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# Videoconferencing support groups for people affected by dementia: a systematic narrative review

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## ABSTRACT

**Objectives:** This systematic review aimed to examine the impact of videoconferencing peer support groups on individuals living with dementia and their caregivers.

**Method:** A narrative synthesis of articles identified via searches of five databases (MEDLINE, PsycINFO, EMBASE, CINAHL, and Web of Science). The search was carried out in January 2024. The review included qualitative, quantitative, and mixed methods research reporting the experiences of dementia patients and/or their caregivers participating in online support groups that took place through video call.

**Results:** 16 studies met the inclusion criteria for the review. In all studies, participants indicated that taking part in a virtual support group was beneficial, as they valued being able to connect with others in a similar situation, receive advice, and learn coping strategies. Videoconferencing support groups were seen as convenient to attend, even though participants sometimes experienced technical difficulties (e.g. internet connectivity issues). The provision of IT training and support helped participants access this type of support effectively.

**Conclusion:** Videoconferencing support groups can be beneficial for caregivers of people living with dementia, especially when groups meet frequently and provide some manner of IT support. More research is needed to understand the potential benefits of videoconferencing for people with dementia.

## ARTICLE HISTORY

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## KEYWORDS

Peer support; dementia support; telehealth

## Introduction

It is estimated that there are over 50 million people living with dementia worldwide and, due to population growth and many countries having ageing populations, this figure could rise to around 150 million people by the year 2050 (Nichols et al., 2022). Living with dementia or caring for someone living with dementia is often associated with social isolation and feelings of loneliness (Lee et al., 2022; Moyle et al., 2011; Victor et al., 2021). This is particularly concerning because social isolation and loneliness are associated with higher instances of psychiatric symptoms in people living with dementia (El Haj et al., 2016; Shub et al., 2011), and with higher levels of caregiver stress and burden, depression, and lower quality of life in caregivers of people living with dementia (Beeson et al., 2000; Ekwall et al., 2005; Sung et al., 2023). Being diagnosed with dementia can be a confusing and distressing experience for the person receiving the diagnosis and their family members (Aminzadeh et al., 2007; Innes et al., 2014). People affected by dementia have reported feeling dissatisfied by the information and advice about dementia given to them by clinicians at the point of diagnosis and being left unsure what to do next (Poyser & Tickle, 2019).

A peer support group is made up of a group of people who come together to provide mutual support for each other. Support groups create a forum for sharing advice and coping strategies, as well as creating a community of people with similar experiences. Peer support groups are a way of supporting people affected by dementia, as they can help people come to

terms with the diagnosis, provide information and advice about dementia and caring, and help prevent loneliness and/or social isolation (Keyes et al., 2016; Söderlund et al., 2024; Willis et al., 2018). However, there can be barriers to attending support groups face-to-face; for example, difficulties with transport, being unable to access respite care or childcare while attending a support group session, or difficulty finding out about local groups (Brodaty et al., 2005; Gumuchian et al., 2018; Mallya et al., 2020). Online peer support groups potentially eliminate some of the barriers that come with attending a support group face-to-face by allowing participants to communicate through videoconferencing software from their own home.

However, the usefulness and acceptability of videoconferencing support groups for this population is not well understood. Previous systematic reviews that have investigated the effectiveness of support groups for people affected by dementia have largely been based on support groups that are delivered face-to-face or through the telephone (Cheston & Ivanecka, 2017; Chien et al., 2011; Dam et al., 2016; Lauritzen et al., 2015; Leung et al., 2015; Thompson et al., 2007). Systematic reviews targeting internet-based interventions mostly identify research about educational websites or text-based forums for dementia caregivers (Boots et al., 2014; Carter et al., 2020; Egan et al., 2018; McKechnie et al., 2014) and assistive technology or cognitive interventions for people living with dementia (García-Casal et al., 2017; Pinto-Bruno et al., 2017; Rai et al., 2022). At present, there are no systematic reviews exclusively examining the use

of videoconferencing support groups for people living with dementia and their caregivers.

Since the outbreak of COVID-19 in 2020 the use of videoconferencing software increased substantially, including in the domain of dementia support services (Caprioli et al., 2023). During periods where there were restrictions around groups meeting face-to-face, support groups needed to transition to using videoconferencing software to deliver sessions remotely. This review is well-timed to also capture research conducted about the experiences of people affected by dementia of attending videoconferencing support groups during COVID-19 lockdowns and establish what can be learned from their experiences.

Therefore, the present work aims to investigate the evidence about videoconferencing support groups for people affected by dementia to address the following research questions:

1. What is the usefulness (or not) of participating in videoconferencing support groups for people affected by dementia (i.e. people living with dementia and caregivers of people living with dementia)?
2. How acceptable are videoconferencing support groups to people affected by dementia?

For this review, 'usefulness' was defined as the perception of being beneficial and helpful by participants and/or researchers. For an intervention to be interpreted as useful, it should result in a form of benefit (e.g. improvement on a wellbeing outcome measure post-intervention), and/or be reported as having valuable features (e.g. being able to receive advice that helped the participant manage their situation). The usefulness of videoconferencing support groups will be assessed through measures of wellbeing and satisfaction with the intervention, and through reports of participants' experiences of taking part in these groups.

Acceptability will be assessed through reports of participants' experiences of participating in a videoconferencing support group. The purpose of this research question is to identify issues that would impact this population's uptake of and willingness to engage with videoconferencing support groups, as well as facilitators that can improve the acceptability and accessibility of videoconferencing.

## Methods

### Search strategy

A comprehensive search was conducted of the MEDLINE, PsycINFO, EMBASE, CINAHL, and Web of Science databases to examine the evidence of the usefulness videoconferencing support groups for people affected by dementia. The search terms were developed to include synonyms and truncations, and MeSH terms were used where possible. Search strategies were kept as similar as possible across databases (see Appendix C for search strategies). The search was conducted on 28 January 2024.

### Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed within a PICOS (Population, Intervention, Comparison, Outcomes and Study design) framework, which is a tool used to develop research

questions for systematic reviews (Liberati et al., 2009). Studies were included if they met the following criteria: (1) the population included people living with dementia and/or non-professional caregivers of someone living with dementia; (2) the article reports findings about a support group or group-based intervention that took place over videoconferencing; and, (3) outcomes included any measure of well-being/mental health, service user experiences, or any other data relevant to usefulness or acceptability. No restrictions were put on study design, study location, or publication date.

Two reviewers appraised studies, and studies were excluded if: (1) the intervention was delivered to an individual or a caregiver-care recipient dyad exclusively; (2) the intervention was telephone conference based or took place through any other medium than videoconferencing; (3) the research was not written in English; and, (4) the record related to conference proceedings, research protocols, case reports, literature reviews, books, or discussion articles. Multi-component interventions where a videoconferencing support group was only part of the intervention and studies that included participants affected by other conditions were included, but only the data relevant to dementia and videoconferencing support groups was analysed. Disputes between reviewers about the inclusion of certain records were resolved through discussion with additional researchers.

### Selection procedure and data extraction

All titles and abstracts were assessed for eligibility and irrelevant studies were discarded. The full text was then accessed and assessed against inclusion/exclusion criteria. For included studies, data was extracted and entered into a pre-designed table with the following headings: (1) Author(s), (2) Publication year, (3) Country, (4) Study design, (5) Number of Participants, (6) Population, (7) Description of Support (8) Key Findings, and (9) Quality Assessments. See Appendix Table A1 for data extraction table.

### Quality assessment

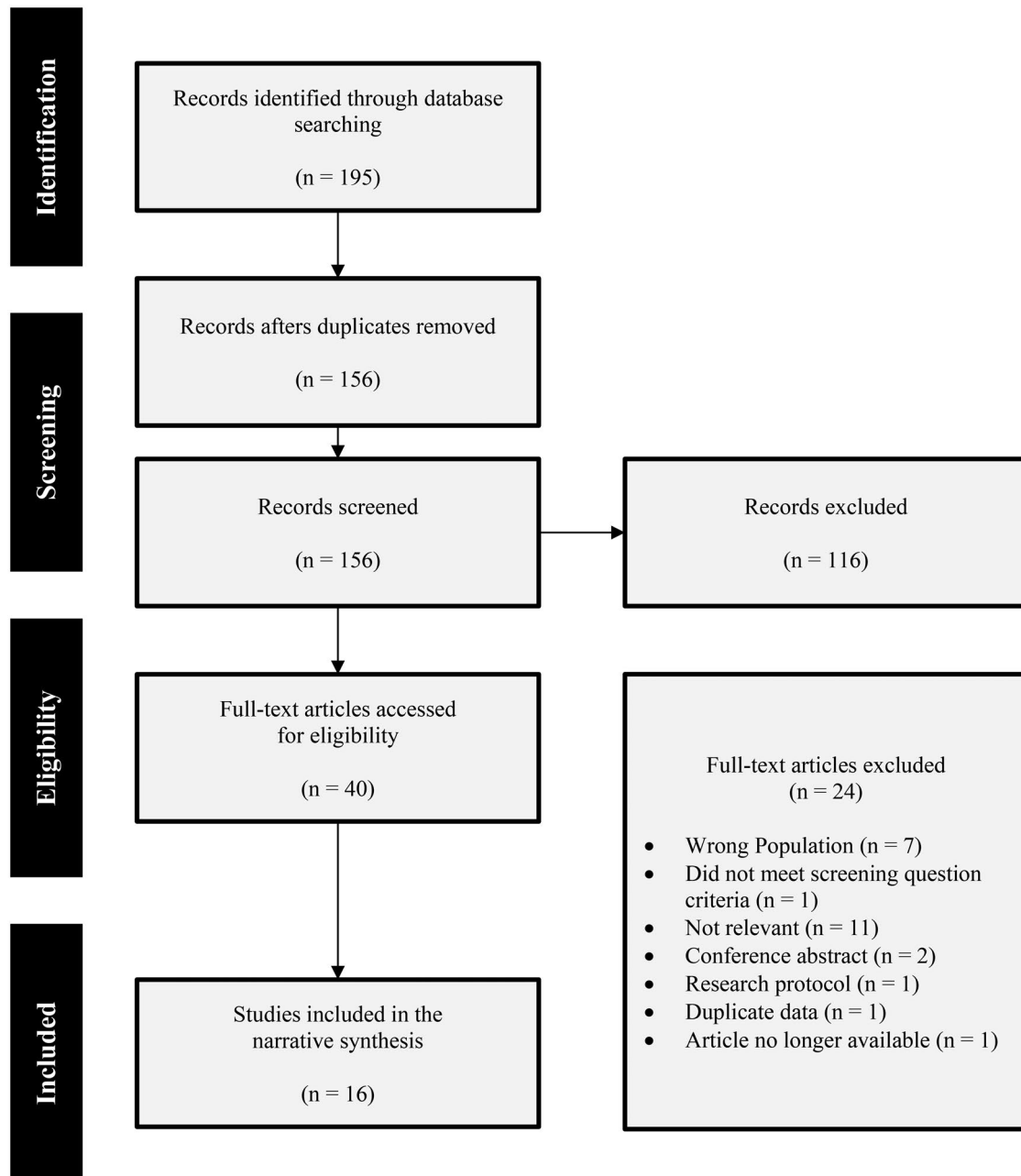
The quality of included studies was assessed using the Mixed-Methods Appraisal Tool (MMAT) checklist which is compatible with qualitative, quantitative, and mixed methods research designs (Hong et al., 2018). Any studies that did not pass the two screening questions would be excluded due to failure to meet minimum quality standards.

