰. Caregivers play a crucial role in dementia care, and their needs and experience are essential for developing effective social support interventions. However, research has shown that the needs of caregivers are often overlooked in the service development process¹¹. Studies have found that interventions developed in collaboration with caregivers have shown better results in reducing care burden and improving mental health of caregivers¹².

Social support refers to the emotional, informational, material, and behavioral assistance individuals receive in social relationships, which helps alleviate stress, enhance psychological resilience, and promote individual mental health¹³. Which refers to subjective or objective effects on individuals of various social relationships embedded in social networks¹⁴, and comes from all aspects of society, including emotional, specific, and informational support¹⁵, and social support encompasses the exchange of emotional connections (affection, love, admiration, and respect), affirmation (agreement, acknowledgement of the appropriateness of an action, statements, or perspectives), and assistance (provision of resources, financial support, information, guidance, or favors)¹⁶. This concept describes the consistent social engagement between individuals and groups with shared values, serving as a source of mental motivation, feedback, assistance, and material support¹⁷. In theoretical terms, social support framework can be seen as a provider-centric model, where one or more people or network participants offer valuable assistance to the beneficiary¹⁸. Social support provides a defense against stress, developing psychological resilience¹⁹ and advancing coping strategies²⁰. Social support also moderates the relationship between self-

efficacy and mental health²¹.

As an external resource, social support can contribute to enhancing the physical well-being of caregivers^{19,20}. The substantial stress of caregiving responsibilities may exacerbate negative emotions like anxiety and depression among caregivers, adversely affecting their mental and physical well-being²⁴and potentially diminishing the quality of care provide. Moreover, the demands of caregiving role may increase loneliness²². Social support is crucial to one's well-being; however, a Chinese study found that due to stigma, caregivers are often reluctant to pursue social support, and this isolation can further aggravate their caregiving load²⁶.Such factors severely affect the caregivers' physical and mental well-being, increasing the potential for heart-related diseases²⁷.

Targeted social support interventions are critical for caregivers of older adults with dementia, a population that often depends on informal support networks to mitigate caregiving burden and sustain psychosocial resilience²⁸. Interventions such as psychological training, therapeutic treatments, and self-care programs have been shown to reduce stress associated with behavioral and emotion issues²⁹. In England, for those caring for advanced dementia, respite care is commonly the top choice³⁰. In terms of delivery of interventions, computer networks have been a key methods since the 1990s³¹. Emerging evidence indicates that technology-based interventions, such as digital communication platforms, can improve social connectedness and alleviate loneliness among older adults, particularly those experiencing social isolation³².As social support improves, individuals find it easier to deal with life's challenges. Concurrently, a study has discovered that the satisfaction levels of social support greatly affects Korean American caregivers' attitude towards people with dementia³³. Despite the growing diversity of social support interventions for dementia caregivers, fragmented evidence—marked by methodological heterogeneity and inconsistent outcome reporting—limits robust synthesis of their effectiveness and implementation fidelity.

Social support interventions for dementia caregivers

This scoping review aimed to integrate social support research currently applied to caregivers of older adults with dementia. This scoping review 1) summarizes the types of existing research evidence, such as studies on social support and evaluation of research populations; 2) provides an overview of the specific content of interventions for social support and the outcomes for specific measurements; and 3) assesses the effectiveness of documented interventions of social support for caregivers.

Methods

Research questions

The review targeted the subsequent research questions: (1) What types of support are designed to improve caregivers of older individuals with dementia's social support? (2) What types of tools are utilized to assess social support and what outcomes were evaluated? (3) What effects are observed after utilizing these interventions for caregivers of older adults with dementia?

Search strategy

This scoping review was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist³⁴. This study followed the requirements of Arksey and O'Malley's methodological framework³⁵, which includes: 1) identifying the research question, 2) searching for relevant studies, 3) selecting studies, 4) charting the data, and 5) collecting, summarizing, and reporting the results. To identify the evidence in this field by mapping out the existing research on this topic, we conducted searches across five key databases: PubMed, Web of Science, Embase, Cochrane Library, and CINAHL. The search strategy aimed to identify studies meeting the inclusion criteria. A preliminary search was performed to locate relevant literature on the topic (see Supplemental search strategy). The search strategy is discussed and formulated by team members, and the retrieval is independently conducted by two master's students with medical experience, the keywords "dementia

Social support interventions for dementia caregivers

caregivers,” “social support,” and “intervention” were comprehensively searched to find pertinent evidence from the inception of the databases up to February 2025.

Eligibility criteria

This scoping review encompassed research on social support interventions aimed at caregivers of older individuals with dementia. Interventions which were designed to target caregivers of older individuals with dementia, at the same time reported social support outcomes. Only original intervention studies with full texts were included. Inclusion was also limited to English language published literatures.

Exclusion criteria

Studies in which the full text was unavailable, vital information was completely lacking, or without an explicit methodology were excluded; studies not published in English were excluded in this review.

Types of sources

Consistent with the review questions, this scoping review incorporated intervention studies, including randomized controlled trials (RCTs), nonrandomized controlled trials (NRCTs), and mixed-methods studies.

Study selection

Citations were imported into EndNote X9 citation management software, and duplicates removed. Before the screening process began, all reviewers received standardized training. Two researchers independently conducted the preliminary screening of eligibility based on the titles and abstracts. Following that, they independently reviewed the full texts for further assessment against the predefined inclusion and exclusion criteria, and meticulously documented the rationale for the exclusion of any studies. Exclusion criteria were documented, discrepancies among the authors were addressed through consultation with an additional. The search results are presented in the Preferred Reporting Items for Scoping Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1).

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Data extraction

A standardized data chart was created in Microsoft Excel based on Arksey and O'Malley's data extraction form ³⁵, after consultation between all authors to extract data from the included records. Two investigators separately collected pertinent information from the eligible studies. A Microsoft Office Excel table was designed, and two reviewers independently extracted details, including information obtained in the studies covering authors' name, country of origin, publication year, study design, characteristics, sample size and assessment tools, intervention strategies (i.e., intervention types, frequency, tools, and outcomes), main findings of the study. Any disagreements were adjudicated by an additional independent reviewer.

Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Results

Overview of findings

The initial search identified 3127 relevant citations (Fig.1). After the deduplication process, 1871 articles were selected for inclusion. Following the review of titles and abstracts, 183 studies were chosen for further assessment in full-text review. Among these, 143 articles were ruled out for the following reasons: research designed with protocols (n = 36), participants did not fulfill the eligibility criteria (n = 24), outcomes that did not include social support (n = 52), not published in English (n = 25), missing full texts (n = 8). Ultimately, 31 studies were incorporated in this scoping review. Figure 1 illustrates the PRISMA flow diagram detailing the screening process. Regarding the article for which the full text cannot be obtained, attempts have been made to contact the author, but no response has been received.

Study characteristics

A total of 31 studies were published spanning the period from 1988 and 2025. Among these, 16 studies were RCTs^{36–51}, eight were NRCTs^{52–59}, and seven were mixed methods studies^{60–66}. The majority of the studies were carried out in the United States (n = 19), Europe (n = 11), Oceania (n = 1), and Asia (n = 2). Table 1 provides an overview of the of the fundamental details of the included studies. From the perspective of intervention settings, two studies were conducted in long-term care institutions^{22,34}, 10 in the community^{36,37,51,52,55,56,58,60,61,64}, and 19 in older adult’s homes^{35–44,46,47,50,52,55,56,58,59,50}. The total sample size of caregivers was 4629, ranging from 12 to 494, with a median of 85 cases. The majority of included studies targeted family caregivers of older adults with dementia, with representation across diverse cultural contexts. Three studies specifically evaluated culturally tailored social support interventions for African American caregivers, highlighting gaps in evidence for underserved populations^{60,62,63}, one focused on caregivers with Turkish and Moroccan backgrounds living in the Netherlands⁴⁹, and one investigated how to enhance social support among Chinese Canadian caregivers⁶⁶. While interventions were frequently delivered in community-based or clinical settings (e.g., day centres, outpatient clinics), the majority targeted family caregivers of people with dementia broadly, with only one study focusing explicitly on spousal caregivers through dyadic, kinship-specific support frameworks⁴⁴.

Quality appraisal

This article conducted a quality appraisal of the included RCTs, and more than 75% of the studies that were included were assessed to have a low risk of bias in the subsequent domains: 1) sequence generation; 2) blinding of outcome assessment; 3) selective reporting; However, less than 60% were rated as low risk for the method of: 1) allocation concealment; 2) blinding of participants and personnel; 3) incomplete outcome data; and 4) other potential biases (Fig. 2).

Table 1 Characteristics of included studies

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Social support interventions for dementia caregivers

Author	Year	Country	Design	Setting	Sample
Neal et al	2024	Netherlands	RCT	Community	150
Xiao et al	2024	China	RCT	Home	266
Xu et al.	2023	USA	Mixed methods	Community	20
Blackberry et al.	2023	Australia	Mixed methods	Rural community	113
Glueckauf et al.	2022	USA	Mixed methods	Home	12
Berwig et al.	2022	Germany	RCT	Facility	280
Christie et al.	2022	Netherlands	RCT	Home	96
Fields et al.	2021	USA	Mixed methods	Home	16
Szcześniak et al.	2021	Italy, Poland, UK, Netherlands	Mixed methods	Community	141
Töpfer et al.	2021	Germany	RCT	Home	51
van Wezel David	2021	Netherlands	RCT	Home	340
Gustafson Jr et al.	2019	USA	RCT	Home	26
Czaja et al.	2018	USA	Non-RCTs	Community	146
Wilkerson et al.	2018	USA	Non-RCTs	Home	60
Smith et al.	2018	UK	Mixed methods	Home	16
Tremont et al.	2017	USA	RCT	Home	250
Lykens et al.	2014	USA	Non-RCTs	Community	494
Whitebird et al.	2013	USA	RCT	Home	78
Bass et al.	2013	USA	RCT	Community	486
Czaja, et al.	2013	USA	Non-RCTs	Home	110
Easom et al.	2013	Georgia	Non-RCTs	Rural home	83
Nichols et al.	2011	USA	Non-RCTs	Home	127
Marziali et al.	2011	Canada	Non-RCTs	Community	91
Wai Tong	2011	China	RCT	Home	92

Social support interventions for dementia caregivers

Author	Year	Country	Design	Setting	Sample
Chien et al.					
Tompkins et al.	2009	USA	Non-RCTs	Community	367
Chiu et al.	2009	Canada	Mixed methods	Home	35
Bank et al.	2006	USA	RCT	Community	41
Roth et al.	2005	USA	RCT	Home	406
Hébert et al.	2003	Canada	RCT	Home	158
Mercedes et al.	2002	Colombia	RCT	Day centers	58
Robinson et al.	1988	USA	RCT	Home	20

Theoretical frameworks utilization research design

Among the 31 studies in this review, 12 were guided by six categories of theories to design their research: the Stress Process Model, Sociocultural Stress and Coping Model, Stress-appraisal Coping and the Crisis Model, Role Transformation Framework, Rural Nursing Theory, Tolsdorf's Conception of Social Support. Among these, five studies followed the Stress Process Model ^{37,51,52,57,62} three studies were guided by the Sociocultural Stress and Coping Model ^{43,60,63}, one study followed Lazarus and Folkman's Stress-Appraisal Coping model and the Crisis Model of Moos and Tsu ⁶⁴, one study was guided by the Framework of Role Transformation ⁵⁹, another implemented the Rural Nursing Theory ⁵⁴, and another one was based on Tolsdorf's Conception of Social Support ⁴¹. Furthermore, other 19 studies did not mention the use of a theoretical framework.

Social support measurements

As shown in Supplemental Table 2, a total of 23 methods were used to measure social support, the most commonly used was the Medical Outcomes Study social support survey (MOS); a total of 5 studies used this scale. MOS is a multidimensional, self-managed, and brief survey developed patients to

Social support interventions for dementia caregivers

measure social support⁶⁷. The Multidimensional Scale of Perceived Social Support (MPSS) was utilized in four studies; another four studies extracted 10-21 items ranging from three different broad scales to measure social support. Others were self-developed scales; examples include a 13-item questionnaire consisting of four domains –satisfaction with support, social support network, received support and negative interactions – to understand the situation of social support; the Interpersonal Support Evaluation List (ISEL); a brief form of the Perceived Social Support Questionnaire (F-SozU), which assesses the extent of social support; experiences of emotional and practical support; social relationships; social support network; social support questionnaire; supporting resources; social support from the perspectives of satisfaction and formal support; social support questionnaire; the Inventory of Socially Supportive Behaviors; and Norbeck's Social Support Questionnaire (NSSQ). Supplemental Table 2 indicates that the majority of studies failed to report on the reliability and validity of their tools.

Social support interventions

As shown in Supplemental Table 3, and according to the specific content of the intervention, the interventions were divided into six categories: peer support (n = 7), counselling group (n = 2), health education (n = 2), mindfulness-based stress reduction (n = 1), individual therapy (n = 1), and multi-component interventions (n = 18). One study mentioned that the formation of intervention methods involves organizing multiple focus groups to assess caregivers' need⁴². The delivery of the interventions divided into online and offline, and a combination of online and offline, among the included studies, 14 studies used online interventions^{36,38,39,42,47,48,50,51,53,56,57,59,62,66}, 10 studies used offline interventions^{40,41,43,45,46,49,58,60,63,64}, and 7 studies used a combination of online and offline interventions^{37,44,52,54,55,61,65}.

Peer support

peer support interventions involve group-based programmes facilitated by

Social support interventions for dementia caregivers

trained peers or mentors with lived caregiving experience, fostering shared experiential learning, mutual problem-solving, and emotional reciprocity among participants. Eight studies used peer-support interventions. Two studies were RCTs, and six were mixed methods. The shortest intervention duration was four hours ⁴⁹, while one study lasted 24 weeks, one implemented the intervention in three steps over 32 weeks ⁶¹, and most studies chose six months as the duration of the intervention^{38,60,65}. The intervention time for one study was three months ⁶³, and that of another study was six weeks ⁵⁹. From the included studies, three studies showed an improvement in perceived social support^{38,63,65}, one study showed an improvement in satisfaction with social support⁶⁰, one study showed an improvement in emotional and informational support⁵⁹, and one study mentioned an increase in support from home care staff, however, the improvement in support from family, friends, neighbors, and advice from doctors was not significant⁴⁹, and one study showed an improvement in overall social support⁶¹.

Counselling group intervention

The counselling group intervention included caregivers participating in support groups that provided personal and family consultations. Two studies used group counselling interventions, both of which were RCTs. The durations were 12 months ⁴⁴ and 6 months ⁴⁷. In those two studies, one mentioned a significant improvement in the utilization of community support services by caregivers, but there was no significant improvement in the utilization of community services and medical resources by the care recipient⁴⁷. Another study mentioned that there were 11 indicators of social support, of which 8 showed significant improvement⁴⁴.

Health education

This intervention included a social skills program providing health education related to dementia care to improve care skills and confidence, and comprised 12 hours of sessions designed to accomplish diverse goals for caregivers (e.g., developing emotional tolerance, acknowledging the disease,

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Social support interventions for dementia caregivers

and taking control). Two studies used health education interventions, one of which was an RCT, while the other was a non-RCT study. The intervention duration were 2 months⁴¹ and 12 hours⁵⁸, respectively. One study reported a significant increase in service usage⁵⁸, while the other study reported no significant increase in social support⁴¹.

Mindfulness-based stress reduction

The content encompassed the caregiver receiving guidance on mindfulness principles and engaging in meditation and gentle yoga sessions, all facilitated by an instructor specialized in mindfulness-based stress reduction, on a weekly basis. One RCT reported a mindfulness-based stress reduction intervention. The duration was two months⁴⁶, this study reported that the intervention significantly improved caregivers' social support.

Individual therapy

The caregivers participated in an expanded Tele.TAnDem program, consisting of 12 individual therapy sessions (each lasting 50 minutes) conducted via telephone across six months period⁴⁸. The 12-session program consisted of 10 therapeutic modules. This study reported the 3-year follow-up results, which showed that informal caregivers experienced a notable reduction in caregiver burden, an enhancement in quality of their social relationships, and improved their ability to manage the behavioral issues of the individual with dementia, this intervention significantly improved social relationships, but did not show significant improvement in service usage.

Multi-component interventions

Multi-component interventions integrate psychological education, systematic communication, and physical therapy. 18 studies used multi-component interventions, of which six were non-RCTs, nine were RCTs, and three were mixed methods. The shortest intervention duration was four weeks⁵¹, the longest was 18 months³⁶, and the most common intervention duration was six months^{42,45,50,52,54,55,57,66}. Among the 18 studies mentioned above, a total of 11 studies reported a slight increase in social support without statistical

Social support interventions for dementia caregivers

significance, but also pointed out that the interventions were in the correct direction^{36,39,42,44,50–52,54,55,57,66}. One study reported an increase in overall social support⁴¹, one mentioned that the intervention improved the perceived social support of caregivers⁶², one mentioned an increase in emotional support⁶⁴, and another mentioned a significant increase in support resources³⁷. Meanwhile, one study reported an increase in social support satisfaction⁵³, another study proposed that social support were associated with lower stress response to cope with the care recipient's decline in function and cognitive impairment⁵⁶, by the way, one study showed that the intervention group's utilization of family services was significantly decreased⁴⁵.

Intervention outcomes

In addition to improved social support, 9 studies showed that intervention reduced caregiver depression^{37,38,46,52,55,57,58,62,66}, 8 studies reported a reduction in caregiver burden^{41,52,53,55,57,59,60,64}, 3 studies reported intervention measures reduced stress^{37,46,59}, 2 studies reported intervention improved caregivers' mental health^{46,56}, 1 study proposed intervention improved caregiver coping skills⁶⁰, and 1 intervention improved caregiver satisfaction⁶⁴, and 1 reported a increase of health related quality of life⁵⁰, another reported the sense of competence were significantly higher compared to care-as-usual⁵¹.

Qualitative research results

Among the included studies, a total of 7 studies conducted qualitative research^{59,60,62–66}, the interviews were all conducted after the intervention. A study conducted interviews with both the older adults with dementia and caregivers, with caregivers reporting positive feedback while the older adults with dementia did not. Other interview results described caregivers provided positive feedback. The theme mainly focused on caregiving skills, mastery of dementia related knowledge, benefits from interventions, satisfaction with interventions, emotions and burdens, and various aspects of social support.

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Discussion

Studies have reported interventions to improve social support of caregivers caring older adults with dementia, nevertheless, evidence on the categories of intervention, implementation, evaluation, and effects of these interventions is dispersed in the literature, and an up-to-date summary is lacking. This scoping review comprehensively summarizes existing interventions enhancing social support for dementia caregivers published in English. Six effective interventions, including peer support, group counseling, health education, mindfulness-based stress reduction, individual therapy, and multi-component interventions were found in this study, which differed in terms of content, duration, acceptance, and effectiveness.

