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## Do communication interventions affect the quality-of-life of people with dementia and their families? A systematic review

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### ABSTRACT

**Objectives:** Speech, language and communication difficulties are prevalent in all dementia subtypes and are likely to considerably impact the quality-of-life of people with dementia and their families. Communication interventions provided by trained professionals are recommended for this population, but little is known about their quality-of-life outcomes. This review aims to explore the quality-of-life outcomes of communication-related interventions for people with dementia and their families.

**Methods:** Seven databases were systematically searched. Reference lists from included studies and relevant systematic reviews were also hand-searched. Primary research with quantitative quality-of-life outcomes were included. Narrative analysis was utilised to identify key intervention features and to describe quality-of-life outcomes.

**Results:** 1,174 studies were identified. Twelve studies were eligible for inclusion. Studies were heterogeneous in location, participant group, methodologies, interventions and outcome measures. Four studies reported increased quality-of-life for people with dementia following intervention. No studies reported increased quality-of-life for family members.

**Conclusion:** Further research is needed in this area. The studies which reported improved quality-of-life involved multi-disciplinary approaches to intervention, involvement of family caregivers, and functional communication intervention. However, data is limited so results should be interpreted with caution. The standardised use of a communication-focused quality-of-life outcome measure would improve sensitivity and comparability of future studies.

### ARTICLE HISTORY

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### KEYWORDS

Dementia; caregivers; quality of life; communication; therapy

### Introduction


Fifty-five million people worldwide currently live with dementia, with prevalence expected to rise to 78 million in 2030 (World Health Organisation (WHO), 2021). Dementia is defined by the International Classification of Diseases – 11 (ICD-11) (WHO, 2019) as ‘a syndrome—usually of chronic or progressive nature ... [that] affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement’, all of which can impact a person’s communication. There are many dementia subtypes: Alzheimer’s Disease is the most common (62%), followed by vascular dementia (17%) and mixed dementia (10%), along with rarer dementia subtypes such as primary progressive aphasia (PPA) (Prince et al., 2014). While symptoms and progression vary, all dementia subtypes can involve communication difficulties associated with impairments in expressing and comprehending language (aphasia); motor speech (dysarthria); reading and writing; and cognitive communication difficulties, such as difficulty retaining information and staying on topic (Banovic et al., 2018; WHO, 2019). Communication difficulties often increase as the disease progresses (Banovic et al., 2018; Ross et al., 1990) and individuals can experience a loss of the ability to communicate thoughts and needs (Woodward, 2013). Communication difficulties have

a range of implications for people with dementia, such as problems with social interactions and maintaining relationships; reductions in hobbies and leisure activities; withdrawal from occupations; and increased behaviours that challenge, such as aggression (Bourgeois et al., 2003; Burgio & Fisher, 2000; Schwam, & Xu, 2010; Woodward, 2013). These issues can considerably impact the quality-of-life of people with dementia and their caregivers (Savundranayagam et al., 2005).

Professional bodies for speech and language therapists (SLTs) worldwide recommend communication interventions for people with dementia and the people that support them (American Speech-Language-Hearing Association (ASHA), 2017; Royal College of Speech and Language Therapists (RCSLT), 2014). Interventions include professional education; impairment-based interventions such as word retrieval; compensatory-based approaches such as communication strategies; and group education and support for managing communication difficulties (ASHA, 2017; RCSLT, 2014; Volkmer et al., 2020). Whilst there are some studies assessing the outcomes of these interventions, including their effects on quality-of-life, the evidence exploring the impact of communication intervention on quality-of-life has not been synthesised in a systematic review.

The World Health Organisation (WHO, 2012, p.11) defines quality-of-life in health as ‘an individual’s’ perceptions of their