### Data synthesis

This review took a narrative approach to synthesis following the guidelines of Popay et al. (2006), which consists of four stages: (1) Developing a theory of how the intervention works, why and for whom; (2) Developing a preliminary synthesis of findings of included studies; (3) Exploring relationships in the data; and, (4) Assessing the robustness of the synthesis.

## Results

A total of 195 records were identified through searching the databases. After removing duplicates, 156 records remained. Through screening titles and abstracts 116 irrelevant records



**Figure 1.** Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flowchart illustrating the inclusion of studies in this review.

were excluded. Following assessment of the full text of 40 articles a total of 16 articles met the inclusion criteria (see Figure 1 for the PRISMA diagram for the screening process). Using the MMAT checklist, nine studies met 100% of the quality criteria, five studies met 80% of the criteria, and two studies met 60% of the quality criteria (see Appendix Table B1 for a summary of quality assessment scores).

Of the 16 studies included in the review, two were quantitative, six were mixed methods, and eight were qualitative. Data collection techniques used included: quantitative questionnaires (eight studies), qualitative semi-structured interviews (eight studies), qualitative observations (six studies), qualitative focus groups (three studies), and a qualitative questionnaire (one study).

Fourteen of the studies involved only caregivers of people living with dementia, one involved only people living with dementia, and one included both people living with dementia and caregivers. Four studies only included caregivers of people living with young-onset and rare types of dementia, and one

study included only people living with young-onset dementia, with the remaining studies being open to people affected by any type of dementia. Five studies were conducted in the UK, four in the USA, four in Canada, two in Australia, and one in Sweden. In total, 499 participants were included across all the studies (range = 5–110). 65.9% of participants were female and 82.5% had a white ethnic background, though nine studies did not provide data about participant ethnicity and one study did not provide details about participant gender (Appendix Table A1). A summary of the key characteristics of the 16 included studies can be found in Table 1.

### Study content

Twelve studies consisted of a videoconferencing support group intervention or a pilot intervention, and the remaining four studies involved interviewing people who had attended a pre-existing videoconferencing support group that took place during COVID-19 lockdowns in the UK and USA due to

**Table 1.** Characteristics of included studies.

Author	Participants	Study design	Setting	Data collection
Austrom et al. (2015)	5 Caregivers	Mixed methods	Pilot intervention (USA)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Focus groups</li> </ul>
Banbury et al. (2019)	69 Caregivers	Mixed methods	Intervention (Australia)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Interviews</li> <li>Observations</li> </ul>
Blackberry et al. (2023)	37 Caregivers	Quantitative	Intervention (Australia)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> </ul>
Cousins et al. (2022)	7 Caregivers 5 PLWD	Qualitative	Non-intervention (UK)	<ul style="list-style-type: none"> <li>Interviews</li> </ul>
Czaja et al. (2013)	110 Caregivers	Quantitative	Intervention (USA)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> </ul>
Damianakis et al. (2018)	24 Caregivers	Qualitative	Intervention (Canada)	<ul style="list-style-type: none"> <li>Observations</li> </ul>
Gerritzen et al. (2022)	20 PLWD	Qualitative	Non-intervention (UK)	<ul style="list-style-type: none"> <li>Focus groups</li> </ul>
Lundberg (2014)	10 Caregivers	Qualitative	Intervention (Sweden)	<ul style="list-style-type: none"> <li>Interviews</li> <li>Observations</li> </ul>
Marziali et al. (2005)	34 Caregivers	Qualitative	Intervention (Canada)	<ul style="list-style-type: none"> <li>Interviews</li> <li>Observations</li> </ul>
Marziali and Garcia (2011)	91 Caregivers	Mixed methods	Intervention (Canada)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Interviews</li> <li>Observations</li> </ul>
McLoughlin et al. (2023)	39 Caregivers	Mixed methods	Non-intervention (UK)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Interviews</li> </ul>
O'Connell et al. (2014)	10 Caregivers	Qualitative	Intervention (Canada)	<ul style="list-style-type: none"> <li>Focus groups</li> </ul>
O'Connor et al. (2023)	10 Caregivers	Qualitative	Non-intervention (USA)	<ul style="list-style-type: none"> <li>Interviews</li> </ul>
Rapley et al. (2023)	9 Caregivers	Qualitative	Intervention (UK)	<ul style="list-style-type: none"> <li>Observations</li> </ul>
Schaffer and Henry (2023)	10 Caregivers	Mixed methods	Intervention (USA)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Qualitative questionnaire</li> </ul>
Stevens-Neck et al. (2023)	9 Caregivers	Mixed methods	Pilot intervention (UK)	<ul style="list-style-type: none"> <li>Quantitative questionnaires</li> <li>Interviews</li> </ul>

Note. PLWD: people living with dementia.

restrictions around groups meeting face-to-face (Cousins et al., 2022; Gerritzen et al., 2023; McLoughlin et al., 2023; O'Connor et al., 2023).

### Intervention studies

In the twelve intervention studies, five held support group meetings weekly (Austrom et al., 2015; Banbury et al., 2019; Damianakis et al., 2018; Marziali et al., 2005; Marziali & Garcia, 2011), three met twice a month (Rapley et al., 2023; Schaffer & Henry, 2023; Stevens-Neck et al., 2023), three met monthly (Czaja et al., 2013; Lundberg, 2014; O'Connell et al., 2014), and one study did not provide information about the frequency of meetings (Blackberry et al., 2023). The length of interventions ranged from six weeks to two years. The majority provided some degree of technical support (including the provision of equipment and/or an internet connection) and additional educational materials (e.g. information handbooks about dementia) to participants (Table 2).

### Support groups for caregivers

Fourteen studies included caregivers of people living with dementia (Austrom et al., 2015; Banbury et al., 2019; Blackberry et al., 2023; Czaja et al., 2013; Damianakis et al., 2018; Lundberg, 2014; Marziali et al., 2005; Marziali & Garcia, 2011; McLoughlin et al., 2023; O'Connell et al., 2014; O'Connor et al., 2023; Rapley et al., 2023; Schaffer & Henry, 2023; Stevens-Neck et al., 2023), and one study included caregivers of people living with dementia and their care recipient (Cousins et al., 2022). Most studies included exclusively caregivers of people living with dementia, but one study included a single participant who cared for someone who had experienced a stroke (Lundberg, 2014). One study included participants who cared for people who had experienced a stroke or have Parkinson's disease, but these

participants were part of separate support groups from the dementia caregivers (Marziali et al., 2005). Where data was presented separately by condition, only data about dementia caregivers specifically was included in the synthesis.

### Support groups for people living with dementia

One study exclusively included participants that were people living with dementia (Gerritzen et al., 2022). In this study participants were people who had a diagnosis of young-onset dementia. Additionally, one study included both people living with dementia and their caregivers (Cousins et al., 2022). Both studies included in this subcategory used qualitative research designs, with Gerritzen et al. (2022) using focus group interviews and Cousins et al. (2022) using semi-structured interviews with individuals or caregiver-care recipient dyads.

### Experiences of videoconferencing support groups

All studies reported that participants benefitted from attending a videoconferencing support group, although quantitative findings about the impact of videoconferencing support groups were more mixed than the qualitative findings. The findings about participants' experiences will be organised in this section in the following three sections: (1) summary of quantitative outcome measures, (2) valued aspects of support groups, and (3) acceptability and the impact of technology (see Table 3 for a summary of themes from each study).

### Quantitative measures

No statistical meta-analysis was conducted due to the heterogeneity in study designs and the outcomes measured, and so

**Table 2.** Description of the technical support and supplemental educational materials provided by intervention studies.

Additional support	Technical support					Supplemental educational content	
	IT support during sessions	IT training before intervention	Provision of equipment	Provision of internet connection	IT training manual	Educational handbook or leaflets	Access to educational videos
Austrom et al. (2015)	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Banbury et al. (2019)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				
Blackberry et al. (2023)	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	
Czaja et al. (2013)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Damianakis et al. (2018)							
Lundberg (2014)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Marziali et al. (2005)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Marziali and Garcia (2011)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
O'Connell et al. (2014)*		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			
Rapley et al. (2023)							
Schaffer and Henry (2023)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Stevens-Neck et al. (2023)						<input checked="" type="checkbox"/>	

Note: \*In this study participants had to travel to a local hospital to use their videoconferencing equipment.

**Table 3.** Themes related to participant experiences with videoconferencing support groups from each study.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Valued connection to others with relatable experiences	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Valued information and advice	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Videoconferencing missing elements of human connection compared to face-to-face support	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			
Participants experienced technical difficulties that impacted their enjoyment	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				
Support group helped participant cope with stress and increased their resilience	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Videoconferencing is convenient	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Valued IT support	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>								
Valued frequent meetings and contact outside of meetings	<input checked="" type="checkbox"/>						<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Valued enjoyable activities at sessions				<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>						<input checked="" type="checkbox"/>			
Support group helped them to identify other services								<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Valued discussion of faith and spirituality						<input checked="" type="checkbox"/>										
Support groups continued to meet after the end of the intervention period/ expressed plans to continue meeting	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	n/a			n/a			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	n/a		n/a		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Note. (1) Austrom et al. (2015), (2) Banbury et al. (2019), (3) Blackberry et al. (2023), (4) Cousins et al. (2022), (5) Czaja et al. (2013), (6) Damianakis et al. (2018), (7) Gerritzen et al. (2023), (8) Lundberg (2014), (9) Marziali et al. (2005), (10) Marziali and Garcia (2011), (11) McLoughlin et al. (2023), (12) O'Connell et al. (2014), (13) O'Connor et al. (2023), (14) Rapley et al. (2023), (15) Schaffer & Henry, (16) Stevens-Neck et al. (2023).

quantitative data was analysed narratively. Of the eight studies that included quantitative data collection techniques, five studies included outcome measures that were analysed with statistical tests (see Table 4 for a summary of quantitative outcome measure findings). Quantitative data was only collected

in studies including caregivers of people living with dementia exclusively.