Characteristics of the participants

Among the included studies, family caregivers consisted of spouses, children, other relatives, neighbors, and friends; only one study mainly focused on spousal caregivers⁴⁴, while the remaining studies included all kinds of caregivers. Individuals with dementia are mostly looked after by informal caregivers, with special focus on spouses who are considered to be at a higher risk of social isolation⁶¹, which shows that spouses and other caregivers exhibit different responses to social support that alleviates caregivers' pain⁶². Meanwhile, social support among African Americans has gradually received more attention, with three studies investigating social support interventions for African Americans^{60,62,63}. And almost 95% of Chinese individuals with dementia are primarily cared for by their family members at home, largely influenced by the cultural values of filial piety and Confucian traditions⁷⁰. Recent research has investigated the cultural adaptation of iSupport in China, highlighting the imperative for contextually tailored interventions. This underscores the growing emphasis on culturally adapted, population-specific support frameworks as a critical priority for future implementation science.

414

Social support measures

A total of 23 different assessment tools were utilized to measure social support, it can be seen from Supplemental Table 2 that most studies use scales that can only measure a certain aspect of social support, such as the subjective perceived social support or the level of social support judged solely by whether caregivers seek help. Only three types of tools were described in terms of their reliability and validity. Since social support is a multidimensional concept, different interventions aim to improve different dimensions. While subjective social support is difficult to measure by quantitative methods, more methods focus on objective social support and consider only some aspects of social support, such as restrictions in social participation ³⁸, measuring supported resources ³⁷, perceived support from significant others, family, and friends ^{39,66}, social networks and the four dimensions of functional social support ²², or satisfaction with support ⁵². Because of the multidimensional nature of the concept of social support, the measurement results can only reflect part of the situation. Therefore, more precise measurement tools need to be developed.

Social support interventions

Six types of interventions to improve social support exist. Apparently, support from others is crucial; caregivers of older adults with dementia need this support initially, and eventually turn to seeking help and support. Caregivers from various regions possess distinct requirements regarding the methods and types of support they need. In the included studies, it was found that peer support can significantly enhance caregiver's perceived social support, satisfaction of social support, emotional and informational support, as well as overall social support. Peer support has demonstrated advantages for individuals with various requirements, including alleviating depressive symptoms⁶³, enhancing coping strategies⁶⁴, and reducing feelings of isolation and loneliness. Support provided by caregivers or volunteers with similar experience is more easily accepted by caregivers who are deeply burdened

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Social support interventions for dementia caregivers

with caregiving. Peer support also performs well in different environments, such as in educational settings where peer support can help improve academic performance and build confidence⁷³, and In chronic disease management, peer support groups have played an effective role in promoting self-management and emotional health⁷⁴. The excellent performance of peer support may be attributed to the same caregiving experience as peers. Caregivers who are burdened with caregiving are more likely to empathize with them and accept their help without reservation. At the same time, as the providers of support, with the same experience, they know better where to provide help and guidance to their caregivers. And counselling group can enhance social support through the utilization of support. Counseling group is widely used in the field of mental health and can effectively improve sexual satisfaction among women with multiple sclerosis⁷⁵. And can also may improve all levels of mental health of midwifery students⁷⁶. Health education Health education, like counseling groups, improves the utilization of support by caregivers. Mindfulness-based stress reduction, and individualized treatment, have good outcomes in improving social support. The findings from the included studies indicate that multi-component interventions enhance social support for caregivers across different domains, such as emotional, practical, and informational support. Multi-component interventions typically combine multiple interventions to address different aspects of complex problems, fit the concept of multidimensional social support, and involve integrating multiple interventions in the fields of health education, care skills, coping strategies, and social support for dementia caregivers, these have been demonstrated to effectively alleviate the burden on caregivers, decrease depressive symptoms, and increase their perceived satisfaction, from the included studies, multi-component interventions demonstrated moderate efficacy in improving caregivers' perceived social support and utilisation rates; however, no significant improvements were observed in overall social support. This

discrepancy may reflect methodological heterogeneity in intervention components (e.g., variable duration, intensity) and limited generalisability due to insufficient sample diversity or longitudinal follow-up. Health education has better effects in Interventions such as consultation groups, however, the angle of improvement is relatively one-dimensional, which can be used as a part of multi-component intervention, so as to achieve multidimensional improvement. Delivery interventions include face-to-face, telephone-based and Internet-based intervention, as well as online and offline combinations. Both face-to-face and online interventions have their advantages and disadvantages. The main disadvantage of face-to-face interaction is that caregivers find it difficult to leave older adults with dementia behind and go to specific institutions to receive specific interventions³⁸. Therefore, telephone and internet-based interventions are increasingly being applied to social support interventions. Another study indicates that technology-assisted interventions help alleviate caregiver burden and enhance support, similar to face-to-face support ⁶⁶. Considering that online and offline interventions have their own characteristics and shortcomings, the combination of the two can effectively reduce inconvenience and provide better and more comprehensive application of intervention measures to caregivers, to ensure they can receive more effective support to reduce their burden, ultimately enhancing the well-being of older individuals with dementia. Only one included study derived its intervention design from prior needs assessments of caregivers in control groups. However, the small sample size limited statistical power to detect intervention effectiveness, precluding robust conclusions. Future studies should prioritise co-design methodologies grounded in user-centred needs assessments, coupled with adequately powered trials to enhance ecological validity and generalisability.

Interventions outcomes

Drawing from the studies that were included, improvement of social support can lay a good foundation for reducing the care burden, depression and stress and eventually enhancing the well-being of caregivers, and multi-

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Social support interventions for dementia caregivers

component interventions can improve multiple dimensions of social support. In the implementation of interventions in the future, smarter and easier-to-operate intervention equipment can be developed for caregivers, such as voice control or AI equipment, so that their operation can be more easily mastered, and the distance between people can be narrowed. Simultaneously, it is crucial to consider the unique requirements of caregivers with diverse backgrounds in order to amplify the benefits of ongoing support initiatives. In the future It is also possible to develop interventions that simultaneously contain the essence of six categories, leverage their respective characteristics, integrate their advantages into one intervention, and maximize their effectiveness. The qualitative research section supplemented the unmeasured parts of the scale. From the results, it can be seen that most caregivers provided positive feedback, and the implementation of interventions not only reduced their caregiving burden, but also enhanced their mastery of dementia related knowledge and improved their social support. However, almost all qualitative studies are conducted after intervention, neglecting the understanding of the needs of caregivers before and after intervention. Future research can consider conducting qualitative studies before and after intervention to fully understand the needs of caregivers, develop interventions based on their reported results, and conduct qualitative studies again after intervention to better improve caregivers' social support and quality of life.

Limitations

Although this study provides a comprehensive overview of social support interventions for dementia caregivers, there are still some methodological limitations, due to language barriers, this review only included English language literature and did not include gray literature, which might have overlooked some information. In addition, we included only primary studies and excluded reviews, which may have resulted in missing on significant findings. And due to the fact that the scoping review does not involve a quality assessment of the raw data,

Page | 19

Social support interventions for dementia caregivers

it may not be possible to completely rule out the impact of low-quality research on the results, in addition, we only assessed the risk of bias of Rcts, so it may not be possible to completely rule out systematic errors.

Conclusion

This scoping review presents an extensive examination of the landscape of social support interventions implemented in the field of dementia care; however, in the process of caring older adults with dementia, problems remain related to seeking support and in delivering interventions. We suggest that combining online and offline interventions with caregivers probably can achieve the results with the effort. Future research can integrate existing technologies and utilize them to provide comprehensive interventions to caregivers. Meanwhile, it is necessary to conduct research with larger sample sizes and different cultures, and identify interventions suitable for different people. At the same time, interventions with more durable effects need to be explored.

Ethical Approval

This scoping review did not require ethical approval as it solely involved the analysis of publicly available literature and did not involve direct research on human or animal subjects. All included studies were published and accessible through academic databases, ensuring compliance with ethical standards for secondary data analysis. We adhered to academic integrity principles throughout the study, including transparency in reporting methods and results, proper citation of sources, and ensuring the integrity of the data used.

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Social support interventions for dementia caregivers

Author contributions

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Declaration of Competing Interests

The authors declare that they have no competing interests.

References:

1. World Alzheimer Report 2023 | Alzheimer's Disease International (ADI). Accessed August 7, 2024. <https://www.alzint.org/resource/world-alzheimer-report-2023/>
2. 2021 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2021;17(3):327-406. doi:10.1002/alz.12328
3. Huisman C, Huisman E, Kort H. Technological Applications Contributing to Relieve Care Burden or to Sleep of Caregivers and People With Dementia: A Scoping Review From the Perspective of Social Isolation. *Front Public Health*. 2022;10:797176. doi:10.3389/fpubh.2022.797176
4. Theißen T, Ullrich A, Oechsle K, Wikert J, Bokemeyer C, Schieferdecker A. "Being an informal caregiver - strengthening resources": mixed methods evaluation of a psychoeducational intervention supporting informal caregivers in palliative care. *BMC Palliat*

Social support interventions for dementia caregivers

Care. 2024;23(1):95. doi:10.1186/s12904-024-01428-0

5. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*. 2003;18(2):250-267. doi:10.1037/0882-7974.18.2.250

6. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA*. 1996;276(21):1725-1731.

7. 2020 Alzheimer’s disease facts and figures. *Alzheimers Dement*. Published online March 10, 2020. doi:10.1002/alz.12068

8. Davies N, Iliffe S, Hopwood J, et al. The key aspects of online support that older family carers of people with dementia want at the end of life: A qualitative study. *Aging Ment Health*. 2020;24(10):1654-1661. doi:10.1080/13607863.2019.1642299

9. Cr V, I R, C Q, et al. The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging & mental health*. 2021;25(7). doi:10.1080/13607863.2020.1753014

10. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatr*. 2018;18(1):189. doi:10.1186/s12877-018-0885-1

11. Jagoda FA, Hirt J, Mueller C, Halek M. Involvement of family caregivers in dementia care research: a scoping review protocol. *Syst Rev*. 2024;13(1):277. doi:10.1186/s13643-024-02696-w

12. Encinas-Monge C, Hidalgo-Fuentes S, Cejalvo E, Martí-Vilar M. Interventions to Relieve the Burden on Informal Caregivers of Older People with Dementia: A Scoping Review. *Nurs Rep*. 2024;14(3):2535-2549. doi:10.3390/nursrep14030187

13. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull*. 1985;98(2):310-357.

14. Kerres Malecki C, Kilpatrick Demary M. Measuring perceived social support: Development of the child and adolescent social support scale (CASSS). *Psychology in the Schools*. 2002;39(1):1-18. doi:10.1002/pits.10004

15. Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer’s disease. *Soc Sci Med*. 2006;63(4):957-967. doi:10.1016/j.socscimed.2006.02.020

16. Antonucci T. Social Supports, and Social Relation-ships. In: ; 1990. Accessed November 9, 2023. <https://www.semanticscholar.org/paper/Social-Supports%2C-and-Social-Relation->

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Social support interventions for dementia caregivers

- ships-Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2
17. Caplan G, Killilea M, Abrahams RB, eds. *Support Systems and Mutual Help: Multidisciplinary Explorations*. Grune & Stratton; 1976.
 18. Hupcey JE. Clarifying the social support theory-research linkage. *J Adv Nurs*. 1998;27(6):1231-1241. doi:10.1046/j.1365-2648.1998.01231.x
 19. Southwick SM, Bonanno GA, Masten AS, Panter-Brick C, Yehuda R. Resilience definitions, theory, and challenges: interdisciplinary perspectives. *Eur J Psychotraumatol*. 2014;5. doi:10.3402/ejpt.v5.25338
 20. Labrague LJ. Psychological resilience, coping behaviours and social support among health care workers during the COVID-19 pandemic: A systematic review of quantitative studies. *J Nurs Manag*. 2021;29(7):1893-1905. doi:10.1111/jonm.13336
 21. Lu J, Wang B, Dou X, et al. Moderating effects of perceived social support on self-efficacy and psychological well-being of Chinese nurses: a cross-sectional study. *Front Public Health*. 2023;11:1207723. doi:10.3389/fpubh.2023.1207723
 22. Cohen S. Social relationships and health. *Am Psychol*. 2004;59(8):676-684. doi:10.1037/0003-066X.59.8.676
 23. Sw W, Cs W, S Z, J M, D D, Pd S. Emotional and physical health of informal caregivers of residents at the end of life: the role of social support. *The journals of gerontology Series B, Psychological sciences and social sciences*. 2008;63(3). doi:10.1093/geronb/63.3.s171
 24. Mehdipanah R, Briceño EM, Malvitz M, et al. Exploring Pathways to Caregiver Health: The Roles of Caregiver Burden, Familism, and Ethnicity. *J Aging Health*. 2025;37(3-4):148-155. doi:10.1177/08982643241235970
 25. Feldstein AC, Nichols GA, Elmer PJ, Smith DH, Aickin M, Herson M. Older women with fractures: patients falling through the cracks of guideline-recommended osteoporosis screening and treatment. *J Bone Joint Surg Am*. 2003;85(12):2294-2302.
 26. Chen L, Zhao Y, Tang J, et al. The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: a qualitative study. *BMC Psychiatry*. 2019;19(1):75. doi:10.1186/s12888-019-2052-4
 27. Elovainio M, Komulainen K, Sipilä PN, et al. Association of social isolation and loneliness with risk of incident hospital-treated infections: an analysis of data from the UK Biobank and Finnish Health and Social Support studies. *Lancet Public Health*. 2023;8(2):e109-e118. doi:10.1016/S2468-2667(22)00253-5
 28. Dam AEH, de Vugt ME, Klinkenberg IPM, Verhey FRJ, van Boxtel MPJ. A systematic review of social support interventions for caregivers of people with dementia: Are they doing what they promise? *Maturitas*. 2016;85:117-130. doi:10.1016/j.maturitas.2015.12.008

Social support interventions for dementia caregivers

29. Cheng ST, Zhang F. A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers. *BMC Geriatr.* 2020;20(1):137. doi:10.1186/s12877-020-01547-2

30. Kampanellou E, Chester H, Davies L, et al. Carer preferences for home support services in later stage dementia. *Aging Ment Health.* 2019;23(1):60-68. doi:10.1080/13607863.2017.1394441

31. Brennan PF, Moore SM, Smyth KA. Alzheimer's disease caregivers' uses of a computer network. *West J Nurs Res.* 1992;14(5):662-673. doi:10.1177/019394599201400508

32. Czaja SJ, Boot WR, Charness N, Rogers WA, Sharit J. Improving Social Support for Older Adults Through Technology: Findings From the PRISM Randomized Controlled Trial. *Gerontologist.* 2018;58(3):467-477. doi:10.1093/geront/gnw249

33. Lee Y, Choi S. Korean American dementia caregivers' attitudes toward caregiving: the role of social network versus satisfaction with social support. *J Appl Gerontol.* 2013;32(4):422-442. doi:10.1177/0733464811431163

34. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169(7):467-473. doi:10.7326/M18-0850

35. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology.* 2005;8(1):19-32. doi:10.1080/1364557032000119616

36. Bank AL, Argüelles S, Rubert M, Eisdorfer C, Czaja SJ. The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist.* 2006;46(1):134-138. doi:10.1093/geront/46.1.134

37. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc.* 2013;61(8):1377-1386. doi:10.1111/jgs.12362

38. Berwig M, Lessing S, Deck R. Telephone-based aftercare groups for family carers of people with dementia - results of the effect evaluation of a randomised controlled trial. *BMC Health Serv Res.* 2022;22(1):177. doi:10.1186/s12913-022-07490-9

39. Christie HL, Dam AEH, van Boxtel M, Köhler S, Verhey F, de Vugt ME. Lessons Learned From an Effectiveness Evaluation of Inlife, a Web-Based Social Support Intervention for Caregivers of People With Dementia: Randomized Controlled Trial. *JMIR Aging.* 2022;5(4):e38656. doi:10.2196/38656

40. Cerquera Córdoba Ara Mercedes, Tiga-Loza Diana Carolina, Álvarez Anaya William Armando, Dugarte Peña Edwin, Jaimes Espíndola Lisseth Rocío, Plata Osma Leidy Johanna. Ensayo controlado aleatorizado de un programa multicomponente para cuidadores informales de pacientes con Alzheimer. *Revista Cuidarte.* 2021;12(2):e2002. <http://dx.doi.org/10.15649/cuidarte.2002>

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Erasmus Hogeschool

Social support interventions for dementia caregivers

41. Robinson KM. A social skills training program for adult caregivers. *ANS Adv Nurs Sci*. 1988;10(2):59-72. doi:10.1097/00012272-198801000-00010
42. Gustafson DH, Gustafson DH, Cody OJ, Chih MY, Johnston DC, Asthana S. Pilot Test of a Computer-Based System to Help Family Caregivers of Dementia Patients. *J Alzheimers Dis*. 2019;70(2):541-552. doi:10.3233/JAD-190052
43. Hébert R, Lévesque L, Vézina J, et al. Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. *J Gerontol B Psychol Sci Soc Sci*. 2003;58(1):S58-67. doi:10.1093/geronb/58.1.s58
44. Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging*. 2005;20(4):634-644. doi:10.1037/0882-7974.20.4.634
45. Chien WT, Lee IYM. Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia²³. *J Adv Nurs*. 2011;67(4):774-787. doi:10.1111/j.1365-2648.2010.05537.x
46. Whitebird RR, Kreitzer M, Crain AL, Lewis BA, Hanson LR, Enstad CJ. Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *Gerontologist*. 2013;53(4):676-686. doi:10.1093/geront/gns126
47. Tremont G, Davis JD, Ott BR, et al. Randomized Trial of the Family Intervention: Telephone Tracking-Caregiver for Dementia Caregivers: Use of Community and Healthcare Resources. *J Am Geriatr Soc*. 2017;65(5):924-930. doi:10.1111/jgs.14684
48. Töpfer NF, Sittler MC, Lechner-Meichsner F, Theurer C, Wilz G. Long-term effects of telephone-based cognitive-behavioral intervention for family caregivers of people with dementia: Findings at 3-year follow-up. *J Consult Clin Psychol*. 2021;89(4):341-349. doi:10.1037/ccp0000640
49. van Wezel N, van der Heide I, Devillé WL, et al. Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: A cluster randomised controlled trial. *Patient Educ Couns*. 2021;104(7):1726-1735. doi:10.1016/j.pec.2020.11.008
50. Xiao L, Ullah S, Hu R, et al. The effects of a facilitator-enabled online multicomponent iSupport for dementia programme: A multicentre randomised controlled trial. *International Journal of Nursing Studies*. 2024;159:104868. doi:10.1016/j.ijnurstu.2024.104868
51. Neal DP, Kucera M, van Munster BC, et al. Cost-effectiveness of the FindMyApps eHealth intervention vs. digital care as usual: results from a randomised controlled trial. *Aging Ment Health*. 2024;28(11):1457-1470. doi:10.1080/13607863.2024.2345128
52. Czaja SJ, Lee CC, Perdomo D, et al. Community REACH: An Implementation of an Evidence-Based Caregiver Program. Meeks S, ed. *The Gerontologist*. 2018;58(2):e130-e137.