Overall, the quantitative findings were somewhat mixed, with there being no significant differences post-intervention for many outcome measures for the included studies. In

**Table 4.** Summary of quantitative outcome measures from included studies.

	Blackberry et al. (2023) (n = 28)	Czaja et al. (2013) (n = 110)	Marziali and Garcia (2011) (n = 91)	Schaffer and Henry (2023) (n = 10)	Stevens-Neck et al. (2023) (n = 9)
Caregiver burden	No difference (ZBI)	Improvement (RMBPC)	–	No difference (BASC)	Improvement (ZBI)
Social support	Improvement (MOS-SSS)	Mixed (various scales)	Improvement (MSPSS)	–	No difference (LSNS-6)
Depression	–	No difference (CES-D)	No difference (CES-D)	–	Improvement (PHQ-9)
Self-efficacy	–	–	Improvement (RSCSE)	No difference (NGSE)	–
Mental health/mood	–	–	Improvement (HSQ-12)	No difference (PANAS)	–
Quality of life	–	–	–	No difference (AC-QoL)	Improvement (DEMQOL)
Positive aspects of caregiving	–	Improvement (REACH)	–	–	–
Physical health	–	–	Improvement (HSQ-12)	–	–
Utilisation of services/plans to institutionalise care recipient	–	–	No difference (Bespoke scale)	–	–
Caregiver distress	–	–	Mixed (SMAF)	–	–
Coping strategies	–	–	–	No difference (Brief COPE)	–
Anxiety	–	–	–	–	No difference (GAD-7)
Resilience	–	–	–	–	No difference (RS-14)
Predeath guilt/preparedness for end of life	–	–	–	–	No difference (CGS / CAQ)

Note. ZBI (Zarit Burden Interview), MOS-SSS (Medical outcomes study social support survey), RMBPC (The Revised Memory and Behavior Problems Checklist), CES-D (Center for Epidemiologic Studies Depression Scale), REACH (Resources for Enhancing Alzheimer's Caregivers Health), MSPSS (The Multidimensional Scale of Perceived Social Support), RSCSE (Revised Scale for Caregiving Self-Efficacy), HSQ-12 (Health Status Questionnaire), SMAF (Social-Functional Autonomy Measurement System), BASC (Brief Assessment Scale for Caregivers), NGSE (New General Self-Efficacy Scale), PANAS (Positive and Negative Affect Scale), AC-QoL (Adult Carer Quality of Life Questionnaire), Brief COPE (Brief Coping Orientation to Problems Experienced), LSNS-6 (Lubben Social Network Scale-6), PHQ-9 (Patient Health Questionnaire-9), DEM-QOL (Dementia Quality of Life Instrument), GAD-7 (Generalised Anxiety Disorder-7), RS-14 (Resilience Scale), CGS (Caregiver Grief Scale), CAQ (Caring Ahead Questionnaire).

Green cells indicate a statistically significant improvement, grey cells indicate there was no significant difference, and yellow cells indicate that there was at least one statistically significant improvement on a sub-section of the measure but no statistically significant improvement overall.

particular, the study conducted by Schaffer and Henry (2023) found no improvements on any quantitative outcome measure. However, when satisfaction questionnaires were distributed, participants' satisfaction with the interventions was high. For example, in the study conducted by Czaja et al. (2013) 85% of participants found participating in the support groups valuable and the intervention reported by Stevens-Neck et al. (2023) was rated as 'very helpful' by 73% of participants. Additionally, three studies reported data about attendance rates which were also high – 83% (Austrom et al., 2015), 87.5% (Schaffer & Henry, 2023), and 97.9% (Stevens-Neck et al., 2023) respectively.

Four studies included measures of caregiver burden, with two studies reporting an improvement (Czaja et al., 2013; Stevens-Neck et al., 2023) while two studies reporting no difference to caregiver burden post-intervention (Blackberry et al., 2023; Schaffer & Henry, 2023). Measures of social support were included in four studies, and two studies found that participants' perceived levels of social support improved post-intervention (Blackberry et al., 2023; Marziali & Garcia, 2011), one study found that satisfaction with their social support improved but there was no change to the frequency of instances of negative interactions or the participants' level of received social support (Czaja et al., 2013), and one study found no difference in participant reports of social support (Stevens-Neck et al., 2023). One study found that participants level of depression improved post-intervention (Stevens-Neck et al., 2023), however two studies reported no significant differences (Czaja et al., 2013; Marziali & Garcia, 2011). Marziali and Garcia (2011) reported improvements to self-efficacy and mental health, but participants in the study conducted by Schaffer and Henry (2023) reported no improvements on these measures. Furthermore, Schaffer and Henry (2023) found no improvements to quality of life but an improvement to quality of life was found by Stevens-Neck et al. (2023).

There were eight outcome measures that were each only utilised by a single study. An improvement was found in participants' beliefs about the positive aspects of caregiving (Czaja et al., 2013). Marziali and Garcia (2011) reported that some aspects of caregiver distress and physical health improved post-intervention. No improvements were found in the utilisation of services or plans to institutionalise their care recipients (Marziali & Garcia, 2011), participant use of coping strategies (Schaffer & Henry, 2023), anxiety, level of resilience, preparedness for end of life, or presence of pre-death guilt (Stevens-Neck et al., 2023).

#### Valued aspects of videoconferencing support groups

The most commonly reported benefit of videoconferencing support groups was the ability to connect with others in a similar situation, as participants valued being able to relate to the experiences of other group members (Austrom et al., 2015; Banbury et al., 2019; Cousins et al., 2022; Damianakis et al., 2018; Gerritzen et al., 2023; Lundberg, 2014; Marziali et al., 2005; McLoughlin et al., 2023; O'Connell et al., 2014; O'Connor et al., 2023; Rapley et al., 2023; Schaffer & Henry, 2023; Stevens-Neck et al., 2023). Participants spoke about how connecting with their peers helped them feel less socially isolated, and they valued the friendships they formed through their support group. Participants also appreciated the information and advice they received during support group sessions (Austrom et al., 2015; Czaja et al., 2013; Damianakis et al., 2018; Gerritzen et al., 2023; Lundberg, 2014; Marziali & Garcia, 2011; McLoughlin et al., 2023; O'Connell et al., 2014; Rapley et al., 2023; Schaffer & Henry, 2023; Stevens-Neck et al., 2023). Many participants reported that taking part in a support group improved their resilience to stress and helped them cope with their responsibilities (Austrom et al., 2015; Cousins et al., 2022; Czaja et al., 2013; Damianakis et al., 2018; Marziali et al., 2005; Marziali & Garcia, 2011; O'Connell

et al., 2014; Rapley et al., 2023; Schaffer & Henry, 2023; Stevens-Neck et al., 2023). Another benefit of attending a support group was that group members could signpost each other to other support and services that are available (Lundberg, 2014; O'Connell et al., 2014; Stevens-Neck et al., 2023).

In three studies, participants expressed that having enjoyable activities as part of support group sessions (e.g. dancing, singing, games etc.) was appreciated and helped improve their mental health (Cousins et al., 2022; Gerritzen et al., 2023; O'Connor et al., 2023). It could be important to note that these three studies all took place during the COVID-19 pandemic, as Cousins et al. (2022) suggested that activities were especially appreciated because lockdown measures prevented participants from participating in their usual hobbies and from meeting up with friends and family.

In three studies included in this review, participants spoke about how they valued having frequent meetings (e.g. weekly meetings) with their support group and found it helpful to have contact with other members outside of support group sessions (Austrom et al., 2015; Gerritzen et al., 2023; Lundberg, 2014; O'Connor et al., 2023; Rapley et al., 2023; Schaffer & Henry, 2023). This informal contact can be facilitated by technology, for example, through having one-on-one video calls with each other or having a group chat where the group members can message each other whenever they like.

In several of the intervention studies, the authors reported that some support groups planned to continue meeting independently without a facilitator after the intervention period ended, sometimes with participants taking on the responsibility of facilitating sessions (Austrom et al., 2015; Banbury et al., 2019; Marziali et al., 2005; Marziali & Garcia, 2011; Schaffer & Henry, 2023; Stevens-Neck et al., 2023). Though the continuation of groups was reported to be generally successful, participants in the study conducted by Austrom and colleagues reported that a handbook about how to facilitate support group sessions may be useful in enabling participants to run their own support groups in the future because, as one caregiver in the study said, 'being without a leader might be difficult.' (Austrom et al., 2015, para. 13).

Damianakis et al. (2018) found that discussions of spirituality at support group meetings were beneficial to participants, and that faith and spirituality was an effective coping mechanism. However, this finding was not reported in any other study. It should be noted that participants were not recruited from faith-based sources (e.g. church groups) and the researchers did not suggest faith as a topic of discussion.

### **Acceptability and the impact of technology**

The participants in the majority of the studies considered videoconferencing a convenient way of taking part in a support group as they could participate without having to leave their home (Austrom et al., 2015; Banbury et al., 2019; Czaja et al., 2013; Gerritzen et al., 2023; Marziali et al., 2005; Marziali & Garcia, 2011; McLoughlin et al., 2023; O'Connell et al., 2014; Stevens-Neck et al., 2023). There were some participants who reported that it would be too difficult to attend a face-to-face support group due to their caregiving responsibilities and viewed videoconferencing support groups as an acceptable alternative. Whereas some participants preferred videoconferencing over face-to-face support groups. One reason for this was because taking part from home made them feel more comfortable and less vulnerable when speaking about their experiences, as one participant said 'you are more apt to open up - you are in your own home.' (Marziali & Garcia, 2011, p. 41).

The major reported disadvantage of videoconferencing support groups was that many participants experienced technical difficulties (e.g. internet problems causing participants to disconnect from calls, freezing and lag) when using videoconferencing software (Austrom et al., 2015; Banbury et al., 2019; Blackberry et al., 2023; Gerritzen et al., 2023; Lundberg, 2014; McLoughlin et al., 2023; O'Connell et al., 2014). Furthermore, many participants reported having little experience with technology and so they had some difficulty navigating the videoconferencing software (e.g. knowing how to join a call, how to unmute themselves etc.) and adjusting to the protocols of videoconferencing conversations. Where tech support and training was provided to participants, this was appreciated and participants reported that it made it easier to take part in sessions (Austrom et al., 2015; Banbury et al., 2019; Gerritzen et al., 2023; Lundberg, 2014). It should also be considered that technical difficulties were not reported in several of the studies, and across the rest of the studies participants were generally reported to have improved their technological skills with time.

The participants in the intervention studies often relied heavily on technical support in order to take part in the intervention (Table 2), such as IT support or access to a helpline when having technical difficulties during support group sessions (Austrom et al., 2015; Banbury et al., 2019; Blackberry et al., 2023; Czaja et al., 2013; Lundberg, 2014; Marziali & Garcia, 2011; Schaffer & Henry, 2023) and IT training and/or IT training manuals (Banbury et al., 2019; Czaja et al., 2013; Lundberg, 2014; Marziali et al., 2005; Marziali & Garcia, 2011; O'Connell et al., 2014; Schaffer & Henry, 2023). Furthermore, some participants lacked access to the technology required to take part in a videoconferencing support group and needed to be provided with hardware (e.g. computer, headphones, webcam) by the researchers (Austrom et al., 2015; Banbury et al., 2019; Blackberry et al., 2023; Czaja et al., 2013; Lundberg, 2014; Marziali et al., 2005; Marziali & Garcia, 2011; O'Connell et al., 2014). In some cases participants also needed to have an internet connection installed in their home or be provided with access to the internet at another location (Austrom et al., 2015; Blackberry et al., 2023; Czaja et al., 2013; Lundberg, 2014; Marziali et al., 2005; Marziali & Garcia, 2011; O'Connell et al., 2014). This level of technological support may not be feasible in situations outside of a research study. For example, the study conducted by Gerritzen et al. (2023) was not intervention based and instead investigated pre-existing support groups that moved to videoconferencing software due to the COVID-19 pandemic, and so participants did not have access to formal IT support offered by researchers. In this study, participants reported finding using technology challenging at times but were able to overcome these challenges with help from family members, other members of the group, and the group facilitator.

Another disadvantage that was reported in several studies is that some participants believed that videoconferencing support groups were less beneficial than face-to-face support groups, as they did not feel as warm or offer as much of a personal touch (Austrom et al., 2015; Banbury et al., 2019; Cousins et al., 2022; Gerritzen et al., 2023; Marziali et al., 2005; Marziali & Garcia, 2011; McLoughlin et al., 2023; O'Connell et al., 2014; O'Connor et al., 2023). For example, some participants felt disappointed that they could not physically comfort each other through videoconferencing, such as giving someone a hug if they started to cry (O'Connor et al., 2023). Other participants spoke about how there can be aspects of body language that



might not be picked up on when using videoconferencing, which can make communicating more difficult (O'Connell et al., 2014). Additionally, some participants disliked that videoconferencing support groups require more structure, such as only one person being allowed to speak at a time to stop people from talking over one another (McLoughlin et al., 2023).

## Discussion

This systematic review investigated the use of videoconferencing support groups for people affected by dementia. The included studies demonstrated that, despite heterogeneity in research location, intervention duration, and differences in the format and content of the support groups, videoconferencing support groups were experienced as acceptable and useful by caregivers. Qualitative findings about the usefulness of support groups were less mixed than quantitative findings, and highlighted the benefits of videoconferencing support groups even when statistical measures did not appear to consistently reflect this. The disparity between qualitative and quantitative findings is an effect that has also been reported in systematic reviews investigating face-to-face support groups for this population (Dam et al., 2016; McLoughlin, 2022). A possible explanation for this pattern of results is the progressive nature of dementia. As the needs of people living with dementia will get more severe over time, this could explain why statistically significant improvements to measures such as caregiver burden and mental health are not consistently found post-intervention because participants may be coping with more challenging life circumstances than they were pre-intervention. Therefore, the findings of this review may suggest that researchers should take care in selecting standardised measures that are specific to and sensitive to the situations of people affected by dementia, and/or use qualitative measures instead of or in tandem with quantitative measures to investigate participant beliefs about an intervention.

Caregivers considered videoconferencing support groups useful because they allowed them to connect with others with similar experiences and to get advice that helped them manage their caregiving responsibilities. The use of videoconferencing software to host support groups was seen as acceptable and convenient even, in some cases, by participants who had little prior experience with such technology. Although technical difficulties and feeling a lack of warmth due to a virtual format did impact some participant's enjoyment of support group sessions, participants across all studies reported high satisfaction levels with their experience of taking part in a videoconferencing support group. This suggests that videoconferencing support groups can be acceptable for this population. However, it should be noted that in some studies many participants relied on sometimes extensive IT support and the provision of hardware to take part, which may not be feasible for all support groups to provide.

Social isolation during the COVID-19 pandemic was particularly severe and led to many negative outcomes in people living with dementia, including an accelerated level of cognitive decline, increased anxiety, and occurrence of neuropsychiatric symptoms (Chen et al., 2021; Soysal et al., 2022; Tuijt et al., 2021). Similarly caregivers of people living with dementia also reported feeling more tired and overwhelmed with higher levels of caregiving burden (Azevedo et al., 2021; Borges-Machado et al.,

2020). There is evidence from the four studies investigating videoconferencing support groups in lockdown that these groups helped people affected by dementia cope during this time (Cousins et al., 2022; Gerritzen et al., 2023; McLoughlin et al., 2023; O'Connor et al., 2023).

There were no differences between the findings about people living with dementia and caregivers, as both considered videoconferencing support groups useful and acceptable. However, this finding should be considered with caution as only two of sixteen studies in this review included people living with dementia. The lack of research including people living with dementia could potentially reflect concerns that people living with dementia may not be able to engage with videoconferencing and may experience more difficulties using technology (Chirico et al., 2022; Yoon & Paek, 2023). Additionally, it is important to consider that the only study that included people living with dementia exclusively only included people living with young-onset dementia (Gerritzen et al., 2023). It is possible that the views of people living with young onset dementia about videoconferencing would differ from people with typical onset dementia because younger people may be more likely to have had more experience with technology. Furthermore, as young-onset dementia is less common, they may not be able to access a face-to-face support group tailored to their condition in their local area and would therefore be more willing to accept a videoconferencing support group that can connect people that live further apart. Although this review established that videoconferencing support groups appear to be beneficial for caregivers, ultimately there is not enough evidence in this review to make judgements about the usefulness of videoconferencing support groups for people living with dementia and how factors, such as dementia severity, could impact their ability to engage with videoconferencing support groups.

## Limitations and future directions

This review includes studies conducted in various countries (five from the UK, four from the USA, four from Canada, two from Australia, and one from Sweden). Generalisation of findings across these studies may not be fully appropriate due to cultural differences regarding caregiving and support for people affected by dementia. Cultural differences about these topics are not well understood (Brooke et al., 2018). Furthermore, as only research reported in English was eligible for inclusion, literature conducted on this topic in other languages may have been missed. The majority of participants across all studies were from white ethnic backgrounds so it is unclear the extent to which the findings of this study apply to those from other ethnic backgrounds. Though, one included study exclusively looked at minority ethnic groups in the USA and found that videoconferencing support groups aimed at minority ethnic groups were beneficial and feasible (Czaja et al., 2013). There is some evidence in the literature that people from ethnic minority groups may be less inclined to engage with online dementia support services due to cultural beliefs and technology-related barriers (Dodd et al., 2022; Parveen et al., 2017; Ramos & Chavira, 2022). Therefore, an important target for future research could be conducting studies that explore the use of videoconferencing support groups by people from ethnic minority groups in order to identify cultural and language accommodations to make videoconferencing support groups more beneficial for people from these populations (Hossain & Khan, 2020; Kishita et al., 2024).

While many studies reported that participants lacked prior experience with videoconferencing, their willingness to take part in a study focused on videoconferencing peer support groups might suggest a heightened interest in such interventions. Furthermore, the studies that were conducted during COVID-19 recruited participants who were already engaged with videoconferencing support groups. Therefore, the findings of this review should be interpreted with this in mind as it is unclear to what extent they can be extrapolated to a more general population of people affected by dementia, as the review may not have captured some of the barriers to accessing videoconferencing-based support for this population.

The quantitative findings in this review should be considered with some caution as they were based on the findings of only five studies, two of which were small scale pilot studies. This highlights a need for larger scale quantitative studies, including RCTs, to be conducted in order to create stronger quantitative evidence around the benefits of videoconferencing support groups for people affected by dementia. Furthermore, this review captured very little evidence of any kind about the usefulness of videoconferencing support groups for people living with dementia, which highlights the need for further research to be conducted that includes people living with dementia as participants. In addition, it is unknown the extent to which videoconferencing support groups that have been evaluated as part of research are representative of groups that have not been included in studies.

From the two included studies that had control groups, there was evidence that caregivers were more satisfied with a videoconferencing support group intervention than receiving text-based advice alone (Czaja et al., 2013; Marziali & Garcia, 2011). However, due to an absence of any other comparative studies, it is not possible to compare the usefulness of videoconferencing support groups to face-to-face support groups or make judgments about the impact of different support group formats or features (e.g. the presence of facilitators, the frequency of support group meetings etc.) on the effectiveness of the intervention. Comparing different types of support group could be a useful target for future research as the findings could be used to help inform best practice and improve service provision.

## Conclusion

This review found that videoconferencing support groups can be useful and acceptable for caregivers of people living with dementia, but training with technology or IT support may be necessary to ensure caregivers can access virtual support groups effectively. There was insufficient evidence available to draw conclusions about the benefits of videoconferencing for people living with dementia. Further research is needed to explore how the format and content of such videoconferencing support groups affects uptake and effectiveness.

## Ethical approval

This work is a systematic review of existing literature and so does not need ethical approval or to be registered as a trial.

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## Appendix A

**Table A1.** Data extraction and quality assessment scores.

1. Use of a multiparty web based videoconference support group for family caregivers (Austrom et al., 2015)	
Authors	Mary Guerriero Austrom, Kristin N. Geros, Kimberly Hemmerlein, Siobhan M. McGuire, Sujuan Gao, Steven A Brown, Christopher M. Callahan, and Daniel O. Clark, PhD
Year of publication	2015
Country	USA
Study design	Mixed methods (quantitative questionnaire and focus group interview)
Number of Participants	5 (4 Completed intervention)
Population	Caregivers of people living with dementia Mean age = 56.2 Female % = 100% Relationship to care recipient* = spouse (4), parent (1), friend (1) Ethnicity = data not provided Employment = data not provided *One caregiver cared for both their spouse and a parent
Description of support	Pilot intervention of a videoconference support group for caregivers of people living with dementia held once a week for six months. The support group was facilitated by the lead author and had guest speakers; sessions were 1 h long. The equipment needed to take part in the support group was provided to participants, and the study had a research assistant to remind participants about meetings and to help with IT issues. Attendance of sessions was 83% overall.
Key findings	Summary of quantitative findings (questionnaires) <ul style="list-style-type: none"> <li>Improvement to anxiety, depression, ability to respond to disruptive behaviour, and controlling upsetting thoughts.</li> <li>Slight increase in caregiver burden and a worsened score on obtaining respite post-intervention.</li> <li>Caregiver's perceived physical health score improved but mental health score stayed similar.</li> </ul> Quantitative findings should be interpreted with caution as this is based off 4 participants and no statistical analysis was carried out. <p>Summary of qualitative findings</p> The support group members took part in a focus group to discuss their experiences during the intervention. They reported: <ul style="list-style-type: none"> <li>Participants appreciated the information they learned from guest speakers and the guidance from the support group facilitator.</li> <li>The group stayed in touch after intervention because 'they have been through so much together' but commented that it might be more difficult to meet without a facilitator.</li> <li>They found videoconferencing appropriate, saying that the only thing missing was hugs. Not having to travel, take time off work, or leave the person they care for alone to attend a support group, or having to find an appropriate meeting place was seen as convenient. Participants conclude that the pros of the videoconferencing support outweighed the cons.</li> <li>Caregivers felt participating in the support group decreased their stress and they valued speaking to people with similar experiences.</li> <li>They considered meeting once a week or even more frequently to be important.</li> <li>Participants experienced some technical problems but were able to resolve these with the help of the research team. Overall, they found the computer programme easy to use.</li> </ul>
Quality assessment	★ ★ ★ ★ ☆ (80%)
2. Implementing a peer-support programme by group videoconferencing for isolated caregivers of people with dementia (Banbury et al., 2019)	
Authors	Annie Banbury, Lynne Parkinson, Steven Gordon, and Denise Wood
Year of publication	2019
Country	Australia
Study design	Mixed methods (quantitative questionnaire and qualitative semi-structured interviews and facilitator field diaries)
Number of Participants	69 (67 Completed intervention)
Population	Caregivers of people living with dementia Mean age = 62.6 Female % = 72% Relationship to care recipient = spouse (39), parent (22), other (8) Ethnicity = data not provided Employment = retired (27), working full-time (10), working part-time (12), other (20)
Description of support	Videoconferencing support group held once a week for 6 wk. Meetings lasted an average of 90 min and had a group facilitator. There were 16 support groups set up for this study. Participants were required to have an existing internet connection but were provided with tablets with Zoom installed if they did not have the technology needed to take part in videoconferencing sessions already. IT support was available for participants. The two participants that dropped out of the intervention did so due to difficulties with technology.