Social support interventions for dementia caregivers

732 doi:10.1093/geront/gny001

733 53. Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial
734 intervention for dementia caregivers. *Am J Geriatr Psychiatry*. 2013;21(11):1071-1081.
735 doi:10.1016/j.jagp.2013.02.019

736 54. Easom LR, Alston G, Coleman R. A Rural Community Translation of a Dementia Caregiving
737 Intervention. *Online Journal of Rural Nursing and Health Care*. 2013;13(1):66-91.
738 doi:10.14574/ojrnhc.v13i1.248

739 55. Lykens K, Moayad N, Biswas S, Reyes-Ortiz C, Singh KP. Impact of a community based
740 implementation of REACH II program for caregivers of Alzheimer’s patients. *PLoS One*.
741 2014;9(2):e89290. doi:10.1371/journal.pone.0089290

742 56. Marziali E, Garcia LJ. Dementia caregivers’ responses to 2 Internet-based intervention
743 programs. *Am J Alzheimers Dis Other Demen*. 2011;26(1):36-43.
744 doi:10.1177/1533317510387586

745 57. Nichols LO, Martindale-Adams J, Burns R, Graney MJ, Zuber J. Translation of a Dementia
746 Caregiver Support Program in a Health Care System—REACH VA. *Arch Intern Med*.
747 2011;171(4). doi:10.1001/archinternmed.2010.548

748 58. Tompkins SA, Bell PA. Examination of a psychoeducational intervention and a respite grant in
749 relieving psychosocial stressors associated with being an Alzheimer’s caregiver. *J Gerontol*
750 *Soc Work*. 2009;52(2):89-104. doi:10.1080/01634370802561877

751 59. Wilkerson DA, Brady E, Yi EH, Bateman DR. Friendsourcing Peer Support for Alzheimer’s
752 Caregivers Using Facebook Social Media. *Journal of Technology in Human Services*.
753 2018;36(2-3):105-124. doi:10.1080/15228835.2018.1449709

754 60. Xu L, Fields NL, Williams IC, et al. The Senior Companion Program Plus (SCP Plus):
755 Examining the Preliminary Effectiveness of a Lay Provider Program to Support African
756 American Alzheimer’s Disease and Related Dementias (ADRD) Caregivers. *Int J Environ Res*
757 *Public Health*. 2023;20(7):5380. doi:10.3390/ijerph20075380

758 61. Blackberry I, Rasekaba T, Morgan D, et al. Virtual Dementia-Friendly Communities (Verily
759 Connect) Stepped-Wedge Cluster-Randomised Controlled Trial: Improving Dementia
760 Caregiver Wellbeing in Rural Australia. *Geriatrics (Basel)*. 2023;8(5):85.
761 doi:10.3390/geriatrics8050085

762 62. Glueckauf RL, Kazmer MM, Nowakowski ACH, et al. African American Alzheimer’s
763 Caregiver Training and Support Project 2 (ACTS2) pilot study: Outcomes analysis. *Rehabil*
764 *Psychol*. 2022;67(4):437-448. doi:10.1037/rep0000470

765 63. Fields NL, Xu L, Richardson VE, Parekh R, Ivey D, Calhoun M. Utilizing the Senior
766 Companion Program as a platform for a culturally informed caregiver intervention: Results
767 from a mixed methods pilot study. *Dementia (London)*. 2021;20(1):161-187.

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Social support interventions for dementia caregivers

- doi:10.1177/1471301219871192
64. Szcześniak D, Rymaszewska J, Saibene FL, et al. Meeting centres support programme highly appreciated by people with dementia and carers: a European cross-country evaluation. *Aging Ment Health*. 2021;25(1):149-159. doi:10.1080/13607863.2019.1683814
65. Smith R, Drennan V, Mackenzie A, Greenwood N. The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Arch Gerontol Geriatr*. 2018;76:188-195. doi:10.1016/j.archger.2018.03.005
66. Chiu T, Marziali E, Colantonio A, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with alzheimer disease and related dementia. *Can J Aging*. 2009;28(4):323-336. doi:10.1017/S0714980809990158
67. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32(6):705-714. doi:10.1016/0277-9536(91)90150-b
68. Zhu X, Chen S, He M, et al. Life experience and identity of spousal caregivers of people with dementia: A qualitative systematic review. *Int J Nurs Stud*. 2024;154:104757. doi:10.1016/j.ijnurstu.2024.104757
69. Burgio L, Stevens A, Guy D, Roth DL, Haley WE. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *Gerontologist*. 2003;43(4):568-579. doi:10.1093/geront/43.4.568
70. Ma KPK, Saw A. An international systematic review of dementia caregiving interventions for Chinese families. *Int J Geriatr Psychiatry*. 2020;35(11):1263-1284. doi:10.1002/gps.5400
71. Mead N, Lester H, Chew-Graham C, Gask L, Bower P. Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis. *Br J Psychiatry*. 2010;196(2):96-101. doi:10.1192/bjp.bp.109.064089
72. Bjorck JP, Klewicki LL. The effects of stressor type on projected coping. *J Trauma Stress*. 1997;10(3):481-497. doi:10.1023/a:1024849522973
73. Santee J, Garavalia L. Peer tutoring programs in health professions schools. *Am J Pharm Educ*. 2006;70(3):70. doi:10.5688/aj700370
74. Ballesteros FJ, Guardiola G, Soriano E. Personal pervasive environments: practice and experience. *Sensors (Basel)*. 2012;12(6):7109-7125. doi:10.3390/s120607109
75. Sazesh S, Esmaelzadeh Saeieh S, Farid M, Refaei M, Yazdkhasti M. Effectiveness of Group Counseling with a Client-Centered Approach Based on the GATHER Principles on Sexual Satisfaction in Women with Multiple Sclerosis: A Randomized Clinical Trial. *Iran J Med Sci*. 2021;46(2):103-111. doi:10.30476/ijms.2020.82616.1074
76. Javid N, Ahmadi A, Mirzaei M, Atghaei M. Effectiveness of Solution-Focused Group

Social support interventions for dementia caregivers

802 Counseling on the Mental Health of Midwifery Students. *Rev Bras Ginecol Obstet.*
803 2019;41(8):500-507. doi:10.1055/s-0039-1693741

804 77. Lee E. Do Technology-Based Support Groups Reduce Care Burden Among Dementia
805 Caregivers? A Review. *J Evid Inf Soc Work.* 2015;12(5):474-487.
806 doi:10.1080/15433714.2014.930362

807 Figure 1: PRISMA flow diagram

808 Figure 2: Risk of bias graph

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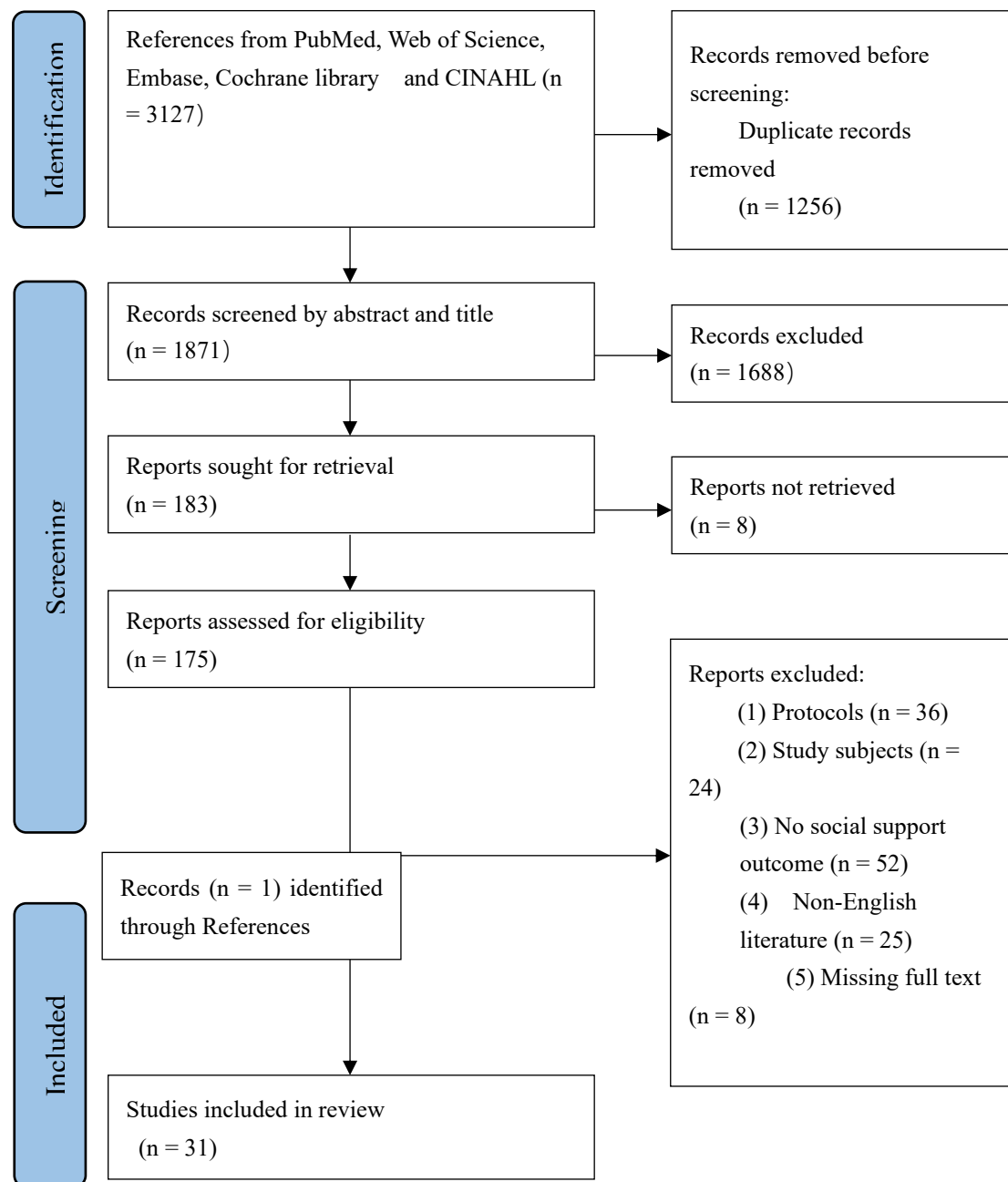
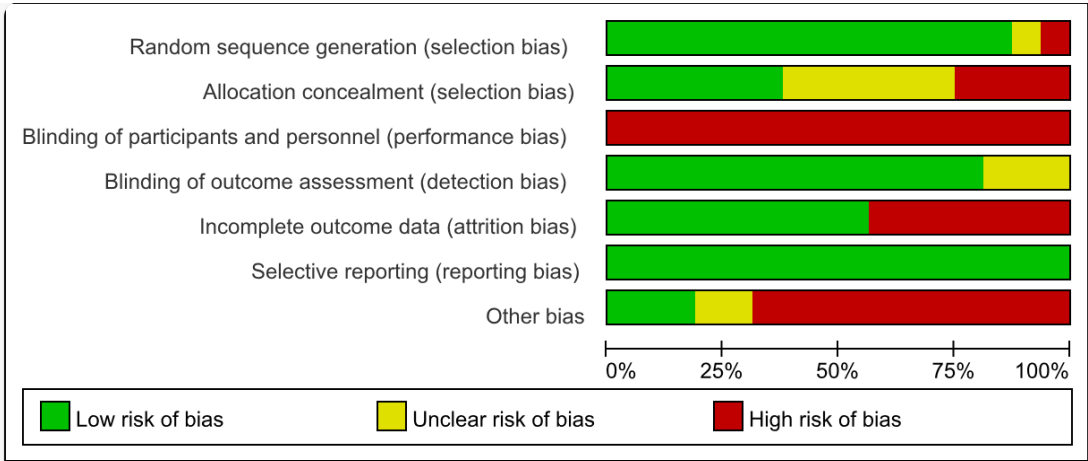


Fig.1 PRISMA flow diagram



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Bank et al. 2006	+	?	+	+	+	+	+
Bass et al. 2013	+	+	+	+	+	+	+
Berwig et al. 2022	+	+	+	+	+	+	+
Christie et al. 2022	+	+	+	+	+	+	+
DavidGustafson Jr et al. 2019	+	+	+	+	+	+	+
Hébert et al. 2003	+	?	+	+	+	+	+
Mercedes et al. 2002	+	?	+	+	+	+	+
Neal 2024	+	+	+	+	+	+	+
Robinson et al. 1988	+	?	+	+	+	+	+
Roth et al. 2005	+	?	+	+	+	+	+
Töpfer et al. 2021	?	?	+	+	+	+	?
Tremont et al. 2017	+	+	+	+	+	+	+
van Wezel 2021	+	+	+	+	+	+	+
Wai Tong Chien et al. 2011	+	+	+	+	+	+	+
Whitebird et al. 2013	+	+	+	+	+	+	+
Xiao 2024	+	+	+	+	+	+	+

Fig.2 Risk of bias graph.

Database	Search strategy
PubMed	<ol style="list-style-type: none"> 1. ("Dementia"[Mesh]) 2. Amentia [Title/Abstract] 3. Senile Dementia [Title/Abstract] 4. Familial Dementia [Title/Abstract] 5. "Alzheimer Disease"[Mesh] 6. Alzheimer Dementias [Title/Abstract] 7. Presenile Alzheimer Dementia [Title/Abstract] 8. (Presenile Alzheimer Dementia [Title/Abstract]) 9. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 10. "Caregivers"[Mesh] 11. Carers [Title/Abstract] 12. 10 OR 11 13. "Social Support"[Mesh] 14. Social care [Title/Abstract] 15. Perceived social Support [Title/Abstract] 16. 13 OR 14 OR 15 17. Interventions [Title/Abstract] 18. program*[Title/Abstract] 19. 17 OR 18 20. 9 AND 12 AND 16 AND 19
Web of Science	<ol style="list-style-type: none"> 1. TS= (dement* OR ament* OR Lewy Body Disease OR

	<p>Alzheimer* OR Alzheimer disease OR senile dementia)</p> <p>2. TS= (caregiver* OR carer*)</p> <p>3. TS= ("social support")</p> <p>4. TS=(intervention*)</p> <p>5. (1 AND 2 AND 3 AND 4)</p>
Cinahl	<p>S1. (MH "Dementia") OR (MH "Dementia, Vascular") OR (MH "Dementia, Senile) OR (MH "Dementia, Presenile) OR (MH "Alzheimer's Disease")</p> <p>S2. AB dement* OR Alzheimers OR cognitive impairment OR memory loss OR amenti*</p> <p>S3. S1 OR S2</p> <p>S4. AB caregiver* OR carer*</p> <p>S5. AB social support OR social network</p> <p>S6. AB interventions OR strategies OR best practices</p> <p>S7. S3 AND S4 AND S5 AND S6</p>
Cochrane	<p>#1. MeSH descriptor: [Dementia] explode all trees</p> <p>#2. MeSH descriptor: [Alzheimer Disease] explode all trees</p> <p>#3. (Amenti* OR Dementi* OR Alheimer* disease): ti,ab,kw</p> <p>#4. #1 OR #2 OR #3</p> <p>#5. MeSH descriptor: [Caregivers] explode all trees</p> <p>#6. (Caregiver* OR Carer*): ti, ab, kw</p> <p>#7. #5 OR #6</p>

	<p>#8. MeSH descriptor:[Social support] explode all trees</p> <p>#9. (social support OR social network): ti, ab, kw</p> <p>#10. #8 OR #9</p> <p>#11. (intervention*): ti, ab, kw</p> <p>#12. #4 AND #7 AND #10 AND #11</p>
EMBASE	<p>#1. 'dementia'/exp</p> <p>#2. amenti*:ti,ab,kw OR dementi*:ti,ab,kw</p> <p>#3. 'alzheimer disease'/exp</p> <p>#4. 'alzheimer disease':ti,ab,kw OR 'alzheimer dementia':ti,ab,kw OR alzheimer*:ti,ab,kw OR 'senile dementia':ti,ab,kw</p> <p>#5. #1 OR #2 OR #3 OR #4</p> <p>#6. 'caregiver'/exp</p> <p>#7. caregiver*:ti,ab,kw OR carer*:ti,ab,kw</p> <p>#8. #6 OR #7</p> <p>#9. 'social support'/exp</p> <p>#10. 'social support':ti,ab,kw</p> <p>#11. #9 OR #10</p> <p>#12. intervention*:ti,ab,kw</p> <p>#13. #5 AND #8 AND #11 AND #12</p>

Table 2. Social support measurement tool

Name	Scale	Cronbach's alpha
Cerquera et al., 2021;		
Blackberry et al.,2023;		
Gustafson et al., 2019;	Medical Outcomes Study (MOS)	0.736-0.921
Whitebird et al., 2013;		
Wilkerson et al., 2018;		
Chiu et al., 2009;		
Christie et al., 2022;		
Marziali and Garcia, 2011;	Multidimensional Scale of Perceived Social Support (MPSS)	NM
Smith et al., 2018;		
Czaja et al., 2013;		
Easom et al.,2013;	10-21 items from three different broad scales measuring social support	NM
Lykens et al., 2014;		
Nichols et al., 2011;		
Fields et al., 2021;		
van Wezel et al., 2021;	self-developed scales	NM
Xu et al.,2023;	13-item questionnaire consisting of 4 domains: satisfaction with support, social support network, received support and negative interactions	NM

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Glueckauf et al., 2022;	Social support: the Interpersonal Support Evaluation List (ISEL)	0.92
Berwig et al., 2022;	brief form of the Perceived Social Support Questionnaire (F – SozU) to assess the extent of social support	0.90
Szczęśniak et al.,2021	experiences of emotional and practical support	NM
Töpfer et al.,2021	social relationships	NM
Roth et al., 2005	social support network	NM
Czaja et al.,2018	social support questionnaire	NM
Bass et al., 2013	supporting resources	NM
Chien and Lee, 2011	social support from the perspectives of satisfaction with social support and formal support	NM
Bank et al., 2006		
Tompkins and Bell,2009	support questionnaire	NM
Hébert et al.,2003	The Inventory of Socially Supportive Behaviors	NM
Robinson,1988	Norbeck's Social Support Questionnaire (NSSQ)	NM
Neal et al ,2024	Social participation was measured using the Maastricht Social Participation Profile (MSPP)	NM

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Xiao et al ,2024	the Carers of Older People in Europe Index-Quality of Social Support (The COPE Index-QS)	0.77
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NM: Not Mentioned; The multiple blank spaces in Table 2 indicate that the authors of these items share the same scale name and reliability value

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Social support interventions for dementia caregivers

Table 3 Description of social support interventions

Author/Year	Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	
Neal/2024	76 vs 74	ICG	Multi-component	4 weeks	Use FindMyApps app twice a week	MSPP	HRQL; SSCQ; MSPP,HRQoL:NS.Costs: ↓.
Xiao/2024	131 vs 135	FCG	Multi-component	6 months	Use iSupport, and host a monthly carer peer support meeting lasting 45–60 min	The COPE Index-QS	Self-efficacy; Behaviours and carer reactions; Caregivers perspective of the QoL of the person living with dementia
Xu/2023	20	African American FCG	Peer support	6 months	The SCP Plus contained a 12 h in-person training with the senior companions.	13 items from four domains.	Burden and/or stress; Coping skills; Caregiver appraisal; Cultural justifications for caregiving; Caregiver well-being
Blackberry/2023	113	FCG	Peer support	32 weeks	Verily Connect model	MOS	ZBI; bespoke surveys

Social support interventions for dementia caregivers

Author/Year	Participants			Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Glueckauf/2022	12	African American FCG	Multi-component	12 weeks	12 weekly telephone sessions, 7 one-hour group sessions and 5 one-hour individual goal-setting and implementation sessions.	ISEL	Severity of CG-identified problems; Depression; Health status; Consequences of caregiving activities	Depression: ↓; Perceived social support: ↑; CAI: NS.
Berwig/2022	107 vs 104	FCG	Peer support	6 months	Telephone-based group meeting	FSozU K22	Restrictions; Depressed mood states; general complaints; Quality of life; Utilization of support services; Performance in different areas of life	The mental health domain of quality of life of family carers and perceived social support: ↑ Depression: ↓;
Christie/2022	48 vs 48	Primary CGs	Multi-component	16 weeks	The intervention group had access to Inlife, participants could use Inlife in at their own pace.	MSPSS; Received support; Number of friends and family ties	Sense of competence; Feelings of loneliness; Anxiety and depression; Quality of life; Perceived stress	Received support; MSPSS; Number of friends and family ties: NS; Sense of competence; Feelings of loneliness; Anxiety and depression; Perceived stress; Quality of life: NS.