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**Table A1.** Continued.

Key findings	<p>Summary of quantitative findings</p> <p>A measure of loneliness was completed by participants prior to the study. They found that the participants had higher levels of social isolation compared to typical older adults. Participants were also asked about their ability to engage in eHealth technology (eHLQ scale), authors describe the participant's scores as 'mid-range'. Participants did not complete the questionnaires again after the intervention, so it is unclear if the support group would have impacted this.</p> <p>Summary of qualitative findings</p> <p>28 participants took part in semi-structured interviews, they reported:</p> <ul style="list-style-type: none"> <li>• Participants often felt nervous about trying videoconferencing if they hadn't used it before. Participants felt it was a positive experience to learn about videoconferencing technology, but often experienced technical difficulties. An IT support person was available to participants during meetings, and this was seen as helpful.</li> <li>• Participants had to adjust to communicating through videoconferencing as only one person can speak at a time. Communication protocols were valued by participants to prevent people from speaking over each other.</li> <li>• Some participants expressed a preference for in-person support groups as they can hug people. However, they said that if meeting in-person was not possible they'd still prefer a videoconferencing support group over not meeting at all or a teleconference support group. Some participants preferred videoconferencing support groups to in-person support groups because they felt more relaxed and comfortable participating from in their own home.</li> <li>• After the intervention ended, 76% of participants indicated that they would like to continue meeting with their support groups by organising the videoconferencing sessions themselves. 8 groups self-organised meetings after the study ended.</li> </ul> <p>Facilitator field diaries reported:</p> <ul style="list-style-type: none"> <li>• Most technical problems happened in the first few meetings. 48% of meetings had no technical difficulties, 35% had minor technical difficulties, and 26% had major technical difficulties (e.g. connection dropouts, bad audio or video quality that prevented people from seeing or hearing each other). IT support was contacted to resolve technical difficulties.</li> <li>• Prior to the intervention participants could do a practice call with IT support where they were taught how to use videoconferencing. More technical difficulties were experienced when participants used a different device than the one they used for the test call.</li> </ul>
Quality assessment	★ ★ ★ ☆ ☆ (60%)
<b>3. Virtual dementia-friendly communities (Verily Connect) stepped-wedge cluster-randomised controlled trial: improving dementia caregiver wellbeing in rural Australia (Blackberry et al., 2023)</b>	
Authors	Blackberry, I., Rasekaba, T., Morgan, D., Royals, K., Greenhill, J., Perkins, D., O'Connell, M., Hamiduzzaman, M., Winbolt, M., Robinson, A., Davis, H., Wilding, C.
Year of publication	2023
Country	Australia
Study design	Randomised control trial
Number of participants	37
Population	<p>Carers of people living with dementia</p> <p>Mean age = 60</p> <p>Female % = 32%</p> <p>Relationship to care recipient = spouse (14), parent (18), sibling (4), friend (1)</p> <p>Ethnicity = data not provided</p> <p>Employment = data not provided</p>
Description of support	<p>Participants had access to a website and mobile app with guidebooks about managing caregiving situations and attended peer support group meetings through Zoom. Volunteers were available to provide technical support and help participants with joining the videoconference meetings. Access to the internet and devices were provided at local libraries and/or health centres. No information was given about the frequency, content, or attendance rates of peer support group meetings.</p>
Key findings	<ul style="list-style-type: none"> <li>• Increase in levels of social support post-intervention compared to pre-intervention on the Medical Outcomes Study Social Support Survey (MOS-SSS) scale.</li> <li>• Caregivers around 55 years old and in their first one to three years of caring experienced the highest increase in perceived social support after using the Verily Connect model. Authors suggest that younger caregivers with less experience in caring may benefit from technology-based interventions more than older and long-term caregivers.</li> <li>• No statistically significant decrease in caregiver burden on the Zarit Burden Interview (ZBI) scale.</li> <li>• There was no statistically significant correlation between age, duration of caregiving, dementia duration, or duration of exposure to intervention and social support levels or burden levels.</li> </ul>
Quality assessment	★ ★ ★ ★ ☆ (80%)
<b>4. Four walls and a garden': Exploring the experiences of families affected by dementia during the COVID-19 pandemic (Cousins et al., 2022)</b>	
Authors	Emily Cousins, Kay De Vries, Karen Harrison Denning
Year of publication	2022
Country	UK
Study design	Qualitative (semi-structured interviews, individually or as a dyad)
Number of participants	12 (5 people living with dementia, 7 caregivers)
Population	<p>People living with dementia (5)</p> <p>Age = 65–69 (2), 70–74 (2), 80–84 (1)</p> <p>Female % = 0%</p> <p>Ethnicity = White British (5)</p> <p>Employment = data not provided</p> <p>Diagnosis = Young onset Alzheimer's disease (1), Frontotemporal dementia (2), Vascular dementia with Lewy bodies (1), Unknown type of dementia (1)</p> <p>Caregivers (7)</p> <p>Mean age = 57.5</p> <p>Female % = 100%</p> <p>Relationship to care recipient = spouse (5), parent (2)</p> <p>Ethnicity = White British (6), Asian/British Asian (1)</p> <p>Employment = data not provided</p>

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**Table A1.** Continued.

Description of support	Participants were recruited from online peer support groups that were running during lockdown, the researchers attended videoconferencing support group sessions to introduce the project to eligible participants.
Key findings	<p>The focus of this work was to understand the impact of COVID-19 and lockdown on people living with dementia and their caregivers. However, the participants reported some experiences with their online support groups:</p> <ul style="list-style-type: none"> <li>• Lockdown was a negative experience for all participants, as their daily routines and activities were disrupted by lockdown and most participants reported feeling isolated and saw a decline in their mental health. However, their online support groups were a source of positivity for participants. The activities and social interaction provided by these groups were beneficial and helped them feel connected to others.</li> <li>• Being a member of a support group helped the participants to feel more resilient and improved their confidence and willpower during lockdown.</li> <li>• One participant reported that online support group sessions were not a good substitute for in-person sessions because they missed the 'personal contact' and it just wasn't the same on Zoom. Some participants spoke about how they were looking forward to socialising face-to-face after lockdown ended.</li> </ul>
Quality assessment	★★★★★ (100%)
<b>5. A videophone psychosocial intervention for dementia caregivers (Czaja et al., 2013)</b>	
Authors	Sara J. Czaja Ph.D., David Loewenstein Ph.D., Richard Schulz Ph.D., Sankaran N. Nair M.S., Dolores Perdomo Ph.D.
Year of publication	2013
Country	USA
Study design	Quantitative (randomised control trial with quantitative questionnaires)
Number of participants	110 Total over three groups: 38 In the intervention group (36 completed the intervention) 36 In the attention control group (34 completed) 36 In the control group (29 completed)
Population	<p>Caregivers of people living with dementia</p> <p>Intervention group (30) Mean age = 57.5 Female % = 76.7% Relationship to care recipient = spouse (9), parent (17), other (8) Ethnicity = African American (46.7), Hispanic (53.3) Employment = data not provided</p> <p>Control groups (63) Mean age = 61.5 Female % = 87.3% Relationship to care recipient = spouse (39), parent (22), sibling (2), other (1) Ethnicity = African American (49.2%), Hispanic (50.8%) Employment = data not provided</p>
Description of support	Participants received six 1-h monthly sessions designed to educate caregivers about dementia and caring. There were also 5 monthly support group sessions through videoconferencing. Videophones were provided to participants. The support groups were made up of 6 caregivers and one facilitator. In the attention control group participants also received 6 educational sessions and 5 support group sessions but the content was aimed towards nutrition and healthy eating, and the information-only control group did not have any individual or group sessions but were provided with a packet of educational materials about caring and dementia.
Key findings	<ul style="list-style-type: none"> <li>• There was a significant improvement to participant's perceptions about positive aspects of caregiving and caregiver burden post-intervention compared to the control groups.</li> <li>• There was an improvement to some aspects of social support measures (satisfaction with social support) but not others (instances of negative interactions/support and received social support).</li> <li>• There was no significant change to participant depression scores post-intervention.</li> <li>• 73% Of participants reported that the intervention was beneficial and 63% thought it improved their caregiving skills.</li> <li>• 85% Reported that they found videoconferencing to be easy to use and 85% of participants found participating in the support groups valuable.</li> <li>• It should be noted that the intervention also included a lot of educational materials so it would be unclear how much the findings would be attributable to the videoconferencing support group portion of the intervention.</li> </ul>
Quality assessment	★★★★☆ (80%)
<b>6. Family caregiver support groups: spiritual reflections' impact on stress management (Damianakis et al., 2018)</b>	
Authors	Thecla Damianakis, Kimberley Wilson, and Elsa Marziali
Year of publication	2018
Country	Canada
Study design	Qualitative (analysis of video recordings of support group sessions)
Number of participants	24
Population	<p>Spousal caregivers of people living with dementia</p> <p>Mean age = 74.2 Female % = 58% Relationship to care recipient = spouse (24) Ethnicity = data not provided Employment = data not provided</p>
Description of support	Videoconferencing support group intervention held once a week for 10 wk and meetings were 1 h long. Groups were made up of 6 caregivers, three groups were made up of caregivers of someone with Alzheimer's disease (AD) and one group was made up of caregivers of someone with Frontotemporal dementia (FTD). Groups were facilitated by a social worker.

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**Table A1.** Continued.