Social support interventions for dementia caregivers

Author/Year	Participants				Intervention	Outcomes		Results
	sample size	Caregiver type	Type	Duration		Social support	Other outcomes	
Fields/2021	16	FCG	Peer support	3 months	Nine in-home psychoeducational session covering one topic per week to their paired ADRD family caregiver over a three-month period were delivered by Each Senior Companion	Self-developed scale	KAD; Coping skills; Caregiver well-being; Burden and/or stress	Received social support: ↑; KAD, overall stress/burden levels, well-being of doing activities, coping skills: NS
Szczeńsiak/2021	45 vs 21 vs 15	FCG	Multi-component	3 months	MCSP for both people living with dementia and their carers	Experience of emotional and practical support	Satisfaction; Reasons for participation in the support programme; Burden	Emotionally supports: ↑; Satisfaction: ↑; Burden: ↓.

1 Social support interventions for dementia caregivers

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Author/Year	Participants		Intervention		Duration		Intervention content		Outcomes		Results
	sample size	Caregiver type	Type						Social support	Other Outcomes	
Töpfer/2021	29 vs 22	FCG	Individual therapy		6 months		The intervention group (IG) received 12 individual therapy sessions (each 50 min) delivered via telephone from Tele.TAnDem intervention.		Social relationships: The German Version of the World Health Organization QoLBREF (WHOQoL-BREF)	Depression; Caregiver burden; Emotional well-being; Utilization of resources	Changes regarding own illnesses, the living situation with the PwD, the living environment, the employment status, care for any other person than the PwD, and severe illness of any close person in the last 3 years: NS; social relationships: ↑, use of support services: NS
van Wezel/2021	202 vs 184	Turkish or Moroccan background FCG	Peer support		Two hour interventions		Two educational sessions on dementia, each last two hours, with other participants (peers) with the same cultural background (Turkish or Moroccan).		The support received: four self-developed questions	The intervention received pressure from informal care; The intervention received ability to talk about dementia; KAD;	Support received from family, friends or neighbors, and advice received from a doctor: NS. support received from home-care staff: ↑

Social support interventions for dementia caregivers

Author/Year	sample size	Caregiver type	Participants Intervention		Duration content	Intervention	Outcomes		Results
			Type				Social support	Other outcomes	
Gustafson Jr/2019	16 vs 15	FCG	Multi-component		6 months	Intervention group receiving D-CHESS. Control group receiving a caregiving book.	MOS	Family conflict; Caregiver burden; Loneliness; Anxiety; Satisfaction with care decisions; Depression; Coping; Competence	All findings: NS; Due to small sample size.
Czaja/2018	146	FCG	Multi-component		6 months	12, 60-min individual (6 telephone and 6 face-to-face) educational sessions and skill building and 5 support groups by telephone.	Social Support Questionnaire	Depression; Affectivity; distress; Burden; Caregiving Self-Efficacy; Memory related problems; disruptive behaviors;	Depression, overall burden, overall bother: ↓ ; Social support, positive aspects of caregiving or obtaining respite services: NS.

1 Social support interventions for dementia caregivers

Author/Year		Participants			Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other Outcomes		
Wilkerson/2018	60	Informal CGs	Peer support	6 weeks	Participants were allotted to two private Facebook groups receiving the intervention over the course of six weeks.	MOS	Burden; Frequency of emotional problems; Learned activities	Burden; ↓ ; Perceived stress: ↓ ; Emotional and informational supports: ↑	
Smith/2018	16	FCG	Peer support	6 months	Carers receiving one-to-one peer support or befriending from volunteers at least a weekly basis.	MSPSS	Depression and Loneliness	Perceived social support: ↑ ; Depression, anxiety and loneliness: NS.	

Social support interventions for dementia caregivers

Author/Year	sample size	Caregiver type	Participants Intervention		Duration	Intervention content	Social support	Outcomes		Results
			Type					Other outcomes		
Tremont/2017	105 vs 94	Informal CGs	Counselling group		6 months	Trained therapists contacted caregivers 16 times use telephone for 6 months, providing recommendations for resources, information about dementia, and emotional support.	Community support services used times, healthcare resource use	Burden; Depression; Beliefs or problems		Caregivers who received the FITT-C used community support services significantly more than those receiving TS; FITT-C caregivers had a significantly lower rate of ED visits and hospital stays; Care recipient use of community or medical resources did not differ according to group.
Lykens/2014	494	FCG	Multi-component		6 months	Certified interventionists deliver the intervention included 12 sessions [9 in-home, and 3 telephone sessions], five structured telephone support group sessions	10 item Risk Assessment of feeling isolated, availability of someone to talk to or assist with caregiving	Caregiver Burden; Depression; Self-Care		Caregiver burden and Depression: ↓, Social support and self-care: a slight but not statistically significant increase after the service, which is in the correct direction.

1 Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcome		Results	
		sample size	Caregiver type	Type	Duration	Intervention content	Social outcomes support	Other	
Whitebird/2013		38 vs 40	Primary CGs	MBSR	8 weeks	8 weekly 2.5-hr in-person group sessions.	MOS	Stress; Mental Health Burden	MBSR was more effective at reducing stress, decreasing depression, and improving overall mental health than CCES. Both interventions improved caregiver mental health and were similarly effective at improving anxiety, social support, and burden.
Bass/2013		299 vs 187	FCG	Multi-component	12 months	Partners in Dementia Care: initial assessment; action plan; Ongoing Monitoring and Reassessment	Support resource: 1) number of informal helpers; 2) use of caregiver support services	Unmet needs; Caregiver strain; Depression	Three types of caregiver strains, depression, unmet needs: ↓ , and two support resources: ↑

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention	Duration	Intervention content	Outcomes		Results
	sample size	Caregiver type				Social support	Other outcomes	
Czaja/2013	36 vs 63	FCG	Multi-component	5 months	A technology based multi-component psychosocial intervention was delivered in-home and via videophone technology over 5 months.	10 items assessing three domains of support: (a) received support(b) satisfaction with support(c) negative interaction s/ supports	Burden; Depression; Positive aspects of caregiving	Caregiver burden: ↓ ; satisfaction with social support: ↑ ; appreciation of the positive aspects of caregiving: ↑ ;
Easom/2013	85	FCG	Multi-component	6 months	Nine face-to-face (in the home) and three telephone sessions, tailored education and support.	A Risk Appraisal Assessment: three questions of social support	A Risk Appraisal Assessment: five questions addressing caregiver safety, five questions assessing caregiver health behaviors, three questions targeting stress, two items on behavioral frustrations	The scores for Self-Care and Social Support increased slightly post-service were not statistically significant, which is in the correct direction.

1 Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Nichols/2011	127	FCG	Multi-component	6 months	The intervention included education, support, and skills training to address 5 caregiving risk areas: safety, social support, problem behaviors, depression, and caregiver health.	The 21- question risk appraisal, adapted from REACH II	caregiving risk areas of advanced cognition, social support, health and healthy behaviors, and caregiving frustrations.	Depression, burden, impact of depression on daily lives, and caregiving frustrations: ↓ ; Social support: NS.
Marziali/2011	91	FCG	Multi-component	10 weeks	Online Chat Group Intervention: the Chat Group was provided with access to the CFO website for 6 months; Online Video Conferencing Support Group Intervention:10 weekly sessions in mutual self-help mode with 1 of the group members manipulating the technical aspects of the video-conferencing meetings.	MSPSS	Caregiver health; Depressive symptoms; Caregiving distress	The Video Group demonstrated greater improvement in mental health status. For the Video Group, improvements in neuroticism, self-efficacy, and social support were associated with lower stress response to coping with the care recipient's decline in function and cognitive impairment.

Author/Year	sample size	Caregiver type	Participants Intervention Type	Duration	Intervention content	Social support	Other outcomes	Results
Chien/2011	46 vs 46	FCG	Multi-component	6 months	DFCP	satisfaction with social support available: SSQ6; Formal support services: FSSI	Burden; QOL	Intervention group's utilization of family services was significantly decreased at the 18-month follow-up, the routine care group's service utilization had a slight increase.
Tompkins and Bell/2009	367	FCG	Health educated	12h	12h training	SCP usage questionnaire.	Overall satisfaction; Depression; Overall services used	Depression: ↓ ; Overall services used: ↑ ;
Chiu/2009	35	FCG	Multi-component	6 months	The ICSS supported two Internet-based communication tools: (a) a caregiver information handbook, and (b) personalized e-mail communication between client and clinician.	MSPSS	Family burden; Caregiver's ability; Depression; Perceived overall health; PAC Care recipients' functioning level	Burden, social support and health behavior: NS; depression: ↓ .

1 Social support interventions for dementia caregivers

Author/Year		Participants Intervention				Outcomes			Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes		
Bank/2006	41	FCG	Multi-component	18 months	Professional provides telephone support group	Support Group Questionnaire	NO		Support group attendance: NS; Intervention Improved relationships among family members, and telephone support groups made them more willing to participate in community support groups
Roth/2005	163 vs 149	Spouse CGs	Counselling group	12 months	Counseling and support	Social support network: caregiver's Satisfaction: methods of Stokes; caregivers' reports of the frequency at which they received information or assistance from support persons.	Stress appraisals of caregiver memory and behavior problems; Depression		Intervention group achieved significant increases after 1 year on 8 of the 11 indicators, which were total size of social network, number of close family members, general satisfaction, satisfaction with assistance, satisfaction with emotional support, telephone calls (no. per month), personal visits (no. per month), sitting with patient (no. per month).

Social support interventions for dementia caregivers

Author/Year	sample size	Caregiver type	Participants Intervention Type	Duration	Intervention content	Social support	Other outcomes	Results
Hébert/2003	60 vs 56	Primary CGs	Multi-component	16 weeks	Participants in the study group had fifteen 2-hr weekly sessions focusing on stress appraisal and coping	The Inventory of Socially Supportive Behaviors	Frequency of behavioral and mental health problems; Desire to institutionalize; Subjective burden	Institutionalization: ↓; personal efficacy: ↑; other outcomes: NS.
Mercedes/2002	19 vs 19 vs 20	FCG	Multi-component	8 weeks	1.multicomponent + respite group; 2. respite group; 3. control group	MOS	Burden	The control group social support: ↓; the multicomponent plus respite group social support: ↑ after10-month follow-up.
Robinson/1988	11 vs 9	FCG	Health education	8 weeks	Social skill training program	NSSQ	Self-esteem; Social skills; Caregiving burden	Objective and subjective burden: ↓; the treatment group and control group of social support: NS.

FCG: Family caregivers; ICG: Informal caregivers; MSPP : Maastricht Social Participation Profile; HRQoL: Health Related Quality of Life; SSCQ: the Short Sense of Competence Questionnaire; QoL:Quality of Life; The COPE Index-QS: the Carers of Older People in Europe Index-Quality of Social Support;;NR: not reported; SSRS: Social Support Scale; CAI: Caregiver Appraisal Inventory; CBI: Caregiver Burden Inventory; SCSO: Simplified Coping Style Questionnaire; GSES: General Self-Efficacy Scale; ↑ : significant improvement; NS: No Significant difference; ↓ : significant reduction; MSPSS: Multidimensional Scale of Perceived Social Support; PAC: Positive Aspects of Caregiving; CGs: Caregivers; MOS: Medical Outcomes Study; KAD: Knowledge of Alzheimer's disease/dementia; NSSQ: Norbeck's Social Support Questionnaire; ISEL: Interpersonal Support Evaluation List; MCSP: Dutch Meeting Centers Support Programme; DFCP: Dementia Family Care Programme; SSQ6: Six-item Social Support Questionnaire; FSSI: Family Support Services Index; MBSR: Mindfulness-Based Stress Reduction; SCP Plus: Senior Companion Program Plus; PwD: people with dementia; ZBI: Zarit Burden Interview

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Social support interventions for caregivers of older adults with dementia: A scoping review

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Social support interventions for dementia caregivers

Social support interventions for caregivers caring old adults with dementia: A scoping review

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Social support interventions for dementia caregivers

Social support interventions for caregivers of older adults with dementia: A scoping review

ABSTRACT

Objectives To identify and assess the social support interventions provided to caregivers of older adults with dementia. By synthesizing the findings, it seeks to provide insights into effective strategies that can enhance caregivers' support.

Design A scoping review.

Data sources The PRISMA Extension for Scoping Reviews was strictly followed in this study. Searches were systematically conducted across five databases (PubMed, Web of Science, Embase, Cochrane Library, CINAHL) from their inception up to February 2025.

Eligibility criteria for selecting studies We included original intervention studies published in English that examined social support interventions for caregivers of older adults with dementia, focusing on outcomes reporting social support.

Data extraction and synthesis Data extraction was conducted using a standardized Microsoft Excel chart based on Arksey and O'Malley's method. Two reviewers independently collected information on study characteristics (authors, country, publication year, design, sample size, assessment tools, interventions, and outcomes). Disagreements were resolved by a third independent reviewer.

Results A total of 31 studies were selected for this review, revealing six distinct categories of social support interventions for caregivers of older adults with dementia. These categories included peer support (n = 7), counselling group intervention (n = 2), health education (n = 2), mindfulness-based stress reduction intervention (n = 1), individual therapy (n = 1), and multicomponent interventions (n = 18). The findings indicate that these interventions significantly enhanced the social support available to caregivers, leading to positive outcomes such as reduced caregivers burden, anxiety, depression, and improved coping skills.

Conclusion This review underscores the variety of interventions designed to enhance social support for caregivers of older adults with dementia. The findings provide valuable insights for caregivers, administrators and other stakeholders, emphasizing the critical need to adopt and promote effective social support strategies for this population.

1 Social support interventions for dementia caregivers

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4 43
5 44 **Registration:** A review protocol was registered on the OSF registries, with the
6 45 following registration doi: <https://doi.org/10.17605/OSF.IO/D9C53>

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8 46 **Strengths and limitations of this study :**

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10 47 ● This scoping review performed a comprehensive search strategy to identify
11 48 articles that focused on interventions specifically designed to support
12 49 caregivers of older adults with dementia.
- 13
14 50 ● We conducted a quality assessment on the included randomized controlled
15 51 trials (RCTs); however, this assessment did not extend to other types of
16 52 studies included in the review.
- 17
18 53 ● This study was limited to articles published in English and did not include
19 54 grey literature or conference literature.

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24 55 **BACKGROUND**

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28 56 According to World Health Organization(WHO) 2023 Report, dementia
29 57 affects over 55 million people globally, with projections indicating a rise to 139
30 58 million by 2050, largely driven by global population ageing¹. Dementia is
31 59 anticipated to become the seventh leading cause of mortality worldwide ².
32
33 60 Caring for older adults with dementia presents significant challenges due to the
34 61 progressive cognitive decline and neuropsychiatric manifestations associated
35 62 with the condition, including behavioural and psychological symptoms of
36 63 dementia (BPSD)³.

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38 64 Caregivers of older adults with dementia can be categorized as formal or
39 65 informal, with informal caregivers—typically family members, friends, or
40 66 relatives —playing a crucial role in supporting older adults suffering from
41 67 advanced, terminal illnesses⁴. These informal caregivers are unpaid⁵ and often
42 68 dedicate substantial time, with approximately 16 million individuals providing
43 69 over 18.6 billion hours of care annually⁷. The caregiving role is a time-intensive,
44 70 demanding substantial personal and temporal commitments. The progressive
45 71 nature of dementia exacerbates the challenges faced by family caregivers,
46 72 particularly in managing neuropsychiatric symptoms and functional decline⁸.

Social support interventions for dementia caregivers

Many caregivers experience feelings of isolation and helpless due to a lack of emotional, informational, and practical support⁹. Research indicates that family caregivers of individuals with dementia experience elevated caregiver burden, depressive symptoms, and reduced quality of life compared to those caring for patients with non-dementia chronic conditions¹⁰. In contrast, formal caregivers refer to professionally trained nursing staff, such as nurses, nursing assistants, and rehabilitation therapists, who provide compensated professional nursing services to individuals with dementia and usually receive compensation⁶. Given the critical role caregivers play in dementia care, understanding their needs and experiences is essential for developing effective social support interventions. However, studies have shown that these needs are often overlooked in the service development process¹¹. Interventions developed in collaboration with caregivers have demonstrated more favorable outcomes in reducing caregiver burden and improving mental health, underscoring the importance of involving caregivers in the design of support programs¹².

Social support encompasses the emotional, informational, material, and behavioral assistance individuals receive within their social relationships, which can alleviate stress, enhance psychological resilience, and promote individual mental health¹³. It reflects both subjective or objective effects of various social relationships embedded in social networks¹⁴, and is derived from multiple societal aspects, including emotional, specific, and informational support¹⁵. This concept involves the exchange of emotional connections—such as affection, love, admiration, and respect—alongside affirmation, which includes agreement and acknowledgement of the appropriate action or perspectives, as well as assistance in the form of resources, financial support, information, guidance, or favors¹⁶. Social support represents the consistent engagement between individuals and groups sharing common values, serving as a source of mental motivation, feedback, assistance, and material aid¹⁷. Theoretically, the social support framework can be viewed as a provider-centric model, in

Social support interventions for dementia caregivers

which one or more individuals or network participants offer valuable assistance to the beneficiary¹⁸. By providing a defense against stress, social support fosters psychological resilience ¹⁹ and coping strategies in individuals²⁰. Additionally, it moderates the relationship between self-efficacy and mental health²¹ , highlighting its critical role in promoting well-being.

As an external resource, social support contribute to enhancing the physical well-being of caregivers^{19,20}. The substantial stress associated with caregiving responsibilities can exacerbate negative emotions such as anxiety and depression, adversely impacting both mental and physical health, ²⁴ which may, in turn, diminish the quality of care provided. Additionally, the demands of caregiving role can lead to increased feelings of loneliness²². While social support is crucial for overall well-being, a study revealed that stigma often leads caregivers to be reluctant to seek out such support, resulting in isolation that further intensifies their caregiving burden²⁶. These factors can severely affect the caregivers' physical and mental health, increasing their vulnerability to heart-related diseases and other health issues²⁷. Therefore, addressing the barriers to social support is essential for improving the well-being of caregivers and the quality of care they provide.

Targeted social support interventions are essential to caregivers of older adults with dementia, a population that frequently relies on informal support networks to alleviate caregiving burden and maintain psychosocial resilience²⁸. Interventions such as psychological training, therapeutic treatments, and self-care programs have demonstrated efficacy in reducing stress associated with emotional and behavioral issues²⁹. In England, respite care is often the preferred option for those caring for individuals with advanced dementia³⁰. Since the 1990s, computer networks have played a pivotal role in delivering these interventions³¹. Emerging evidence indicates that technology-based interventions, such as digital communication platforms, can improve social connectedness and reduce feelings of loneliness among older adults,

Social support interventions for dementia caregivers

particularly those experiencing social isolation³². As social support improves, individuals find it easier to deal with life's challenges. Another, a study has shown that the levels of satisfaction with social support significantly influence the attitudes of Korean American caregivers towards individuals with dementia³³. However, despite the increasing diversity of social support interventions for dementia caregivers, the fragmented nature of existing evidence—characterized by methodological heterogeneity and inconsistent outcome reporting—hinders a robust synthesis of their effectiveness and implementation fidelity.

This scoping review aimed to synthesize the existing research on social support interventions specifically targeting caregivers of older adults with dementia. It seeks to achieve three main objectives: (1) to summarize the various types of research evidence available, including studies focused on social support and evaluation of the research populations; (2) to provide an overview of the specific content of interventions for social support and their associated outcomes as measured by various metrics; and (3) to assess the effectiveness of documented social support interventions for caregivers. By integrating these elements, this review aims to clarify the current landscape of social support research in this critical area and identify potential gaps for future investigation.

METHODS

Research questions

The review addressed the following research questions: (1) What types of interventions are designed to improve the social support of caregivers of older adults with dementia? (2) What assessment tools are utilized to evaluate social support, and what specific outcomes are measured? (3) What effects are observed following the implementation of these interventions for caregivers of older adults with dementia?

Search strategy

This scoping review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist ³⁴and adhered to Arksey and O'Malley's methodological framework ³⁵. The framework includes five key steps: identifying the research question, searching for relevant studies, selecting studies, charting the data, and collecting, summarizing, and reporting the results. To map the existing research in this field, we conducted comprehensive searches across five major databases: PubMed, Web of Science, Embase, Cochrane Library, and CINAHL, with the aim of identifying studies that met the inclusion criteria. A preliminary search was performed to locate relevant literature on the topic (see Supplemental search strategy). The search strategy was collaboratively developed by team members, and the literature retrieval was carried out independently by two master's students with medical experience. Our search utilized the keywords "dementia caregivers," "social support," and "intervention" to ensure a thorough exploration of pertinent evidence, covering the period from the inception of the databases up to February 2025.

Inclusion criteria

This scoping review focused on research examining social support interventions specifically designed for caregivers of older individuals with dementia. Eligible studies included those that targeted these caregivers and reported outcomes related to social support. Only original intervention studies with full texts were considered for inclusion. Additionally, the review was limited to literature published in English to ensure the synthesis of globally accessible evidence align with the review's objective.

Exclusion criteria

Studies were excluded if the full text was unavailable, vital information was absent, an explicit methodology was absent, or the publication language was not English.

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Types of sources

In alignment with the review questions, this scoping review included a variety of intervention studies, specifically randomized controlled trials (RCTs), nonrandomized controlled trials (NRCTs), and mixed-methods studies.

Study selection

The study selection process involved importing citations into EndNote X9 citation management software, followed by the removal of duplicates. Prior to screening, all reviewers received standardized training to ensure consistency in the evaluation process. Two researchers independently conducted an initial screening of eligibility based on the titles and abstracts, subsequently reviewing the full texts for further assessment against the predefined inclusion and exclusion criteria. The rationale for excluding any studies was meticulously documented. Any discrepancies among the authors were resolved through consultation with an additional author. The search results are illustrated in the Preferred Reporting Items for Scoping Reviews and Meta-analyses (PRISMA) flow diagram (Figure 1).

Data extraction

A standardized extraction data chart was developed in Microsoft Excel, drawing on Arksey and O'Malley's data extraction form³⁵, following consultation among all authors to ensure comprehensive data collection from the included studies. Two investigators independently gathered relevant information from the eligible records. The Excel table was designed to facilitate the extraction of key details, including authors' name, country of origin, publication year, study design, sample characteristics, sample size, assessment tools, intervention strategies (such as types, frequency, tools, and outcomes), and the main findings of each study. Any disagreements in the data extraction process were resolved by an additional independent reviewer, ensuring the accuracy and reliability of the collected data.

Patient and public involvement

Patients and the public were not involved in the design, conduct, reporting,

Social support interventions for dementia caregivers

or dissemination plans of this research.

RESULTS

Overview of findings

The initial search identified 3,127 relevant citations (see Fig.1). After deduplication, 1,871 articles were selected for inclusion. A review of titles and abstracts led to the identification of 183 studies for full-text assessment. Of these, 143 articles were excluded for various reasons: 36 were designed with protocols, 24 had participants who did not meet the eligibility criteria, 52 focused on outcomes that did not include social support, 25 were not published in English, and 8 had missing full texts. Ultimately, 31 studies were incorporated in this scoping review. Efforts were made to contact the author of the article for which the full text cannot be obtained; however, no response were received.

Study characteristics

The 31 studies were published between 1988 and 2025. Among these, 16 were RCTs^{36–51}, eight were NRCTs^{52–59}, and seven were mixed methods studies^{60–66}. The majority of the studies were conducted in the United States (n = 19), followed by Europe (n = 11), Oceania (n = 1), and Asia (n = 2). Table 1 presents an overview of the of the fundamental details of the included studies. In terms of intervention settings, two studies were conducted in long-term care institutions^{22,34}, ten in community settings^{36,37,51,52,55,56,58,60,61,64}, and nineteen in the older adults' homes^{35–44,46,47,50,52,55,56,58,59,60}. The total sample size of caregivers across the studies was 4,629, with individual study sizes ranging from 12 to 494 participants and a median of 85 cases. The majority of studies targeted family caregivers of older adults with dementia, with representation across diverse cultural contexts. Notably, three studies specifically evaluated social support interventions tailored for African American caregivers, highlighting gaps in evidence for underserved populations^{60,62,63}. Additionally,

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Social support interventions for dementia caregivers

one study focused on caregivers of Turkish and Moroccan backgrounds living in the Netherlands ⁴⁹, while another investigated ways to enhance social support among Chinese Canadian caregivers ⁶⁶. Although interventions were frequently delivered in community-based or clinical settings, the majority targeted family caregivers of individuals with dementia broadly, with only one study explicitly focusing on spousal caregivers through dyadic, kinship-specific support frameworks⁴⁴.

Quality appraisal

This scoping review also conducted a quality appraisal of the included RCTs, revealing that over 75% of the studies were assessed to have a low risk of bias in the subsequent domains, including sequence generation, blinding of outcome assessment, and selective reporting. However, less than 60% of the studies were rated as low risk in other critical areas, such as allocation concealment, blinding of participants and personnel, incomplete outcome data; and the presence of other potential biases (see Fig. 2). This assessment underscores the variability in methodological rigor across the included RCTs.

Table 1 Characteristics of included studies

Author	Year	Country	Design	Setting	Sample
Neal et al	2024	Netherlands	RCT	Community	150
Xiao et al	2024	China	RCT	Home	266
Xu et al.	2023	USA	Mixed methods	Community	20
Blackberry et al.	2023	Australia	Mixed methods	Rural community	113
Glueckauf et al.	2022	USA	Mixed methods	Home	12
Berwig et al.	2022	Germany	RCT	Facility	280
Christie et al.	2022	Netherlands	RCT	Home	96
Fields et al.	2021	USA	Mixed methods	Home	16
Szcześniak et al.	2021	Italy, Poland, UK,	Mixed methods	Community	141

Social support interventions for dementia caregivers

Author	Year	Country	Design	Setting	Sample
		Netherlands			
Töpfer et al.	2021	Germany	RCT	Home	51
van Wezel	2021	Netherlands	RCT	Home	340
David					
Gustafson Jr	2019	USA	RCT	Home	26
et al.					
Czaja et al.	2018	USA	Non-RCTs	Community	146
Wilkerson et					
al.	2018	USA	Non-RCTs	Home	60
Smith et al.	2018	UK	Mixed methods	Home	16
Tremont et					
al.	2017	USA	RCT	Home	250
Lykens et al.	2014	USA	Non-RCTs	Community	494
Whitebird et					
al.	2013	USA	RCT	Home	78
Bass et al.	2013	USA	RCT	Community	486
Czaja, et al.	2013	USA	Non-RCTs	Home	110
Easom et al.	2013	Georgia	Non-RCTs	Rural home	83
Nichols et al.	2011	USA	Non-RCTs	Home	127
Marziali et al.	2011	Canada	Non-RCTs	Community	91
Wai Tong					
Chien et al.	2011	China	RCT	Home	92
Tompkins et					
al.	2009	USA	Non-RCTs	Community	367
Chiu et al.	2009	Canada	Mixed methods	Home	35
Bank et al.	2006	USA	RCT	Community	41
Roth et al.	2005	USA	RCT	Home	406
Hébert et al.	2003	Canada	RCT	Home	158
Mercedes et					
al.	2002	Colombia	RCT	Day centers	58
Robinson et					
al.	1988	USA	RCT	Home	20

Theoretical frameworks utilization research design

Among the 31 studies, 12 studies were guided by six distinct theoretical frameworks to inform their research design: the Stress Process Model, the Sociocultural Stress and Coping Model, the Stress-appraisal Coping and the Crisis Model, the Role Transformation Framework, Rural Nursing Theory, and Tolsdorf's Conception of Social Support. Specifically, five studies followed the Stress Process Model^{37,51,52,57,62}, while three adhered to the Sociocultural Stress and Coping Model^{43,60,63}. Additionally, one study employed Lazarus and Folkman's Stress-Appraisal Coping model alongside the Crisis Model of Moos and Tsu⁶⁴, one was guided by the Framework of Role Transformation⁵⁹, another implemented the Rural Nursing Theory⁵⁴, and another one was based on Tolsdorf's Conception of Social Support⁴¹. Furthermore, 19 studies did not reference any theoretical framework, indicating a gap in the theoretical grounding of a significant portion of the research.

Social support measurements

As detailed in Supplemental Table 2, a total of 23 methods were employed to measure social support across the studies reviewed, with the Medical Outcomes Study social support survey (MOS) being the most frequently utilized, appearing in five studies. The MOS is a multidimensional, self-administered, and concise survey designed to measure social support among patients⁶⁷. Additionally, the Multidimensional Scale of Perceived Social Support (MPSS) was utilized in four studies, while another four studies extracted between 10 and 21 items from three different broad scales to measure social support. Several studies also developed their own measurement tools, including a 13-item questionnaire consisting of four domains: satisfaction with support, social support network, received support and negative interactions. Other instruments included the Interpersonal Support Evaluation List (ISEL), a brief form of the Perceived Social Support Questionnaire (F-SozU), which assesses various dimensions of social support, and the Inventory of Socially Supportive

Social support interventions for dementia caregivers

Behaviors, among others. Supplemental Table 2 indicates that the majority of studies did not report on scale reliability and validity.

Social support interventions

As presented in Supplemental Table 3, the social support interventions identified in the reviewed studies were categorized into six distinct types based on their specific content: peer support (n = 7), counselling group (n = 2), health education (n = 2), mindfulness-based stress reduction (n = 1), individual therapy (n = 1), and multi-component interventions (n = 18). Notably, one study highlighted that the development of intervention methods involved organizing multiple focus groups to assess caregivers' need⁴². The delivery of the interventions varied, encompassing online and offline, and hybrid formats. Fourteen studies utilized online interventions^{36,38,39,42,47,48,50,51,53,56,57,59,62,66}, ten studies employed offline interventions^{40,41,43,45,46,49,58,60,63,64}, and seven studies implemented a combination of online and offline approaches^{37,44,52,54,55,61,65}. This diversity in intervention types and delivery methods underscores the multifaceted nature of social support interventions aimed at addressing various needs within different populations.

Peer support

Peer support interventions are characterized by group-based programs facilitated by trained peers or mentors who possess lived caregiving experience. These programs foster shared experiential learning, mutual problem-solving, and emotional reciprocity among participants. In the reviewed studies, eight utilized peer-support interventions, comprising two randomized controlled trials (RCTs), and six employing mixed methods. The duration of these interventions varied, with the shortest lasting four hours⁴⁹, while others spanned up to 24 weeks; one study implemented a three steps intervention over 32 weeks⁶¹, and the majority opted for a six months duration^{38,60,65}. Additionally, one study was conducted three months⁶³, and another lasted six weeks⁵⁹. Among the findings,

Social support interventions for dementia caregivers

three studies showed improvement in perceived social support^{38,63,65}, one indicated enhanced satisfaction with social support⁶⁰, and another demonstrated advancements in emotional and informational support⁵⁹. Furthermore, one study noted an increase in support from home care staff ; however, improvements in support from family, friends, neighbors, and advice from doctors were not statistically significant⁴⁹. Overall, one study highlighted an enhancement in overall social support⁶¹, underscoring the potential effectiveness of peer support interventions.

Counselling group intervention

Counselling group intervention involves caregivers participating in support groups that provided personal and family consultations. In the reviewed literature, two studies implemented group counselling interventions, both of which were RCTs. With durations of 12 months⁴⁴ and 6 months⁴⁷. One study reported a significant improvement in caregivers' utilization of community support services ; however, it noted no significant improvement in the utilization of community services and medical resources by the care recipient⁴⁷. Additionally, another study identified 11 indicators of social support, with 8 showed significant improvement⁴⁴.

Health education

Health education intervention in the context of dementia care encompasses social skills program aimed at enhancing caregivers' care skills and confidence. These programs typically involve 12 hours of sessions designed to achieve various objectives, such as developing emotional resilience, understanding the disease, and fostering a sense of control. In the reviewed studies, two utilized health education interventions, one was an RCT, while the other was a non-RCT study. The intervention duration were 2 months⁴¹ and 12 hours⁵⁸, respectively. One study reported a significant increase in service utilization⁵⁸, , indicating that the educational component effectively encouraged caregivers to seek additional resources. In contrast, the other

Social support interventions for dementia caregivers

study reported no significant increase in social support among participants⁴¹. These findings highlight the potential benefits of health education interventions in enhancing caregivers' skills, although the impact on social support may vary.

Mindfulness-based stress reduction

Mindfulness-based stress reduction interventions for caregivers involve weekly guidance on mindfulness principles, complemented by meditation and gentle yoga sessions led by a trained instructor. One RCT examined the effectiveness of such an intervention, which lasted for two months ⁴⁶. The results indicated a significant improvement in caregivers' social support following participation in the program.

Individual therapy

The expanded Tele.TAnDem program provided caregivers with 12 individual therapy sessions, each lasting 50 minutes, conducted via telephone across six months period⁴⁸. This comprehensive program included 10 therapeutic modules designed to address various aspects of caregiving. A three-year follow-up of the study revealed that informal caregivers experienced a significant reduction in caregiver burden, improved quality of social relationships, and enhanced skills in managing the behavioral issues associated with dementia. While the intervention significantly improved caregivers' social relationships, it did not demonstrate significant increase in service utilization.

Multi-component interventions

Multi-component interventions integrate psychological education, systematic communication, and physical therapy. 18 studies used multi-component interventions, of which six were non-RCTs, nine were RCTs, and three were mixed methods. The shortest intervention duration was four weeks⁵¹, the longest was 18 months ³⁶, and the most common intervention duration was six months ^{42,45,50,52,54,55,57,66}. Among the 18 studies mentioned above, a total of 11 studies reported a slight increase in social support without statistical significance, but also pointed out that the interventions were in the correct

Social support interventions for dementia caregivers

direction^{36,39,42,44,50–52,54,55,57,66}. One study reported an increase in overall social support⁴¹, one mentioned that the intervention improved the perceived social support of caregivers⁶², one mentioned an increase in emotional support⁶⁴, and another mentioned a significant increase in support resources³⁷. Meanwhile, one study reported an increase in social support satisfaction⁵³, another study proposed that social support were associated with lower stress response to cope with the care recipient's decline in function and cognitive impairment⁵⁶, by the way, one study showed that the intervention group's utilization of family services was significantly decreased⁴⁵.

Intervention outcomes

In addition to enhancing social support, nine studies showed that intervention significantly reduced caregiver depression^{37,38,46,52,55,57,58,62,66}. Furthermore, eight studies reported reduced caregiver burden^{41,52,53,55,57,59,60,64}, while three studies reported reduced stress^{37,46,59}, two studies reported improved mental health of the caregivers^{46,56}, one study reported improved caregiver coping skills⁶⁰. Additionally, one study reported improved caregiver satisfaction⁶⁴, one study reported increased health-related quality of life⁵⁰, and one study reported a significantly higher sense of competence among caregivers compared to care-as-usual⁵¹.