Key findings	The focus of the study was reporting themes about the participant's experiences with caregiving and the coping strategies they utilise based on observations of support group sessions. There is limited information about the caregiver's opinion about the intervention or whether it impacted their wellbeing. However, the following impressions about the intervention were reported: <ul style="list-style-type: none"> <li>• Participants were able to identify with the struggles of the other caregivers in their group, and attending the support group made them feel understood, validated, and comforted.</li> <li>• At the group, participants were able to share problem solving and coping strategies with each other which they felt had improved their caregiving and self-esteem.</li> <li>• Caregivers discussed spiritual beliefs with their support group and reported that engaging with spirituality and faith helped them to think more positively about their caring situation.</li> </ul>
Quality assessment	★★★★★ (100%)
<b>7. Peer support through video meetings: experiences of people with young onset dementia (Gerritzen et al., 2023)</b>	
Authors	Esther Vera Gerritzen, Gianna Kohl, Martin Orrell, and Orii McDermott
Year of publication	2023
Country	UK
Study design	Qualitative (focus group interviews)
Number of participants	20
Population	People with young-onset dementia Mean age = 59.6 Female % = 45% Ethnicity = data not provided Employment = yes (4), no (16) Diagnosis = Alzheimer's disease (7), frontotemporal dementia (4), posterior cortical atrophy (3), primary progressive aphasia (3), Lewy body dementia (2), semantic dementia (1)
Description of support	Participants were part of four different support groups that took place through videoconferencing during COVID-19 (Zoom or GoToMeeting). All of these group met once a month and had a facilitator (1 group had a former caregiver as a facilitator, the other three were facilitated by a healthcare professional).
Key findings	Four focus group sessions were held, and the following four themes were found: <ul style="list-style-type: none"> <li>• Participants reported a lack of awareness of support groups due to lack of signposting and barriers to attending in-person services. Many participants said that they didn't feel that groups aimed at people with typical-onset dementia were age-appropriate for them, and this left them reluctant to join a support group if they were not aware of groups aimed at people with young-onset dementia.</li> <li>• All participants reported that joining the online support group had a positive impact on their lives due to increased social support and being able to speak to people with similar experiences. The social support and advice they gained from the support group helped them handle with their daily lives.</li> <li>• Participants reported that they valued support group meetings having an agenda or providing meaningful activities (e.g. creative activities, advocacy, or research activities). But also enjoyed meetings with no agenda where they can just socialise.</li> <li>• Participants reported that they valued attending videoconferencing support groups from their own home because they felt comfortable and less nervous to speak. It was also convenient for participants as they didn't have to travel to a group meeting in-person and participants valued that the group being online offered an opportunity for them to speak to people from different places.</li> <li>• Where there was also a WhatsApp group associated with their online support group, participants enjoyed this and said it helped them to keep in touch with others.</li> <li>• Participants found videoconferencing support groups especially valuable during COVID-19 lockdown as it was a difficult and isolating time for them.</li> <li>• Participants reported that they experienced some technical difficulties when using videoconferencing support groups and appreciated help with using technology from other group members, family members, and from the group facilitators.</li> <li>• For some people online meetings couldn't replace in-person meetings because they didn't have the same level of 'human connection'. They also reported that some people who had previously attended their support group when it met in-person before the pandemic were not able to join in the videoconferencing version and lost contact with the group during lockdown.</li> </ul>
Quality assessment	★★★★★ (100%)
<b>8. The results from a two-year case study of an information and communication technology support system for family caregivers (Lundberg, 2014)</b>	
Authors	Stefan Lundberg
Year of publication	2014
Country	Sweden
Study design	Qualitative (semi-structured interviews and observations)
Number of participants	10
Population	Spousal caregivers of people living with dementia or stroke (9 dementia caregivers) Mean age = 80.2 Female % = 60% Relationship to care recipient = data not provided Ethnicity = data not provided Employment = data not provided
Description of support	The study reports the findings of a two-year case study (2006–2008) of a videoconferencing support group. The support group met once or twice a month. Participants were provided with the equipment to take part in the group and given ICT training.

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**Table A1.** Continued.

Key findings	<ul style="list-style-type: none"> <li>Participants reported that they found caregiving stressful and isolating in baseline interviews prior to the intervention. After the intervention, participants reported similar levels of happiness but reported feeling more exhausted. Before the intervention 5/10 participants said they were depressed, after the intervention 6/10 participants reported they were depressed.</li> <li>All participants reported that they found the support group helpful, and 7/10 participants were satisfied with their experience.</li> <li>In the support group meetings, participants spoke about their problems they encountered as caregivers and felt able to speak freely as they were around people with similar experiences. Participants valued the advice they got from each other and also from the educational resources they were provided with.</li> <li>Participants reported that one of the key benefits of taking part in the group was becoming more aware of the services available to them and how to access support. Care service use increased slightly post-intervention.</li> <li>The members of the support group formed a social network and also used to meet face-to-face outside of the support group sessions. They also often contacted each other through videoconferencing outside of the formal sessions.</li> <li>Many of the participants had difficulty using the technology and they needed help from tech support.</li> <li>One male participant indicated that he did not relate to the other members of the group because they were 'old ladies' and had a different situation to him.</li> <li>One participant's care recipient went into a care home during the study, and as she did not meet the inclusion criteria of the study anymore, she was excluded from the support group. This was distressing to the remaining participants of the study and to the excluded participant and she expressed that she still would have benefitted from the support group.</li> </ul>
Quality assessment	★ ★ ★ ☆ ☆ (60%)
<b>9. Caring for others: internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's disease (Marziali et al., 2005)</b>	
Authors	Elsa Marziali, Peter Donahue, and Gillian Crossin
Year of publication	2005
Country	Canada
Study design	Qualitative (structured interviews and observations of recorded support group sessions)
Number of participants	34
Population	Caregivers of a person with Alzheimer's disease, stroke, or Parkinson's disease (12 of each) Mean age = 67.8 Female % = 76% Relationship to care recipient = data not provided Ethnicity = data not provided Employment = data not provided
Description of support	Groups of 6 caregivers took part in a weekly videoconferencing support group with a facilitator for 10 wk, followed by weekly meetings without a facilitator for 3 months.
Key findings	<p>Analysis of recordings of group sessions and interviews with intervention participants yielded the following themes about videoconferencing support groups:</p> <ul style="list-style-type: none"> <li>Members of the support groups bonded easily with each other and were able to empathise with each other's situations. The use of videoconferencing protocols (i.e. only one person can speak at a time) did not make communication difficult.</li> <li>Participants reported that taking part in the support group led to improvements in their mental and physical health, and helped them cope with stressful situations.</li> <li>90% Of participants reported that their participation in the videoconferencing support group was extremely or very positive. The other 10% of participants found their experience 'somewhat helpful' and this was due to them not relating as well to the other group members or having a preference for meeting one-on-one.</li> <li>95% of participants reported that the group met their expectations and helped them cope with caregiving (e.g. learning how to manage stress). The 5% of caregivers who felt like the group 'somewhat met their expectations' stated that they preferred face-to-face contact.</li> <li>Approximately half of the participants in the study had never used a computer before. And 91% of participants reported that participating in the intervention helped them to gain 'considerable skill in using the computer' and conduct other activities on the computer.</li> <li>61% Of participants felt that taking part in a videoconferencing support group was just as helpful as meeting people face-to-face and is convenient because it can be done from home. The other participants felt that it was almost as helpful (example quote from participant - "I think face-to-face is best, but I think this is second best when you can't have access to a support group face-to-face.")</li> <li>Participants voiced that they would have wanted the intervention to continue, after the intervention ended some groups continued speaking through email, telephone, and face-to-face meetings.</li> </ul>
Quality assessment	★ ★ ★ ★ ★ (100%)
<b>10. Dementia caregivers' responses to 2 internet-based intervention programs (Marziali &amp; Garcia, 2011)</b>	
Authors	Elsa Marziali and Linda J. Garcia
Year of publication	2011
Country	Canada
Study design	Mixed Methods (qualitative semi-structured interviews and observations of recorded support group sessions, and quantitative questionnaires)
Number of participants	91 (51 In videoconferencing support groups, 40 in text-based chat groups)
Population	Caregivers of people living with dementia Mean age = 65.5 Female % = 72% Relationship to care recipient = spouse (74%), parent (26%) Ethnicity = data not provided Employment = data not provided
Description of support	Participants were able to choose to participate in either a text-based chat support group or an online videoconferencing support group facilitated by a clinician. Videoconferencing support group meetings were 1 h long and met weekly for 10 wk. There were 6 caregivers in each group and groups were organised to be made up exclusively of spousal caregivers or caregivers caring for their parents. After the 10-week intervention period, the groups continued to meet for an additional 10 wk without a facilitator.

(Continued)

Table A1. Continued.

Key findings	<p>Summary of quantitative findings</p> <ul style="list-style-type: none"> <li>Both the videoconferencing and text-based group saw a significant increase to self-efficacy and social support post-intervention, but there was no difference in their utilisation of health and social services or plans to institutionalise their care recipient in either group.</li> <li>Compared to the text-based group the videoconferencing group showed a significantly greater improvement in mental health and distress at managing cognitive deterioration in their care recipient. However, the text-based group reported greater improvement at managing distress from activities of daily living.</li> </ul> <p>Summary of qualitative findings</p> <p>Use of the text-based groups was very limited, on average participants only access the text-based forum once. The videoconferencing group attended on average 7/10 facilitated sessions and 5/10 non-facilitated sessions. The content of what was discussed at these sessions was summarised through the following four themes; (a) sadness associated with observations of changes in the care recipient due to progression of the disease, (b) the psychological and physical impact of caregiving, (c) coping strategies used, and (d) approaches to caregiver self-care.</p> <p>Post intervention interviews were held with participants and participants had much more favourable views about the videoconferencing intervention. The following themes were reported by the videoconferencing group:</p> <ul style="list-style-type: none"> <li>Mutual help and support – attending the group helped them to ‘get through tough times’ and they valued being able to relate to other people’s problems and receive social support.</li> <li>New knowledge and skills – participants were able to share advice and strategies for coping with different situations.</li> <li>Using technology – There were often problems with accessing the videoconferencing software but, as participants had help from IT technicians, they were able to solve these problems. They also reported that it was convenient to take part in a support group from their own home and that it’s better than being on the phone because you can see each other.</li> </ul>
Quality assessment	★ ★ ★ ★ ☆ (80%)
11. Online support groups for caregivers of people living with dementia: an investigation of videoconferencing support groups in lockdown (McLoughlin et al., 2023)	
Authors	Bethany McLoughlin, Helen Atherton, John MacArtney, and Jeremy Dale
Year of publication	2023
Country	UK & Ireland
Study design	Mixed methods (quantitative questionnaire and qualitative semi-structured interviews)
Number of participants	39 (16 Interview participants)
Population	<p>Caregivers of people living with dementia</p> <p>Age = 31–40 (3), 41–50 (3), 51–60 (6), 61–70 (13), 71–80 (10), 81+ (4)</p> <p>Female % = 79.5%</p> <p>Relationship to care recipient = spouse (24), parent (13), other (2)</p> <p>Ethnicity = White (100%)</p> <p>Employment = retired (24), working full-time (8), working part-time (6), unemployed (1)</p>
Description of support	This article did not include an intervention and recruited participants that were part of various support groups that met face-to-face prior to lockdown and met online during COVID-19 lockdown. The majority of groups met over videoconferencing software, such as Zoom, with one group using WhatsApp calls. Most groups met once a week (24, 61.5%) or once a month (11, 28.2%); three met every other week (3, 7.7%), and one met at irregular intervals (1, 2.6%). Participants described that their online support group sessions were attended by an average of 10.8 members with a range of 3–26 people.
Key findings	<p>Summary of quantitative findings</p> <ul style="list-style-type: none"> <li>Participants reported that they found online groups more convenient but found face-to-face groups more enjoyable and helpful. They had an overall preference for face-to-face groups.</li> <li>Twenty-one (53.8%) reported that they missed around the same number of face-to-face and online sessions, twelve (30.8%) reported that they missed more face-to-face sessions, and six (15.4%) participants missed online sessions more frequently.</li> <li>Four (10.3%) participants said that they would only be interested in attending online sessions from now on, while 26 (66.6%) expressed a preference for attending a mixture of face-to-face and online sessions once the pandemic is over; eight (20.5%) wanted to return to face-to-face sessions.</li> </ul> <p>Summary of qualitative findings</p> <ul style="list-style-type: none"> <li>16 Of the 39 participants that completed the questionnaire volunteered to do an interview to further discuss their experiences with support groups. The following information was reported:</li> <li>There was a learning curve to taking part in a videoconferencing support group because the majority of participants were unfamiliar with videoconferencing. Having a protocol in place for the meeting was helpful and over time participants mostly adapted to using videoconferencing. Some participants never were able to adapt to the technology and therefore dropped out of their support groups because it was too difficult. Some participants reported that other members of their support group dropped out/never attended the online support group and were worried about them.</li> <li>Participants thought online support groups were convenient and accessible, many participants expressed it was difficult to get to a face-to-face meeting (e.g. finding respite care, travel, convincing the person they care for to attend with them).</li> <li>Some participants thought that videoconferencing lacked the ‘personal touch’ of meeting face-to-face as you could not give people hugs or share food and drink together. Some participants felt that using videoconferencing made conversations feel awkward or ‘cold’ because of the protocols or because of technical difficulties (e.g. people may accidentally talk over each other, or lag or disconnecting may disrupt conversations).</li> <li>Some participants reported that their care recipient was able to engage with videoconferencing support groups and this had a positive effect on them. Others said that, due to their dementia symptoms, their care recipient was not able to understand videoconferencing and take part effectively.</li> <li>Participants expressed an interest in accessing a mixture of online and in-person support in the future. Participants were also interested in a hybrid approach to support groups where the group meets face-to-face but offers a way to attend remotely through videoconferencing. Participants also thought that training with technology would be beneficial for caregivers to help them be able to access online support.</li> </ul>
Quality assessment	★ ★ ★ ★ ★ (100%)
12. Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias (O’Connell et al., 2014)	
Authors	Megan E O’Connell, Margaret Crossley, Allison Cammer and Debra Morgan Wendy Allingham, Betty Cheavins, Donna Dalziel, Maurice Lemire, Sheri Mitchell and Ernie Morgan (Collaborators)
Year of publication	2014
Country	Canada