Qualitative research results

Among the included studies, seven studies conducted qualitative research^{59,60,62–66}, with all interviews conducted after the intervention. One study conducted interviews with both caregivers and older adults with dementia, the caregivers reported positive feedback while the older adults with dementia did not. Other studies described caregivers' positive feedback from the interviews. The theme mainly focused on caregiving skills, mastery of dementia related knowledge, benefits from interventions, satisfaction with interventions, emotions and burdens, and various aspects of social support.

DISCUSSION

Previous studies have reported interventions aimed at improving the social support of caregivers caring older adults with dementia. Nevertheless, evidence on the categories of intervention, implementation, evaluation, and effects of these interventions is dispersed in the literature, and an up-to-date summary is lacking. This scoping review comprehensively summarizes existing studies published in English that describe interventions to enhance social support for dementia caregivers. Six effective interventions, including peer support, group counseling, health education, mindfulness-based stress reduction, individual therapy, and multi-component interventions were identified in this review. These interventions differed in terms of content, duration, acceptance, and effectiveness.

Characteristics of the participants

Among the included studies, family caregivers consisted of spouses, children, other relatives, neighbors, and friends; only one study focused on spousal caregivers⁴⁴, while the remaining studies included all categories of caregivers. Individuals with dementia are mostly looked after by informal caregivers, particularly spouses who are considered to be at a higher risk of social isolation⁶¹. This finding shows that spouses and other caregivers exhibit different responses to social support aimed at alleviating caregivers' pain ⁶². Meanwhile, social support among African Americans has gradually received more attention, with three studies investigating social support interventions for African-Americans ^{60,62,63}. According to one systematic review, almost 95% of Chinese individuals with dementia are primarily cared for by their family members at home, largely influenced by the cultural values of filial piety and Confucian traditions⁷⁰. Recent research has explored the cultural adaptation of iSupport, a global online intervention developed by the World Health Organization for informal caregivers of people with dementia. This investigation

Social support interventions for dementia caregivers

underscores the critical need for contextually tailored interventions that align with local cultural practices and values⁷¹, ensuring that support for caregivers is both relevant and effective in addressing their unique challenges.

Social support measures

A total of 23 different assessment tools were utilized to measure social support. Supplemental Table 2 shows that most studies used scales that can only measure a certain aspect of social support, such as subjective perceived social support or the level of social support judged solely by whether caregivers seek help. Only three types of tools were described in terms of their reliability and validity. Since social support is a multidimensional concept, different interventions aim to improve different dimensions. While subjective social support is difficult to measure using quantitative methods, more methods focus on objective social support and consider only some aspects of social support, such as restrictions in social participation³⁸, measuring supported resources³⁷, perceived support from significant others, family, and friends^{39,66}, social networks and the four dimensions of functional social support²², or satisfaction with support⁵². Because of the multidimensional nature of the concept of social support, the measurement results can only reflect part of the situation. Therefore, more precise measurement tools need to be developed.

Social support interventions

According to the current study, six types of interventions to improve social support exist. Apparently, support from others is crucial; caregivers of older adults with dementia need this support initially, and eventually seeking help and support. Caregivers from various regions possess distinct requirements regarding the methods and types of support they need. In the included studies, this review found that peer support can significantly enhance caregiver's perceived social support, satisfaction of social support, emotional and informational support, as well as overall social support. Peer support has

Social support interventions for dementia caregivers

demonstrated advantages for individuals with various requirements, including alleviating depressive symptoms⁶³, enhancing coping strategies⁶⁴, and reducing feelings of isolation and loneliness. Support provided by caregivers or volunteers with similar experience is more easily accepted by caregivers who are deeply burdened with caregiving⁷⁴. Peer support also performs well in different environments, such as in educational settings where peer support can help improve academic performance and build confidence⁷⁵, and in chronic disease management, peer support groups have played an effective role in promoting self-management and emotional health⁷⁶. The excellent performance of peer support may be attributed to the same caregiving experience as peers^{77,78}. Caregivers who are burdened with caregiving are more likely to empathize with them and accept their help without reservation. At the same time, as the providers of support, with the same experience, they know better where to provide help and guidance to their caregivers.

And counselling group can enhance social support through the utilization of support. Counseling group is widely used in the field of mental health and can effectively improve sexual satisfaction among women with multiple sclerosis⁷⁹. And can also may improve all levels of mental health of midwifery students⁸⁰. Health education, like counseling groups, improves the utilization of support by caregivers⁵⁸. Mindfulness-based stress reduction, and individualized treatment, have good outcomes in improving social support. The findings from the included studies indicate that multi-component interventions enhance social support for caregivers across different domains, such as emotional, practical, and informational support. According to the current study, multi-component interventions typically combine multiple interventions to address different aspects of complex problems, fit the concept of multidimensional social support, and involve integrating multiple interventions in the fields of health education, care skills, coping strategies, and social support for dementia caregivers, these have been demonstrated to effectively alleviate the burden on

Social support interventions for dementia caregivers

caregivers^{52,55,57,64,81}, decrease depressive symptoms^{37,52,55,57,62,66}, and increase their perceived satisfaction⁵³, from the included studies, multi-component interventions demonstrated moderate efficacy in improving caregivers' perceived social support and utilisation rates⁶²; however, only one study explored the impact of multi-component interventions on overall social support⁴¹.

According to the included studies this discrepancy may reflect methodological heterogeneity in intervention components (e.g., variable duration, intensity) and limited generalisability due to insufficient sample diversity or longitudinal follow-up. Health education has better effects in Interventions such as consultation groups, however, the angle of improvement is relatively one-dimensional, which can be used as a part of multi-component intervention, so as to achieve multidimensional improvement. Delivery interventions include face-to-face, telephone-based and Internet-based intervention, as well as online and offline combinations. Both face-to-face and online interventions have their advantages and disadvantages. The main disadvantage of face-to-face interaction is that caregivers find it difficult to leave older adults with dementia behind and go to specific institutions to receive specific interventions³⁸. Therefore, telephone and internet-based interventions are increasingly being applied to social support interventions. Another study indicates that technology-assisted interventions help alleviate caregiver burden and enhance support, similar to face-to-face support⁶⁶.

Considering that online and offline interventions have their own characteristics and shortcomings, the combination of the two can effectively reduce inconvenience and provide better and more comprehensive application of intervention measures to caregivers, to ensure they can receive more effective support to reduce their burden, ultimately enhancing the well-being of older individuals with dementia. Only one included study derived its intervention design from prior needs assessments of caregivers in control groups. However,

Social support interventions for dementia caregivers

the small sample size limited statistical power to detect intervention effectiveness, precluding robust conclusions. Future studies should prioritise co-design methodologies grounded in user-centred needs assessments, coupled with adequately powered trials to enhance ecological validity and generalisability⁶¹.

Interventions outcomes

Drawing from the studies that were included, improvement of social support can lay a good foundation for reducing the care burden, depression and stress and eventually enhancing the well-being of caregivers, and multi-component interventions can improve multiple dimensions of social support. In the implementation of interventions in the future, smarter and easier-to-operate intervention equipment can be developed for caregivers, such as voice control or AI equipment, so that their operation can be more easily mastered, and the distance between people can be narrowed. Simultaneously, it is crucial to consider the unique requirements of caregivers with diverse backgrounds in order to amplify the benefits of ongoing support initiatives. In the future It is also possible to develop interventions that simultaneously contain the essence of six categories, leverage their respective characteristics, integrate their advantages into one intervention, and maximize their effectiveness. The qualitative research section supplemented the unmeasured parts of the scale. From the results, it can be seen that most caregivers provided positive feedback, and the implementation of interventions not only reduced their caregiving burden, but also enhanced their mastery of dementia related knowledge and improved their social support. However, almost all qualitative studies are conducted after intervention, neglecting the understanding of the needs of caregivers before and after intervention. Future research can consider conducting qualitative studies before and after intervention to fully understand the needs of caregivers, develop interventions based on their reported results, and conduct qualitative

Social support interventions for dementia caregivers

studies again after intervention to better improve caregivers' social support and quality of life.

Limitations

Although this study provides a comprehensive overview of social support interventions for dementia caregivers, some methodological limitations must be mentioned. Due to language barriers, this review only included English language literature and did not include gray literature, which might have overlooked pertinent information. In addition, we included only primary studies and excluded reviews, which may have resulted in missing on significant findings. Since this scoping review did not involve a quality assessment of the raw data, it may not be possible to completely rule out the impact of low-quality research on the results, in addition, as we only assessed the risk of bias of RCTs, it may not be possible to completely rule out systematic errors.

CONCLUSION

This scoping review comprehensively examined the landscape of social support interventions implemented in the field of dementia care; however, in the process of caring older adults with dementia, problems remain related to caregivers seeking support and in the delivery of interventions. We suggest that combining online and offline interventions for caregivers can probably achieve the best results. Future research should integrate existing technologies and utilize them to provide comprehensive interventions to caregivers. Meanwhile, it is necessary to conduct research with larger sample sizes and different cultures, and identify the interventions most suitable for different types of people. Interventions with more durable effects also need to be explored.

Ethical approval

This scoping review did not require ethical approval because it solely analyzed publicly available literature and did not involve direct research on

Social support interventions for dementia caregivers

human or animal subjects. All included studies were published, and were accessible through academic databases, ensuring compliance with ethical standards for secondary data analysis. We adhered to academic integrity principles throughout the study, including transparency in reporting methods and results, proper citation of sources, and integrity of the data used.

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The authors declare that they have no competing interests.

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Social support interventions for dementia caregivers

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612 **References:**

613 1. World Alzheimer Report 2023 | Alzheimer's Disease International (ADI). Accessed
614 August 7, 2024. <https://www.alzint.org/resource/world-alzheimer-report-2023/>

615 2. 2021 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2021;17(3):327-406.
616 doi:10.1002/alz.12328

617 3. Huisman C, Huisman E, Kort H. Technological Applications Contributing to Relieve
618 Care Burden or to Sleep of Caregivers and People With Dementia: A Scoping Review
619 From the Perspective of Social Isolation. *Front Public Health*. 2022;10:797176.
620 doi:10.3389/fpubh.2022.797176

621 4. Theißen T, Ullrich A, Oechsle K, Wikert J, Bokemeyer C, Schieferdecker A. "Being an
622 informal caregiver - strengthening resources": mixed methods evaluation of a
623 psychoeducational intervention supporting informal caregivers in palliative care. *BMC*
624 *Palliat Care*. 2024;23(1):95. doi:10.1186/s12904-024-01428-0

625 5. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in
626 psychological health and physical health: a meta-analysis. *Psychol Aging*.
627 2003;18(2):250-267. doi:10.1037/0882-7974.18.2.250

Social support interventions for dementia caregivers

6. Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. *JAMA*. 1996;276(21):1725-1731.

7. 2020 Alzheimer’s disease facts and figures. *Alzheimers Dement*. Published online March 10, 2020. doi:10.1002/alz.12068

8. Davies N, Iliffe S, Hopwood J, et al. The key aspects of online support that older family carers of people with dementia want at the end of life: A qualitative study. *Aging Ment Health*. 2020;24(10):1654-1661. doi:10.1080/13607863.2019.1642299

9. Cr V, I R, C Q, et al. The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging & mental health*. 2021;25(7). doi:10.1080/13607863.2020.1753014

10. Karg N, Graessel E, Randzio O, Pendergrass A. Dementia as a predictor of care-related quality of life in informal caregivers: a cross-sectional study to investigate differences in health-related outcomes between dementia and non-dementia caregivers. *BMC Geriatr*. 2018;18(1):189. doi:10.1186/s12877-018-0885-1

11. Jagoda FA, Hirt J, Mueller C, Halek M. Involvement of family caregivers in dementia care research: a scoping review protocol. *Syst Rev*. 2024;13(1):277. doi:10.1186/s13643-024-02696-w

12. Encinas-Monge C, Hidalgo-Fuentes S, Cejalvo E, Martí-Vilar M. Interventions to

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Erasmushogeschool

Social support interventions for dementia caregivers

- 647 Relieve the Burden on Informal Caregivers of Older People with Dementia: A Scoping
648 Review. *Nurs Rep.* 2024;14(3):2535-2549. doi:10.3390/nursrep14030187
- 649 13. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull.*
650 1985;98(2):310-357.
- 651 14. Kerres Malecki C, Kilpatrick Demary M. Measuring perceived social support:
652 Development of the child and adolescent social support scale (CASSS). *Psychology*
653 *in the Schools.* 2002;39(1):1-18. doi:10.1002/pits.10004
- 654 15. Drentea P, Clay OJ, Roth DL, Mittelman MS. Predictors of improvement in social
655 support: Five-year effects of a structured intervention for caregivers of spouses with
656 Alzheimer's disease. *Soc Sci Med.* 2006;63(4):957-967.
657 doi:10.1016/j.socscimed.2006.02.020
- 658 16. Antonucci T. Social Supports, and Social Relation-ships. In; 1990. Accessed
659 November 9, 2023.[https://www.semanticscholar.org/paper/Social-Supports%2C-and-](https://www.semanticscholar.org/paper/Social-Supports%2C-and-Social-Relation-ships/Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2)
660 [Social-Relation-ships](https://www.semanticscholar.org/paper/Social-Supports%2C-and-Social-Relation-ships/Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2)
661 [Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2](https://www.semanticscholar.org/paper/Social-Supports%2C-and-Social-Relation-ships/Antonucci/fbbaca478fb74e5f35c8594be1d1e3840927db8a?sort=relevance&page=2)
- 662 17. Caplan G, Killilea M, Abrahams RB, eds. *Support Systems and Mutual Help:*
663 *Multidisciplinary Explorations.* Grune & Stratton; 1976.
- 664 18. Hupcey JE. Clarifying the social support theory-research linkage. *J Adv Nurs.*
665 1998;27(6):1231-1241. doi:10.1046/j.1365-2648.1998.01231.x

Social support interventions for dementia caregivers

19. Southwick SM, Bonanno GA, Masten AS, Panter-Brick C, Yehuda R. Resilience definitions, theory, and challenges: interdisciplinary perspectives. *Eur J Psychotraumatol.* 2014;5. doi:10.3402/ejpt.v5.25338

20. Labrague LJ. Psychological resilience, coping behaviours and social support among health care workers during the COVID-19 pandemic: A systematic review of quantitative studies. *J Nurs Manag.* 2021;29(7):1893-1905. doi:10.1111/jonm.13336

21. Lu J, Wang B, Dou X, et al. Moderating effects of perceived social support on self-efficacy and psychological well-being of Chinese nurses: a cross-sectional study. *Front Public Health.* 2023;11:1207723. doi:10.3389/fpubh.2023.1207723

22. Cohen S. Social relationships and health. *Am Psychol.* 2004;59(8):676-684. doi:10.1037/0003-066X.59.8.676

23. Sw W, Cs W, S Z, J M, D D, Pd S. Emotional and physical health of informal caregivers of residents at the end of life: the role of social support. *The journals of gerontology Series B, Psychological sciences and social sciences.* 2008;63(3). doi:10.1093/geronb/63.3.s171

24. Mehdipanah R, Briceño EM, Malvitz M, et al. Exploring Pathways to Caregiver Health: The Roles of Caregiver Burden, Familism, and Ethnicity. *J Aging Health.* 2025;37(3-4):148-155. doi:10.1177/08982643241235970

25. Feldstein AC, Nichols GA, Elmer PJ, Smith DH, Aickin M, Herson M. Older women

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Erasmushogeschool

Social support interventions for dementia caregivers

- 685 with fractures: patients falling through the cracks of guideline-recommended
686 osteoporosis screening and treatment. *J Bone Joint Surg Am.* 2003;85(12):2294-2302.
- 687 26. Chen L, Zhao Y, Tang J, et al. The burden, support and needs of primary family
688 caregivers of people experiencing schizophrenia in Beijing communities: a qualitative
689 study. *BMC Psychiatry.* 2019;19(1):75. doi:10.1186/s12888-019-2052-4
- 690 27. Elovainio M, Komulainen K, Sipilä PN, et al. Association of social isolation and
691 loneliness with risk of incident hospital-treated infections: an analysis of data from the
692 UK Biobank and Finnish Health and Social Support studies. *Lancet Public Health.*
693 2023;8(2):e109-e118. doi:10.1016/S2468-2667(22)00253-5
- 694 28. Dam AEH, de Vugt ME, Klinkenberg IPM, Verhey FRJ, van Boxtel MPJ. A systematic
695 review of social support interventions for caregivers of people with dementia: Are they
696 doing what they promise? *Maturitas.* 2016;85:117-130.
697 doi:10.1016/j.maturitas.2015.12.008
- 698 29. Cheng ST, Zhang F. A comprehensive meta-review of systematic reviews and meta-
699 analyses on nonpharmacological interventions for informal dementia caregivers. *BMC*
700 *Geriatr.* 2020;20(1):137. doi:10.1186/s12877-020-01547-2
- 701 30. Kampanellou E, Chester H, Davies L, et al. Carer preferences for home support
702 services in later stage dementia. *Aging Ment Health.* 2019;23(1):60-68.
703 doi:10.1080/13607863.2017.1394441

Social support interventions for dementia caregivers

31. Brennan PF, Moore SM, Smyth KA. Alzheimer's disease caregivers' uses of a computer network. *West J Nurs Res.* 1992;14(5):662-673. doi:10.1177/019394599201400508

32. Czaja SJ, Boot WR, Charness N, Rogers WA, Sharit J. Improving Social Support for Older Adults Through Technology: Findings From the PRISM Randomized Controlled Trial. *Gerontologist.* 2018;58(3):467-477. doi:10.1093/geront/gnw249

33. Lee Y, Choi S. Korean American dementia caregivers' attitudes toward caregiving: the role of social network versus satisfaction with social support. *J Appl Gerontol.* 2013;32(4):422-442. doi:10.1177/0733464811431163

34. Tricco AC, Lillie E, Zarin W, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169(7):467-473. doi:10.7326/M18-0850

35. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology.* 2005;8(1):19-32. doi:10.1080/1364557032000119616

36. Bank AL, Argüelles S, Rubert M, Eisdorfer C, Czaja SJ. The value of telephone support groups among ethnically diverse caregivers of persons with dementia. *Gerontologist.* 2006;46(1):134-138. doi:10.1093/geront/46.1.134

37. Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care:

Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies. Erasmushogeschool

Social support interventions for dementia caregivers

- 723 effect of a care coordination program for veterans with dementia and their family
 724 members and friends. *J Am Geriatr Soc.* 2013;61(8):1377-1386.
 725 doi:10.1111/jgs.12362
- 726 38. Berwig M, Lessing S, Deck R. Telephone-based aftercare groups for family carers of
 727 people with dementia - results of the effect evaluation of a randomised controlled trial.
 728 *BMC Health Serv Res.* 2022;22(1):177. doi:10.1186/s12913-022-07490-9
- 729 39. Christie HL, Dam AEH, van Boxtel M, Köhler S, Verhey F, de Vugt ME. Lessons
 730 Learned From an Effectiveness Evaluation of Inlife, a Web-Based Social Support
 731 Intervention for Caregivers of People With Dementia: Randomized Controlled Trial.
 732 *JMIR Aging.* 2022;5(4):e38656. doi:10.2196/38656
- 733 40. Cerquera Córdoba Ara Mercedes, Tiga-Loza Diana Carolina, Álvarez Anaya William
 734 Armando, Dugarte Peña Edwin, Jaimes Espíndola Lisseth Rocío, Plata Osma Leidy
 735 Johanna. Ensayo controlado aleatorizado de un programa multicomponente para
 736 cuidadores informales de pacientes con Alzheimer. *Revista Cuidarte.*
 737 2021;12(2):e2002. <http://dx.doi.org/10.15649/cuidarte.2002>
- 738 41. Robinson KM. A social skills training program for adult caregivers. *ANS Adv Nurs Sci.*
 739 1988;10(2):59-72. doi:10.1097/00012272-198801000-00010
- 740 42. Gustafson DH, Gustafson DH, Cody OJ, Chih MY, Johnston DC, Asthana S. Pilot Test
 741 of a Computer-Based System to Help Family Caregivers of Dementia Patients. *J*
 742 *Alzheimers Dis.* 2019;70(2):541-552. doi:10.3233/JAD-190052

Social support interventions for dementia caregivers

43. Hébert R, Lévesque L, Vézina J, et al. Efficacy of a psychoeducative group program for caregivers of demented persons living at home: a randomized controlled trial. *J Gerontol B Psychol Sci Soc Sci*. 2003;58(1):S58-67. doi:10.1093/geronb/58.1.s58

44. Roth DL, Mittelman MS, Clay OJ, Madan A, Haley WE. Changes in social support as mediators of the impact of a psychosocial intervention for spouse caregivers of persons with Alzheimer's disease. *Psychol Aging*. 2005;20(4):634-644. doi:10.1037/0882-7974.20.4.634

45. Chien WT, Lee IYM. Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia²³. *J Adv Nurs*. 2011;67(4):774-787. doi:10.1111/j.1365-2648.2010.05537.x

46. Whitebird RR, Kreitzer M, Crain AL, Lewis BA, Hanson LR, Enstad CJ. Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *Gerontologist*. 2013;53(4):676-686. doi:10.1093/geront/gns126

47. Tremont G, Davis JD, Ott BR, et al. Randomized Trial of the Family Intervention: Telephone Tracking-Caregiver for Dementia Caregivers: Use of Community and Healthcare Resources. *J Am Geriatr Soc*. 2017;65(5):924-930. doi:10.1111/jgs.14684

48. Töpfer NF, Sittler MC, Lechner-Meichsner F, Theurer C, Wilz G. Long-term effects of telephone-based cognitive-behavioral intervention for family caregivers of people with dementia: Findings at 3-year follow-up. *J Consult Clin Psychol*. 2021;89(4):341-349. doi:10.1037/ccp0000640

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Social support interventions for dementia caregivers

49. van Wezel N, van der Heide I, Devillé WL, et al. Effects of an educational peer-group intervention on knowledge about dementia among family caregivers with a Turkish or Moroccan immigrant background: A cluster randomised controlled trial. *Patient Educ Couns*. 2021;104(7):1726-1735. doi:10.1016/j.pec.2020.11.008
50. Xiao L, Ullah S, Hu R, et al. The effects of a facilitator-enabled online multicomponent iSupport for dementia programme: A multicentre randomised controlled trial. *International Journal of Nursing Studies*. 2024;159:104868. doi:10.1016/j.ijnurstu.2024.104868
51. Neal DP, Kucera M, van Munster BC, et al. Cost-effectiveness of the FindMyApps eHealth intervention vs. digital care as usual: results from a randomised controlled trial. *Aging Ment Health*. 2024;28(11):1457-1470. doi:10.1080/13607863.2024.2345128
52. Czaja SJ, Lee CC, Perdomo D, et al. Community REACH: An Implementation of an Evidence-Based Caregiver Program. Meeks S, ed. *The Gerontologist*. 2018;58(2):e130-e137. doi:10.1093/geront/gny001
53. Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial intervention for dementia caregivers. *Am J Geriatr Psychiatry*. 2013;21(11):1071-1081. doi:10.1016/j.jagp.2013.02.019
54. Easom LR, Alston G, Coleman R. A Rural Community Translation of a Dementia Caregiving Intervention. *Online Journal of Rural Nursing and Health Care*. 2013;13(1):66-91. doi:10.14574/ojrnhc.v13i1.248

Social support interventions for dementia caregivers

55. Lykens K, Moayad N, Biswas S, Reyes-Ortiz C, Singh KP. Impact of a community based implementation of REACH II program for caregivers of Alzheimer’s patients. *PLoS One*. 2014;9(2):e89290. doi:10.1371/journal.pone.0089290

56. Marziali E, Garcia LJ. 22 Dementia caregivers’ responses to 2 Internet-based intervention programs. *Am J Alzheimers Dis Other Demen*. 2011;26(1):36-43. doi:10.1177/1533317510387586

57. Nichols LO, Martindale-Adams J, Burns R, Graney MJ, Zuber J. Translation of a Dementia Caregiver Support Program in a Health Care System—REACH VA. *Arch Intern Med*. 2011;171(4). doi:10.1001/archinternmed.2010.548

58. Tompkins SA, Bell PA. Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer’s caregiver. *J Gerontol Soc Work*. 2009;52(2):89-104. doi:10.1080/01634370802561877

59. Wilkerson DA, Brady E, Yi EH, Bateman DR. Friendsourcing Peer Support for Alzheimer’s Caregivers Using Facebook Social Media. *Journal of Technology in Human Services*. 2018;36(2-3):105-124. doi:10.1080/15228835.2018.1449709

60. Xu L, Fields NL, Williams IC, et al. The Senior Companion Program Plus (SCP Plus): Examining the Preliminary Effectiveness of a Lay Provider Program to Support African American Alzheimer’s Disease and Related Dementias (ADRD) Caregivers. *Int J Environ Res Public Health*. 2023;20(7):5380. doi:10.3390/ijerph20075380

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Social support interventions for dementia caregivers

61. Blackberry I, Rasekaba T, Morgan D, et al. Virtual Dementia-Friendly Communities (Verily Connect) Stepped-Wedge Cluster-Randomised Controlled Trial: Improving Dementia Caregiver Wellbeing in Rural Australia. *Geriatrics (Basel)*. 2023;8(5):85. doi:10.3390/geriatrics8050085
62. Glueckauf RL, Kazmer MM, Nowakowski ACH, et al. African American Alzheimer's Caregiver Training and Support Project 2 (ACTS2) pilot study: Outcomes analysis. *Rehabil Psychol*. 2022;67(4):437-448. doi:10.1037/rep0000470
63. Fields NL, Xu L, Richardson VE, Parekh R, Ivey D, Calhoun M. Utilizing the Senior Companion Program as a platform for a culturally informed caregiver intervention: Results from a mixed methods pilot study. *Dementia (London)*. 2021;20(1):161-187. doi:10.1177/1471301219871192
64. Szcześniak D, Rymaszewska J, Saibene FL, et al. Meeting centres support programme highly appreciated by people with dementia and carers: a European cross-country evaluation. *Aging Ment Health*. 2021;25(1):149-159. doi:10.1080/13607863.2019.1683814
65. Smith R, Drennan V, Mackenzie A, Greenwood N. The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Arch Gerontol Geriatr*. 2018;76:188-195. doi:10.1016/j.archger.2018.03.005
66. Chiu T, Marziali E, Colantonio A, et al. Internet-based caregiver support for Chinese Canadians taking care of a family member with alzheimer disease and related

Social support interventions for dementia caregivers

dementia. *Can J Aging*. 2009;28(4):323-336. doi:10.1017/S0714980809990158

67. Sherbourne CD, Stewart AL. The MOS social support survey. *Soc Sci Med*. 1991;32(6):705-714. doi:10.1016/0277-9536(91)90150-b

68. Zhu X, Chen S, He M, et al. Life experience and identity of spousal caregivers of people with dementia: A qualitative systematic review. *Int J Nurs Stud*. 2024;154:104757. doi:10.1016/j.ijnurstu.2024.104757

69. Burgio L, Stevens A, Guy D, Roth DL, Haley WE. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *Gerontologist*. 2003;43(4):568-579. doi:10.1093/geront/43.4.568

70. Ma KPK, Saw A. An international systematic review of dementia caregiving interventions for Chinese families. *Int J Geriatr Psychiatry*. 2020;35(11):1263-1284. doi:10.1002/gps.5400

71. Xiao L, Ullah S, Hu R, et al. The effects of a facilitator-enabled online multicomponent iSupport for dementia programme: A multicentre randomised controlled trial. *Int J Nurs Stud*. 2024;159:104868. doi:10.1016/j.ijnurstu.2024.104868

72. Mead N, Lester H, Chew-Graham C, Gask L, Bower P. Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis. *Br J Psychiatry*. 2010;196(2):96-101. doi:10.1192/bjp.bp.109.064089

73. Bjorck JP, Klewicki LL. The effects of stressor type on projected coping. *J Trauma*

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Social support interventions for dementia caregivers

- 842 *Stress*. 1997;10(3):481-497. doi:10.1023/a:1024849522973
- 843 74. Olesen LK, la Cour K, Thorne S, With H, Handberg C. Perceived benefits from peer-
844 support among family caregivers of people with amyotrophic lateral sclerosis and
845 cognitive impairments in a palliative rehabilitation blended online learning programme.
846 *J Eval Clin Pract*. 2023;29(4):602-613. doi:10.1111/jep.13808
- 847 75. Santee J, Garavalia L. Peer tutoring programs in health professions schools. *Am J*
848 *Pharm Educ*. 2006;70(3):70. doi:10.5688/aj700370
- 849 76. Ballesteros FJ, Guardiola G, Soriano E. Personal pervasive environments: practice
850 and experience. *Sensors (Basel)*. 2012;12(6):7109-7125. doi:10.3390/s120607109
- 851 77. Thoits PA. Social support as coping assistance. *J Consult Clin Psychol*.
852 1986;54(4):416-423. doi:10.1037//0022-006x.54.4.416
- 853 78. Thoits PA. Stress, coping, and social support processes: where are we? What next? *J*
854 *Health Soc Behav*. 1995;Spec No:53-79.
- 855 79. Sazesh S, Esmaelzadeh Saeieh S, Farid M, Refaei M, Yazdkhasti M. Effectiveness of
856 Group Counseling with a Client-Centered Approach Based on the GATHER Principles
857 on Sexual Satisfaction in Women with Multiple Sclerosis: A Randomized Clinical Trial.
858 *Iran J Med Sci*. 2021;46(2):103-111. doi:10.30476/ijms.2020.82616.1074
- 859 80. Javid N, Ahmadi A, Mirzaei M, Atghaei M. Effectiveness of Solution-Focused Group
860 Counseling on the Mental Health of Midwifery Students. *Rev Bras Ginecol Obstet*.

Social support interventions for dementia caregivers

2019;41(8):500-507. doi:10.1055/s-0039-1693741

81. Czaja SJ, Loewenstein D, Schulz R, Nair SN, Perdomo D. A videophone psychosocial intervention for dementia caregivers. *Am J Geriatr Psychiatry*. 2013;21(11):1071-1081. doi:10.1016/j.jagp.2013.02.019

82. Lee E. Do Technology-Based Support Groups Reduce Care Burden Among Dementia Caregivers? A Review. *J Evid Inf Soc Work*. 2015;12(5):474-487. doi:10.1080/15433714.2014.930362

Figure 1: PRISMA flow diagram

Figure 2: Risk of bias graph

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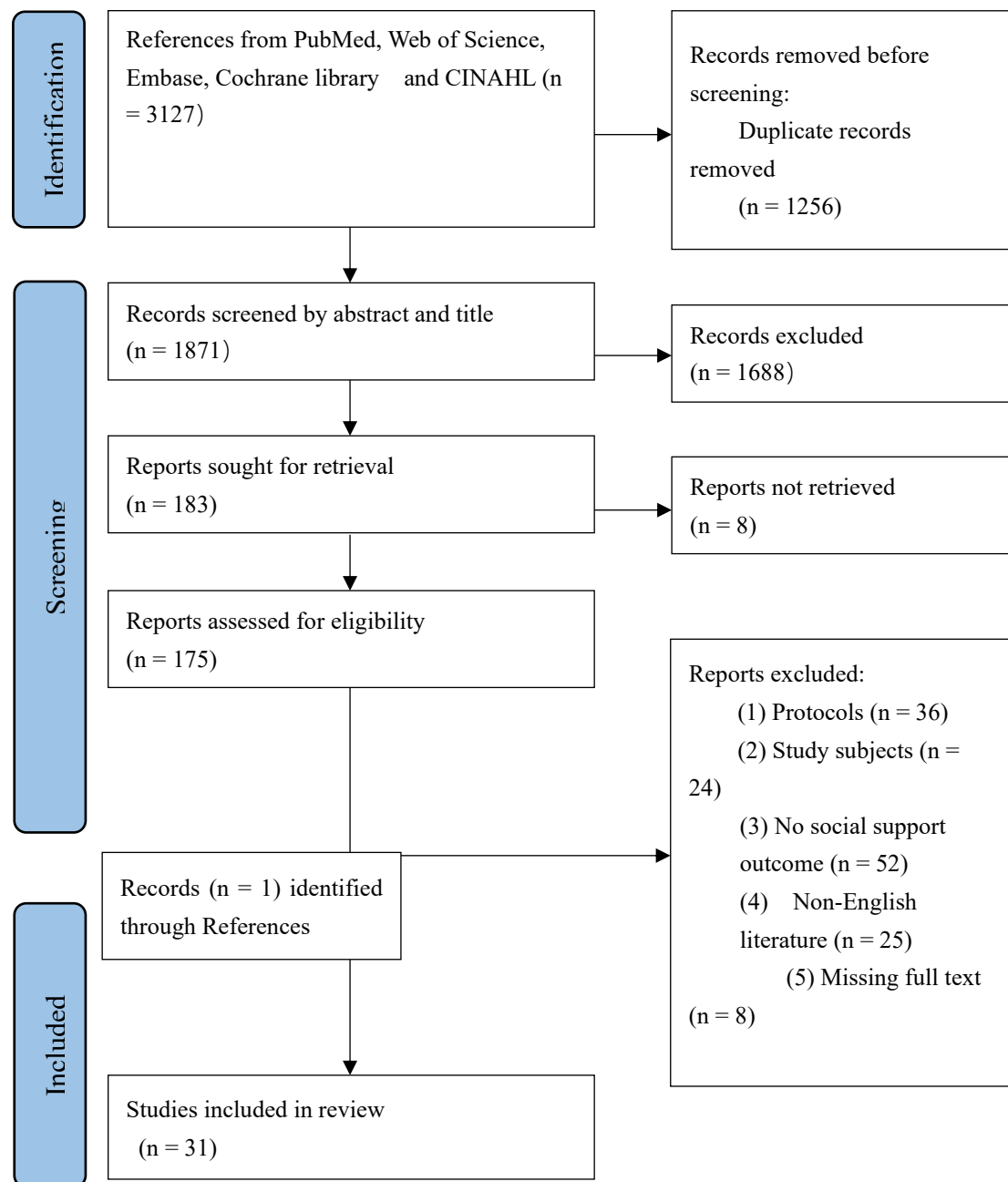
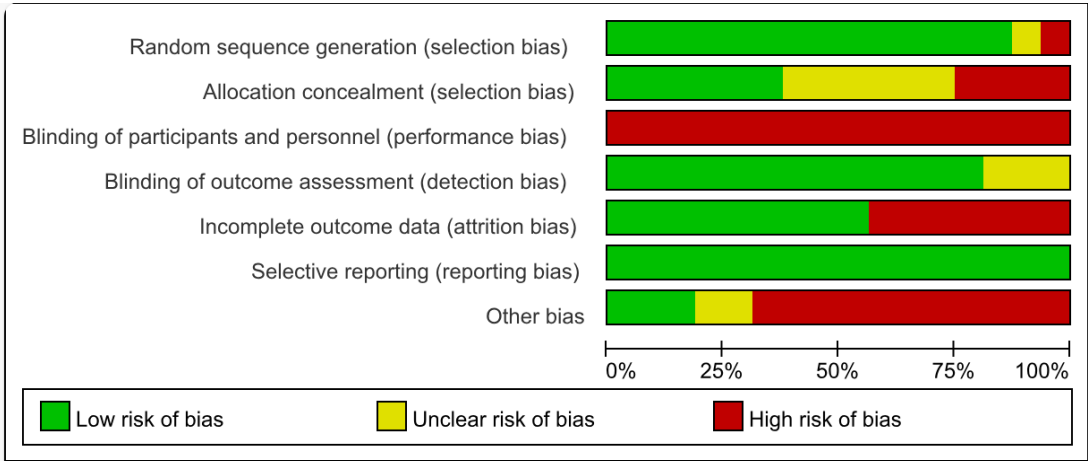


Fig.1 PRISMA flow diagram



	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Bank et al. 2006	+	?	+	+	+	+	+
Bass et al. 2013	+	+	+	+	+	+	+
Berwig et al. 2022	+	+	+	+	+	+	+
Christie et al. 2022	+	+	+	+	+	+	+
DavidGustafson Jr et al. 2019	+	+	+	+	+	+	+
Hébert et al. 2003	+	?	+	+	+	+	+
Mercedes et al. 2002	+	?	+	+	+	+	+
Neal 2024	+	+	+	+	+	+	+
Robinson et al. 1988	+	?	+	+	+	+	+
Roth et al. 2005	+	?	+	+	+	+	+
Töpfer et al. 2021	?	?	+	+	+	+	?
Tremont et al. 2017	+	+	+	+	+	+	+
van Wezel 2021	+	+	+	+	+	+	+
Wai Tong Chien et al. 2011	+	+	+	+	+	+	+
Whitebird et al. 2013	+	+	+	+	+	+	+
Xiao 2024	+	+	+	+	+	+	+

Fig.2 Risk of bias graph.