(Continued)

**Table A1.** Continued.

Study design	Qualitative (focus group)
Number of participants	10 (9 took part in the focus group)
Population	Spousal caregivers of people living with young-onset dementia or frontotemporal dementia No demographic data given
Description of support	Monthly 90-minute videoconferencing support group meetings facilitated by two psychologists. Group members had to travel to a local hospital to use their videoconferencing equipment. A focus group to evaluate the group was held 18-months after the start of the group.
Key findings	<p>Participants took part in a focus group to discuss what they felt were the key aspects of the intervention that they liked and didn't like:</p> <ul style="list-style-type: none"> <li>• Participants felt that support groups should be composed of people with similar circumstances for them to be successful (i.e. similar age group, caring for someone with similar types of dementia, only spousal caregivers). However, having members in the group that are caring for people at different stages of dementia progression was helpful as they could help each other with advice for the future.</li> <li>• Participants felt that support groups should meet at least once a month and that support groups should be made up of no more than 10 people to ensure that everyone gets the maximum benefit. They felt like people should not be limited to a strict number of sessions and should be able to attend a support group for as long as they think they need to.</li> <li>• Participants said that attending a support group helped them avoid social isolation as their care responsibilities had led them to feel isolated. Additionally, they felt like they could connect with other caregivers and speak more openly with each other than non-caregivers because they understood each other's experiences.</li> <li>• Participants appreciated advice from their peers and learning about their coping strategies. They also appreciated practical advice about things such as claiming benefits and navigating the home care system. Caregivers also valued providing this advice to others as it made them feel like they were helping others.</li> <li>• Participants wanted more opportunities to socialise with each other, including in-person socialising, and wanted the group to be open to people from other areas and for them to be allowed to speak to each other outside of the sessions. However, they felt that the videoconferencing nature of the group made them less willing to reach out to each other for help (e.g. helping each other with respite) because they lived far apart.</li> <li>• Participants experienced some technical problems that would disrupt the discussions. They reported that sometimes it was difficult to pick up on non-verbal cues during videoconferencing sessions.</li> <li>• Travelling to the hospital to use their videoconferencing equipment was difficult for some participants, but still easier than travelling to the nearest in-person support group because they were caring for someone with a rare type of dementia and lived in a rural area.</li> </ul>
Quality assessment	★★★★★ (100%)
<b>13. Telehealth support for dementia caregivers during the COVID-19 pandemic: lessons learned from the NYU Family Support Program (O'Connor et al., 2023)</b>	
Authors	Maureen K. O'Connor Psy.D., Roscoe Nicholson M.A., Cynthia Epstein L.C.S.W., Tiffany Donley D.H.Sc., Rebecca Salant B.A., Andrew H. Nguyen M.A., Steven Shirk Ph.D., Elizabeth Stevenson M.S., Mary S. Mittelman Dr.P.H.
Year of publication	2023
Country	USA
Study design	Qualitative (semi-structured interviews)
Number of participants	10
Population	Spousal caregivers of people living with dementia Age range = 55–86 Female % = 70% Relationship to care recipient = spouse/partner (10) Ethnicity = White (9), Black (1) Employment = data not provided
Description of support	Caregivers of people living with dementia that had taken part in one or more videoconferencing support groups made available during COVID-19 were recruited.
Key findings	<p>The article reports the caregiver's experiences during COVID-19, and experience with support groups before and during the pandemic:</p> <ul style="list-style-type: none"> <li>• Participants described feeling more stress during the pandemic because they lost access to support services and lost social support, as well as being concerned for their and their care recipient's health and wellbeing.</li> <li>• However, a positive aspect of the pandemic for the participants is that they were able to make more frequent contact with people (especially those that live further away) due to the adoption of video conferencing.</li> <li>• All participants felt supported by their videoconferencing support group and found it to be a highly positive experience. They valued having a place to talk with others who could understand their situation and express their frustrations.</li> <li>• Some participants felt they connected more with other support group members through videoconferencing than they did face-to-face because the pandemic encouraged them to open up and stay in touch more.</li> <li>• Some participants felt that the group felt a little awkward before they got used to using videoconferencing technology (e.g. they might have had difficulty hearing or seeing members, or might have been accidentally talking over each other). Some said that they didn't enjoy the group as much as they did when it was face-to-face because they couldn't hug each other or socialise with each other before or after the group session.</li> <li>• Participants thought that having videoconferencing sessions that had musical components or were aimed at more casual conversation would be helpful in addition to a support group.</li> </ul>
Quality assessment	★★★★★ (100%)
<b>14. Video conferencing peer support and rarer forms of dementia: an exploration of family carers' positive experiences (Rapley et al., 2023)</b>	
Authors	Rapley, Jessica M.; Camic, Paul M.; Brotherhood, Emilie; Crutch, Sebastian James; Harding, Emma
Year of publication	2023
Country	United Kingdom
Study design	Qualitative (observations, thematic analysis)
Number of participants	9
Population	Caregivers of people living with rare types of dementia Mean age = 59.31 Female % = 77.77% Relationship to care recipient = spouse (8), parent (1) Ethnicity = White British (5), Irish (1), Other White Background, (1), British Indian (1) Employment = data not provided

(Continued)

Table A1. Continued.

Description of support	Six sessions of peer support group sessions were delivered through videoconferencing. Each session lasted 1–2 h and was co-facilitated by two members of staff. Sessions were themed around 'independence and identity'. Recordings of sessions were analysed using thematic analysis.
Key findings	<ol style="list-style-type: none"> <li>1. <i>Protecting, maintaining, enjoying and finding strength in their relationship with their care recipient.</i></li> <li>2. Having breaks from caregiving helped maintain relationships because they felt rested and better able to communicate with their care recipient. Having dementia-friendly shared activities to do together also helped maintain their relationships.</li> <li>3. <i>Using tools and resources in response to challenges.</i></li> <li>4. Attending a support group enabled caregivers to discuss different tools and resources they can use to cope with daily activities and maintain their wellbeing.</li> <li>5. <i>Positive impact of interactions and others' responses to the dementia.</i></li> <li>6. Participants benefitted from interacting with other family caregivers at peer support groups and found support groups that were tailored specifically to rare dementia more valuable. Caregivers appreciated support being consistent, easy to access, and appreciated the advice of other caregivers because they were experts by experience. The peer support group described in this study provided a sense of belonging, as well as a space to access information, share experiences and express vulnerabilities without social boundaries for caregivers, and participants reported that listening to others in similar situations seemed to affirm their feelings and reduce feelings of isolation.</li> <li>7. <i>Overcoming barriers to taking a break while maintaining their wellbeing</i></li> <li>8. Pursuing interests helped caregivers maintain their wellbeing, but participants reported they found it difficult to find time to do this.</li> <li>9. <i>Maintaining positive outlooks and showing psychological resilience in adversity.</i></li> <li>10. Reframing their perspective to help maintain a positive outlook was beneficial to caregivers. Attending a support group helped caregivers to gain a sense of acceptance of their situation and build resilience.</li> <li>11. <i>Attributing meaning to the caring role.</i></li> <li>12. Identifying positive aspects of caregiving can help caregivers see their situation as meaningful and enjoyable.</li> </ol>
Quality assessment	★★★★★ (100%)
15. Implementing a telehealth-delivered psychoeducational support group for care partners of individuals with primary progressive aphasia (Schaffer & Henry, 2023)	
Authors	Kristin M. Schaffer, Maya L. Henry
Year of publication	2023
Country	USA
Study design	Mixed methods (quantitative questionnaire and qualitative questionnaire)
Number of participants	10
Population	Spousal caregivers of people living with Primary Progressive Aphasia (PPA) Mean age = 68.9 Female % = 70% Relationship to care recipient = spouse (10) Ethnicity = White (100%) Employment = retired (7), employed (3)
Description of support	As a pilot study, eight one-hour support group sessions were held (two per month for four months) on Zoom. The group was facilitated by a speech language pathologist. Two guest speakers attended for two group meetings (a lawyer and a social worker). Session topics included information about PPA and its progression, caregiving coping strategies, legal advice, and information about local services. Sessions began with a 30-minute PowerPoint presentation giving information, followed by a 30-minute group discussion. Following each meeting, the facilitator sent all group members an email with a document summarizing the psychoeducational content and resources provided during the meeting. Some technical support was available to help participants use the videoconferencing software, but participants were required to have their own computer equipment and internet connection.
Key findings	<p>Summary of quantitative findings</p> <ul style="list-style-type: none"> <li>• No significant difference post-intervention on any scale (quality of life, adaptive and maladaptive coping mechanisms, self-efficacy, positive and negative mood, caregiver burden)</li> <li>• Participants completed a Likert scale questionnaire to measure satisfaction with intervention. Participants reported that the intervention had a positive impact on their quality of life, ability to connect with other caregivers, ability to provide care, and level of education about PPA and caring.</li> <li>• The intervention had a high attendance rate (87.5%)</li> </ul> <p>Summary of qualitative findings</p> <p>Open ended questions on a questionnaire were analysed using thematic analysis. The following three themes were reported:</p> <ul style="list-style-type: none"> <li>• (1) <i>Enhancing knowledge about PPA.</i></li> <li>• Participants reported that psychoeducational content and information about coping strategies were valued parts of the support group experience.</li> <li>• (2) <i>Feeling connected and mutually supported.</i></li> <li>• Participants appreciated forming social connections with other caregivers.</li> <li>• (3) <i>Desire for more time together.</i></li> <li>• Some group members reported that they wished group meetings were longer and allowed for more time for group members to talk in-depth about their personal experiences as a care partner. Authors conclude that the group size of 10 may have led to individuals not having enough opportunities to speak. One group member expressed a desire to connect with group members in person.</li> <li>• Participants continued support group meetings independently after the intervention ended (for over a year as of date of publication).</li> </ul>
Quality assessment	★★★★☆ (80%)