Table 2. Social support measurement tool

Name	Scale	Cronbach's alpha
Cerquera et al., 2021; Blackberry et al., 2023; Gustafson et al., 2019; Whitebird et al., 2013; Wilkerson et al., 2018;	Medical Outcomes Study (MOS)	0.736-0.921
Chiu et al., 2009; Christie et al., 2022; Marziali and Garcia, 2011; Smith et al., 2018;	Multidimensional Scale of Perceived Social Support (MPSS)	NM
Czaja et al., 2013; Easom et al., 2013; Lykens et al., 2014; Nichols et al., 2011;	10-21 items from three different broad scales measuring social support	NM
Fields et al., 2021; van Wezel et al., 2021;	self-developed scales	NM
Xu et al., 2023;	13-item questionnaire consisting of 4 domains: satisfaction with support, social support network, received support and negative interactions	NM

Glueckauf et al., 2022;	Social support: the Interpersonal Support Evaluation List (ISEL)	0.92
Berwig et al.,2022;	brief form of the Perceived Social Support Questionnaire (F – SozU) to assess the extent of social support	0.90
Szcześniak et al.,2021	experiences of emotional and practical support	NM
Töpfer et al.,2021	social relationships	NM
Roth et al.,2005	social support network	NM
Czaja et al.,2018	social support questionnaire	NM
Bass et al.,2013	supporting resources	NM
Chien and Lee,2011	social support from the perspectives of satisfaction with social support and formal support	NM
Bank et al.,2006		
Tompkins and Bell,2009	support questionnaire	NM
Hébert et al.,2003	The Inventory of Socially Supportive Behaviors	NM
Robinson,1988	Norbeck's Social Support Questionnaire (NSSQ)	NM
Neal et al ,2024	Social participation was measured using the Maastricht Social Participation Profile (MSPP)	NM

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Xiao et al ,2024	the Carers of Older People in Europe Index-Quality of Social Support (The COPE Index-QS)	0.77
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NM: Not Mentioned; The multiple blank spaces in Table 2 indicate that the authors of these items share the same scale name and reliability value

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Social support interventions for dementia caregivers

Table 3 Description of social support interventions

Author/Year	Participants		Intervention		Duration	Intervention content	Social support	Outcomes		Results
	sample size	Caregiver type	Type					Other	Outcomes	
Neal/2024	76 vs 74	ICG	Multi-component		4 weeks	Use FindMyApps app twice a week	MSPP	HRQL; SSCQ; Costs		SSCQ: ↑; MSPP,HRQoL:NS.Costs: ↓.
Xiao/2024	131 vs 135	FCG	Multi-component		6 months	Use iSupport, and host a monthly carer peer support meeting lasting 45–60 min	The COPE Index-QS	QoL; Self-efficacy; Behaviours and carer reactions; Carers perspective of the QoL of the person living with dementia		Mental related QoL: ↑; Self- efficacy, social support: NS;
Xu/2023	20	African American FCG	Peer support		6 months	The SCP Plus contained a 12 h in-person training with the senior companions.	13 items from four domains.	Burden and/or stress; Coping skills; Caregiver appraisal; Cultural justifications for caregiving; Caregiver well-being		KAD, social support satisfaction, coping skills: ↑; Burden: ↓.
Blackberry/2023	113	FCG	Peer support		32 weeks	Verily Connect model	MOS	ZBI; bespoke surveys		Social support: ↑; ZBI: ↓

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention		Duration		Intervention content		Social support		Outcomes		Results
	sample size	Caregiver type	Type								Other outcomes		
Glueckauf/2022	12	African American FCG	Multi-component		12 weeks		12 weekly telephone sessions, 7 one-hour group sessions and 5 one-hour individual goal-setting and implementation sessions.		ISEL		Severity of CG-identified problems; Depression; Health status; Consequences of caregiving activities		Depression: ↓; Perceived social support: ↑; CAI: NS.
Berwig/2022	107 vs 104	FCG	Peer support		6 months		Telephone-based group meeting		FSozU K22		Restrictions; Depressed mood states; general complaints; Quality of life; Utilization of support services; Performance in different areas of life.		The mental health domain of quality of life of family carers and perceived social support: ↑ Depression: ↓;
Christie/2022	48 vs 48	Primary CGs	Multi-component		16 weeks		The intervention group had access to Inlife, participants could use Inlife in at their own pace.		MSPSS; Received support; Number of friends and family ties		Sense of competence; Feelings of loneliness; Anxiety and depression; Quality of life; Perceived stress		Received support; MSPSS; Number of friends and family ties: NS; Sense of competence; Feelings of loneliness; Anxiety and depression; Perceived stress; Quality of life: NS.

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Fields/2021	16	FCG	Peer support	3 months	Nine in-home psychoeducational sessions covering one topic per week to their paired AD/ RD family caregiver over a three-month period were delivered by Each Senior Companion MCSP for both people living with dementia and their carers	Self-developed scale	KAD; Coping skills; Caregiver well-being; Burden and/or stress	Received social support: ↑ ; KAD, overall stress/burden levels, well-being of doing activities, coping skills: NS
Szcześniak/2021	45 vs 21 vs 15	FCG	Multi-component	3 months	MCSP for both people living with dementia and their carers	Experience of emotional and practical support	Satisfaction; Reasons for participation in the support programme; Burden	Emotionally supports: ↑ ; Satisfaction: ↑ ; Burden: ↓ .

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention		Duration		Outcomes		Results
	sample size	Caregiver type	Type			Intervention content	Social support	Other Outcomes	
Töpfer/2021	29 vs 22	FCG	Individual therapy		6 months	The intervention group (IG) received 12 individual therapy sessions (each 50 min) delivered via telephone from Tele.TAnDem intervention.	Social relationships: The German Version of the World Health Organization QoLBREF (WHOQoL-BREF)	Depression; Caregiver burden; Emotional well-being; Utilization of resources	Changes regarding own illnesses, the living situation with the PwD, the living environment, the employment status, care for any other person than the PwD, and severe illness of any close person in the last 3 years: NS; social relationships: ↑, use of support services: NS
van Wezel/2021	202 vs 184	Turkish or Moroccan background FCG	Peer support		Two-hour interventions	Two educational sessions on dementia, each last two hours, with other participants (peers) with the same cultural background (Turkish or Moroccan).	The support received: four self-developed questions	The intervention received pressure from informal care; The intervention received ability to talk about dementia; KAD;	Support received from family, friends or neighbors, and advice received from a doctor: NS. support received from home-care staff: ↑

1 Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Gustafson Jr/2019	16 vs 15	FCG	Multi-component	6 months	Intervention group receiving D-CHESS. Control group receiving a caregiving book.	MOS	Family conflict; Caregiver burden; Loneliness; Anxiety; Satisfaction with care decisions; Depression; Coping; Competence	All findings: NS; Due to small sample size.
Czaja/2018	146	FCG	Multi-component	6 months	12, 60-min individual (6 telephone and 6 face-to-face) educational sessions and skill building and 5 support groups by telephone.	Social Support Questionnaire	Depression; Affectivity; Burden; Caregiving Self-Efficacy; Memory related problems; disruptive behaviors;	Depression, overall burden, overall bother: ↓ ; Social support, positive aspects of caregiving or obtaining respite services: NS.

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	
Wilkerson/2018	60	Informal CGs	Peer support	6 weeks	Participants were allotted to two private Facebook groups receiving the intervention over the course of six weeks.	MOS	Burden; ↓ ; Perceived stress: ↓ ; Emotional and informational supports: ↑
Smith/2018	16	FCG	Peer support	6 months	Carers receiving one-to-one peer support or befriending from volunteers at least a weekly basis.	MSPSS	Perceived social support: ↑ ; Depression, anxiety and loneliness: NS.

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Tremont/2017	105 vs 94	Informal CGs	Counselling group	6 months	Trained therapists contacted caregivers 16 times use telephone for 6 months, providing recommendations for resources, information about dementia, and emotional support.	Community support services used times, healthcare resource use	Burden; Depression; Beliefs or problems	Caregivers who received the FITT-C used community support services significantly more than those receiving TS; FITT-C caregivers had a significantly lower rate of ED visits and hospital stays; Care recipient use of community or medical resources did not differ according to group.
Lykens/2014	494	FCG	Multi-component	6 months	Certified interventionists deliver the intervention included 12 sessions [9 in-home, and 3 telephone sessions], five structured telephone support group sessions	10 item Risk Assessment of feeling isolated, availability of someone to talk to or assist with caregiving	Caregiver Burden; Depression; Self-Care	Caregiver burden and Depression: ↓, Social support and self-care: a slight but not statistically significant increase after the service, which is in the correct direction.

Social support interventions for dementia caregivers

Author/Year	Participants		Intervention	Duration	Intervention content	Outcome		Results
	sample size	Caregiver type	Type			Social outcomes support	Other	
Whitebird/2013	38 vs 40	Primary CGs	MBSR	8 weeks	8 weekly 2.5-hr in-person group sessions.	MOS	Stress; Mental Health Burden	MBSR was more effective at reducing stress, decreasing depression, and improving overall mental health than CCES. Both interventions improved caregiver mental health and were similarly effective at improving anxiety, social support, and burden.
Bass/2013	299 vs 187	FCG	Multi-component	12 months	Partners in Dementia Care: initial assessment; action plan; Ongoing Monitoring and Reassessment	Support resource: 1) number of informal helpers; 2) use of caregiver support services	Unmet needs; Caregiver strain; Depression	Three types of caregiver strains, depression, unmet needs: ↓, and two support resources: ↑

Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes	
Czaja/2013	36 vs 63	FCG	Multi-component	5 months	A technology based multi-component psychosocial intervention was delivered in-home and via videophone technology over 5 months.	10 items assessing three domains of support: (a) received support(b) satisfaction with support(c) negative interaction s/ supports	Burden; Depression; Positive aspects of caregiving	Caregiver burden: ↓ ; satisfaction with social support: ↑ ; appreciation of the positive aspects of caregiving: ↑ ;
Easom/2013	85	FCG	Multi-component	6 months	Nine face-to-face (in the home) and three telephone sessions, tailored education and support.	A Risk Appraisal Assessment: three questions of social support	A Risk Appraisal Assessment: five questions addressing caregiver safety, five questions assessing caregiver health behaviors, three questions targeting stress, two items on behavioral frustrations	The scores for Self-Care and Social Support increased slightly post-service were not statistically significant, which is in the correct direction.

Social support interventions for dementia caregivers

Author/Year	sample size	Caregiver type	Participants Intervention		Duration	Intervention content	Outcomes		Results
			Type				Social support	Other outcomes	
Nichols/2011	127	FCG	Multi-component		6 months	The intervention included education, support, and skills training to address 5 caregiving risk areas: safety, social support, problem behaviors, depression, and caregiver health.	The 21-question risk appraisal, adapted from REACH II	caregiving risk areas of advanced cognition, education, health and healthy behaviors, and caregiving frustrations.	Depression, burden, impact of depression on daily lives, and caregiving frustrations: ↓ ; Social support: NS.
Marziali/2011	91	FCG	Multi-component		10 weeks	Online Chat Group Intervention: the Chat Group was provided with access to the CFO website for 6 months; Online Video Conferencing Support Group Intervention: 10 weekly sessions in mutual self-help mode with 1 of the group members manipulating the technical aspects of the video-conferencing meetings.	MSPSS	Caregiver health; Depressive symptoms; Caregiving distress	The Video Group demonstrated greater improvement in mental health status. For the Video Group, improvements in neuroticism, self-efficacy, and social support were associated with lower stress response to coping with the care recipient's decline in function and cognitive impairment.

Author/Year	sample size	Caregiver type	Participants Intervention Type	Duration	Intervention content	Social support	Other Outcomes	Results
Chien/2011	46 vs 46	FCG	Multi-component	6 months	DFCP	satisfaction with social support available: SSQ6; Formal support services: FSSI	Burden; QOL	Intervention group's utilization of family services was significantly decreased at the 18-month follow-up, the routine care group's service utilization had a slight increase.
Tompkins and Bell/2009	367	FCG	Health educated	12h	12h training	SCP usage questionnaire.	Overall satisfaction; Depression; Overall services used	Depression: ↓ ; Overall services used: ↑ ;
Chiu/2009	35	FCG	Multi-component	6 months	The ICSS supported two Internet-based communication tools: (a) a caregiver information handbook, and (b) personalized e-mail communication between client and clinician.	MSPSS	Family burden; Caregiver's ability; Depression; Perceived overall health; PAC Care recipients' functioning level	Burden, social support and health behavior: NS; depression: ↓ .

Social support interventions for dementia caregivers

Author/Year	Participants				Intervention			Outcomes		Results
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other	Outcomes		
Bank/2006	41	FCG	Multi-component	18 months	Professional provides telephone support group	Support Group Questionnaire	NO		Support group attendance: NS; Intervention Improved relationships among family members, and telephone support groups made them more willing to participate in community support groups	
Roth/2005	163 vs 149	Spouse CGs	Counselling group	12 months	Counseling and support	Social support network: caregiver's Satisfaction: methods of Stokes; caregivers' reports of the frequency at which they received information or assistance from support persons.	Stress appraisals of caregiver and behavior problems; Depression		Intervention group achieved significant increases after 1 year on 8 of the 11 indicators, which were total size of social network, number of close family members, general satisfaction, satisfaction with assistance, satisfaction with emotional support, telephone calls (no. per month), personal visits (no. per month), sitting with patient (no. per month).	

1 Social support interventions for dementia caregivers

Author/Year		Participants		Intervention		Outcomes		Results	
	sample size	Caregiver type	Type	Duration	Intervention content	Social support	Other outcomes		
Hébert/2003	60 vs 56	Primary CGs	Multi-component	16 weeks	Participants in the study group had fifteen 2-hr weekly sessions focusing on stress appraisal and coping	The Inventory of Socially Supportive Behaviors	Frequency of behavioral and mental problems; Desire to institutionalize; Subjective burden	Institutionalization: ↓ ;personal efficacy: ↑ ;other outcomes: NS.	
Mercedes/2002	19 vs 19 vs 20	FCG	Multi-component	8 weeks	1.multicomponent + respite group; 2. respite group; 3. control group	MOS	Burden	The control group social support: ↓ ; the multicomponent plus respite group social support: ↑ after10-month follow-up.	
Robinson/1988	11 vs 9	FCG	Health education	8 weeks	Social skill training program	NSSQ	Self-esteem; Social skills; Caregiving burden	Objective and subjective burden: ↓ ; the treatment group and control group of social support: NS.	

30 FCG: Family caregivers; ICG: Informal caregivers; MSPP : Maastricht Social Participation Profile; HRQoL: Health Related Quality of Life; SSCQ: the Short Sense of Competence Questionnaire; QoL:Quality of Life; The COPE Index-QS: the Carers of Older People in Europe Index-Quality of Social Support;;NR: not reported; SSRS: Social Support Scale; CAI: Caregiver Appraisal Inventory; CBI: Caregiver Burden Inventory; SCSO: Simplified Coping Style Questionnaire; GSES: General Self-Efficacy Scale; ↑ : significant improvement; NS: No Significant difference; ↓ : significant reduction; MSPSS: Multidimensional Scale of Perceived Social Support; PAC: Positive Aspects of Caregiving; CGs: Caregivers; MOS: Medical Outcomes Study; KAD: Knowledge of Alzheimer's disease/dementia; NSSQ: Norbeck's Social Support Questionnaire; ISEL: Interpersonal Support Evaluation List; MCSP: Dutch Meeting Centers Support Programme; DFCP: Dementia Family Care Programme; SSQ6: Six-item Social Support Questionnaire; FSSI: Family Support Services Index; MBSR: Mindfulness-Based Stress Reduction; SCP Plus: Senior Companion Program Plus; PwD: people with dementia; ZBI: Zarit Burden Interview

Database	Search strategy
PubMed	<ol style="list-style-type: none"> 1. ("Dementia"[Mesh]) 2. Amentia [Title/Abstract] 3. Senile Dementia [Title/Abstract] 4. Familial Dementia [Title/Abstract] 5. "Alzheimer Disease"[Mesh] 6. Alzheimer Dementias [Title/Abstract] 7. Presenile Alzheimer Dementia [Title/Abstract] 8. (Presenile Alzheimer Dementia [Title/Abstract]) 9. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 10. "Caregivers"[Mesh] 11. Carers [Title/Abstract] 12. 10 OR 11 13. "Social Support"[Mesh] 14. Social care [Title/Abstract] 15. Perceived social Support [Title/Abstract] 16. 13 OR 14 OR 15 17. Interventions [Title/Abstract] 18. program*[Title/Abstract] 19. 17 OR 18 20. 9 AND 12 AND 16 AND 19
Web of Science	<ol style="list-style-type: none"> 1. TS= (dement* OR ament* OR Lewy Body Disease OR

	<p>Alzheimer* OR Alzheimer disease OR senile dementia)</p> <p>2. TS= (caregiver* OR carer*)</p> <p>3. TS= ("social support")</p> <p>4. TS=(intervention*)</p> <p>5. (1 AND 2 AND 3 AND 4)</p>
Cinahl	<p>S1. (MH "Dementia") OR (MH "Dementia, Vascular") OR (MH "Dementia, Senile) OR (MH "Dementia, Presenile) OR (MH "Alzheimer's Disease")</p> <p>S2. AB dement* OR Alzheimers OR cognitive impairment OR memory loss OR amenti*</p> <p>S3. S1 OR S2</p> <p>S4. AB caregiver* OR carer*</p> <p>S5. AB social support OR social network</p> <p>S6. AB interventions OR strategies OR best practices</p> <p>S7. S3 AND S4 AND S5 AND S6</p>
Cochrane	<p>#1. MeSH descriptor: [Dementia] explode all trees</p> <p>#2. MeSH descriptor: [Alzheimer Disease] explode all trees</p> <p>#3. (Amenti* OR Dementi* OR Alheimer* disease): ti,ab,kw</p> <p>#4. #1 OR #2 OR #3</p> <p>#5. MeSH descriptor: [Caregivers] explode all trees</p> <p>#6. (Caregiver* OR Carer*): ti, ab, kw</p> <p>#7. #5 OR #6</p>

	<p>#8. MeSH descriptor:[Social support] explode all trees</p> <p>#9. (social support OR social network): ti, ab, kw</p> <p>#10. #8 OR #9</p> <p>#11. (intervention*): ti, ab, kw</p> <p>#12. #4 AND #7 AND #10 AND #11</p>
EMBASE	<p>#1. 'dementia'/exp</p> <p>#2. amenti*:ti,ab,kw OR dementi*:ti,ab,kw</p> <p>#3. 'alzheimer disease'/exp</p> <p>#4. 'alzheimer disease':ti,ab,kw OR 'alzheimer dementia':ti,ab,kw OR alzheimer*:ti,ab,kw OR 'senile dementia':ti,ab,kw</p> <p>#5. #1 OR #2 OR #3 OR #4</p> <p>#6. 'caregiver'/exp</p> <p>#7. caregiver*:ti,ab,kw OR carer*:ti,ab,kw</p> <p>#8. #6 OR #7</p> <p>#9. 'social support'/exp</p> <p>#10. 'social support':ti,ab,kw</p> <p>#11. #9 OR #10</p> <p>#12. intervention*:ti,ab,kw</p> <p>#13. #5 AND #8 AND #11 AND #12</p>