(Continued)

**Table A1.** Continued.

16. A mixed methods evaluation of a program exploring predeath grief and loss for carers of people with rarer dementias (Stevens-Neck et al., 2023)	
Authors	Stevens-Neck, R.; Walton, J.; Alterkawi, S.; Brotherhood, E. V.; Camic, P. M.; Crutch, S. J.; Gerritzen, E. V.; Harding, E.; McKee-Jackson, R.; Rossi-Harries, S.; Street, R. E.; Williams, M. V.; Waddington, C.; Wood, O.; Moore, K. J.
Year of publication	2023
Country	UK
Study design	Mixed methods (quantitative questionnaires and semi-structured qualitative interviews)
Number of participants	9
Population	Caregivers of people living with rare types of dementia Mean age = 58 Female % = 88.88% Relationship to care recipient = spouse (7), parent (2) Ethnicity = White British (8), White Irish (1) Employment = data not provided
Description of support	As a pilot study, six 2-h long fortnightly support group sessions led by two facilitators. The content of the support group sessions was to explore and accept feelings of grief and loss.
Key findings	<p>Summary of quantitative findings</p> <p>Participants completed a battery of questionnaires pre and post intervention and as a follow up 3-months after the intervention ended:</p> <ul style="list-style-type: none"> <li>• Positive impact on quality of life on the C-DEMQOL scale and depression scores on the PHQ-9 questionnaire. A positive impact on carer burden on the ZBI scale was seen at the three-month post-intervention stage.</li> <li>• No significant difference to scores on any other quantitative measure post-intervention or at 3-month follow up (anxiety, resilience, guilt, predeath guilt, preparedness for end of life, social support).</li> <li>• The attendance rate was 97.9%.</li> <li>• The program was rated as “very helpful” by 73% of participants and “helpful” by 27% of participants. Participants found the following aspects of the programme valuable: speaking to others in a similar position, understanding the condition of their care recipient, having the opportunity to ask questions, to take part in facilitated discussions, to take part in informal conversation, to receive guidance and advice, to be signposted to services, being able to learn from others, and the consistency of support.</li> </ul> <p>Summary of qualitative findings</p> <p>Interviews were analysed through thematic analysis and 4 themes were identified:</p> <ul style="list-style-type: none"> <li>• (1) <i>Overall impressions.</i></li> <li>• Participants overall impressions of the program were ‘overwhelmingly positive’. All participants felt that the programme should be offered to other caregivers and felt that the videoconferencing format didn’t impact their enjoyment of the support group. Participants commented that attending the support group sessions online allowed them to fit sessions around their caregiving responsibilities and made it easier to attend. Additionally, they felt that attending from their own home made them feel more able to open up as they were in a ‘familiar environment’.</li> <li>• (2) <i>Emotional processing.</i></li> <li>• Participants valued that the support group helped them take time to process their emotions and reflect on their experiences as a caregiver. Several participants reported that the support group helped them accept their emotions and felt validated by speaking to others with similar experiences. They found speaking about their feelings cathartic, but sometimes found talking about feelings emotionally draining.</li> <li>• (3) <i>Outlook.</i></li> <li>• Several participants made comments about how the program had helped them to see things from a different perspective and felt their outlook had been improved (e.g. reduced their feelings of guilt). Some participants found talking about the future helpful and necessary, but emotionally upsetting. Some participants reported they felt more confident after attending the programme and felt more able to cope with their caregiving situation.</li> <li>• (4) <i>Social impact.</i></li> <li>• All participants valued the opportunity to meet other people in a similar situation. The majority of participants mentioned feeling less alone, commenting on how isolating caring can be, and how reassuring it was to know others were having similar experiences. It was particularly important for these caregivers to speak with others in a similar situation because their care recipient had a rare type of dementia, and so felt that other people didn’t typically understand their care recipient’s condition. Most participants remained in contact after the end of the program.</li> </ul>
Quality assessment	★★★★ (100%)

## Appendix B

**Table B1.** Quality assessment summary table.

Studies	Criteria from the mixed methods appraisal tool																				Score (%)						
	1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	4.1	4.2	4.3	4.4	4.5		5.1	5.2	5.3	5.4	5.5	
1																						1	1	1	1	0	80
2																						0	1	1	1	0	60
3						1	1	1	0	1																	80
4	1	1	1	1	1																						100
5						0	1	1	1	1																	80
6	1	1	1	1	1																						100
7	1	1	1	1	1																						100
8	1	1	1	1	0	0																					60
9	1	1	1	1	1																						100
10																						1	1	1	1	0	80
11																						1	1	1	1	1	100
12	1	1	1	1	1																						100
13	1	1	1	1	1																						100
14	1	1	1	1	1																						100
15																						1	1	1	1	0	80
16																						1	1	1	1	1	100

Note. (1) Austrom et al. (2015), (2) Banbury et al. (2019), (3) Blackberry et al. (2023), (4) Cousins et al. (2022), (5) Czaja et al. (2013), (6) Damianakis et al. (2018), (7) Gerritzen et al. (2023), (8) Lundberg (2014), (9) Marziali et al. (2005), (10) Marziali & Garcia (2011), (11) McLoughlin et al. (2023), (12) O'Connell et al. (2014), (13) O'Connor et al. (2023), (14) Rapley et al. (2023), (15) Schaffer & Henry, (16) Stevens-Neck et al. (2023). Scores are presented as percentage of the quality assessment criteria met and correspond to a star rating: 5\*\*\*\*\* for 100% quality criteria met; 4\*\*\*\* for 80% quality criteria met; 3\*\*\* for 60% quality criteria met; 2\*\* for 40% quality criteria met; 1\* for 20% quality criteria met.

## Appendix C. Full database search strategies

### Web of science search terms

Videoconferenc\* OR "Video conference\*" OR Zoom OR Skype OR "Video call\*" OR "Video chat\*" AND dementia OR Alzheimer\* AND "support group" OR "peer support" OR "self-help group" OR "therapy group" OR "group based" OR group-based

### CINAHL search terms

TX (Videoconferenc\* OR "Video conference\*" OR Zoom OR Skype OR "Video call\*" OR "Video chat\*") AND (dementia OR Alzheimer\*) AND TX ("support group" OR "peer support" OR "self-help group" OR "therapy group" OR "group based" OR group-based)

### PsychInfo search terms

1 Videoconferenc\*.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 2 Video conference\*.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 3 Zoom.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 4 Skype.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 5 Video call\*.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 6 Video chat\*.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 7 exp Videoconferencing/  
 8 1 or 2 or 3 or 4 or 5 or 6 or 7  
 9 dementia.mp. or (exp Senile Dementia/ or exp Semantic Dementia/ or exp Dementia/ or exp "Dementia (Senile)"/ or exp "Dementia (Multi Infarct)"/ or exp Multi Infarct Dementia/ or exp "Dementia of Alzheimers Type"/ or exp Frontotemporal Dementia/ or exp Dementia Paralytica/ or exp "Dementia (Presenile)"/ or exp Dementia Praecox/ or exp AIDS Dementia Complex/ or exp Alzheimer's Disease/ or exp Creutzfeldt Jakob Syndrome/ or exp Dementia with Lewy Bodies/ or exp Picks Disease/ or exp Presenile Dementia/ or exp Pseudodementia/ or exp Senile Psychosis/ or exp Vascular Dementia/) [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 10 Alzheimer\*.mp. or (Alzheimers Disease/ or Alzheimer Disease/ or Alzheimer's Disease/ or "Dementia of Alzheimers Type"/) [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 11 9 or 10  
 12 support group.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 13 peer support.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 14 self-help group.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 15 therapy group.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 16 group based.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 17 group-based.mp. [mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]  
 18 Support Groups/ or (Support Groups or "Referral to support group").mp.  
 19 12 or 13 or 14 or 15 or 16 or 17 or 18  
 20 8 and 11 and 19

**EMBASE search terms**


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1	(Videoconferenc* or Video conference* or Zoom or Skype or Video call* or Video chat*).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
2	exp telemedicine/ or exp videoconferencing/
3	(dementia or Alzheimer*).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
4	exp multiinfarct dementia/ or exp frontal variant frontotemporal dementia/ or exp Pick presenile dementia/ or exp presenile dementia/ or exp semantic dementia/ or exp frontotemporal dementia/ or exp dementia/ or exp senile dementia/ or exp HIV associated dementia/ or exp mixed dementia/
5	exp Alzheimer disease/
6	(support group or peer support or self-help group or therapy group or group based or group-based).mp. [mp = title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]
7	exp support group/ or exp social support/ or exp self help/
8	1 or 2
9	3 or 4 or 5
10	6 or 7
11	8 and 9 and 10

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**MEDLINE search terms**


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1	(Videoconferenc* or Video conference* or Zoom or Skype or Video call* or Video chat*).mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
2	exp Telecommunications/ or exp Telemedicine/ or exp Videoconferencing/
3	(dementia or alzheimer*).mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
4	exp Dementia, Vascular/ or exp AIDS Dementia Complex/ or exp Dementia/ or Frontotemporal Dementia/ or exp Dementia, Multi-Infarct/
5	exp Alzheimer Disease/
6	(support group or peer support or self-help group or therapy group or group based or group-based).mp. [mp = title, book title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms, population supplementary concept word, anatomy supplementary concept word]
7	exp Self-Help Groups/
8	1 or 2
9	3 or 4 or 5
10	6 or 7
11	8 and 9 and 10

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