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position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'. Quality-of-life is complex and depends on a wide number of factors, with important features of quality-of-life described by people with dementia including feeling accepted, being understood, and enhancing meaning in life (Dröes et al., 2006). More recently, the IDEAL study identified factors influencing caregivers' (Clare, Wu, Jones, et al., 2019) and people with dementia's (Clare, Wu, Quinn, et al. 2019) ability to live well. For caregivers the primary factors were psychological health, physical health, social resources and relationship with the person with dementia. The only independent predictor of living well for the person with dementia was psychological health. Communication between the person with dementia and caregiver is likely to influence psychological health, social resources and relationships. Links have also been found between dementia progression, communication changes, increased behaviours that challenge, and caregiver burden, which impact quality-of-life (Savundranayagam et al., 2005). Communication is related to improved relationships, social engagement and functional ability, which are also associated with better quality-of-life for people with dementia (Martyr et al., 2018). Indeed, communication has been described as a key domain and subdomain within the quality-of-life of this population (Banerjee et al., 2010; Brod et al., 1999), and communication difficulties also have considerable implications for those who support people with dementia (Olthof-Nefkens et al., 2023; Stiadle et al., 2014). Olthof-Nefkens et al. (2023) identified an association between self-perceived communication abilities and the quality-of-life of people affected by dementia.

In recent years, there has been a societal shift away from the negative consequences of dementia, towards an improved recognition of quality-of-life, with healthcare policies focusing on 'living well' with dementia (Clare, 2017; Clarke et al., 2020; Department of Health, 2020; Quinn et al., 2022). The importance of timely psychosocial interventions to reduce disability in dementia is widely acknowledged (Prince et al., 2011; WHO, 2015). Some non-pharmacological interventions, such as cognitive stimulation therapy, have been found to improve the quality-of-life of people with dementia and their families in some studies (e.g. Woods et al., 2006), but to have no effect in others (e.g. Clare, Kudlicka, et al. 2019). With increased recognition of quality-of-life in dementia, it is timely to review the existing evidence exploring the effect of communication interventions on this important outcome. This has implications for clinical decision-making, policy and practice.

## Study aims

This systematic literature review aims to explore the effect of communication interventions on the quality-of-life of people with dementia and their families.

## Methodology

### Study design

A systematic review was conducted to explore the effect of communication interventions on the quality-of-life of people with dementia and their families. The protocol was registered with PROSPERO on 23/06/2021 (registration number 261926).

### Literature search

The searches were conducted during May 2020, and repeated August 2022, in the databases: PsycINFO, CINAHL, EMBASE, EMCARE, MEDLINE, BNI and AMED.

The search terms were identified and adapted to corresponding terms depending on the database. Each individual search term was supplemented with relevant free text terms. Where appropriate, the free text terms were truncated so as not to exclude alternative word endings.

The search results were limited to articles written in English, published in or after 2005, and included only adults or older adults as the target population. The full search string is included in [Appendix 1](#). The database searches were supplemented with a manual review of reference lists of relevant articles and systematic reviews.

### Eligibility criteria

This review included primary research with quantitative quality-of-life outcome measures, to establish the quality-of-life effects of interventions which target communication. Studies included interventions targeting verbal or non-verbal communication/interaction of people with dementia and/or their family caregivers. Studies were not excluded based on the professional backgrounds of those delivering interventions. Study participants were either people with dementia (of any type and severity, living at home) or their family members. Studies were excluded if participants' primary diagnosis was not dementia, or if they had other co-morbidities potentially affecting language. Studies published after 2005 were included, to reflect current practice. Please see [Appendix 2](#) for full eligibility criteria and rationale.

### Screening

1,689 studies were identified through database searching and 32 through other search methods, for example reference lists of relevant systematic reviews ([Figure 1](#)). 547 duplicate studies were removed. Three reviewers (AH, ZC and JL) screened all titles and abstracts as a team, discussed any disagreements, and came to a consensus. 1,079 studies were excluded based on title and abstract. Six further studies were excluded because full texts were unavailable. Three reviewers (AH, ZC and DM) independently screened the full texts of the remaining 89 studies. If there was uncertainty regarding eligibility, the paper was read independently by another team member and a consensus was reached. Seventy-seven studies were excluded after screening full texts. Twelve studies remained: three randomised controlled trials (RCTs) and nine non-RCTs including case studies, comparison-group studies and pre- post- intervention studies.

### Risk of bias

The 12 studies were evaluated using risk of bias tools: the ROB-1 tool for RCTs ([Appendix 3](#)), and the ROBINS-1 tool for non-RCTs ([Appendix 4](#)), to inform the interpretation of the findings. Two reviewers (AH and DM) assessed each study's risk of bias independently, then compared their results. Where disagreement arose, a third reviewer's (ZC) opinion was sought. One author was contacted and additional information on missing and unclear data was obtained.

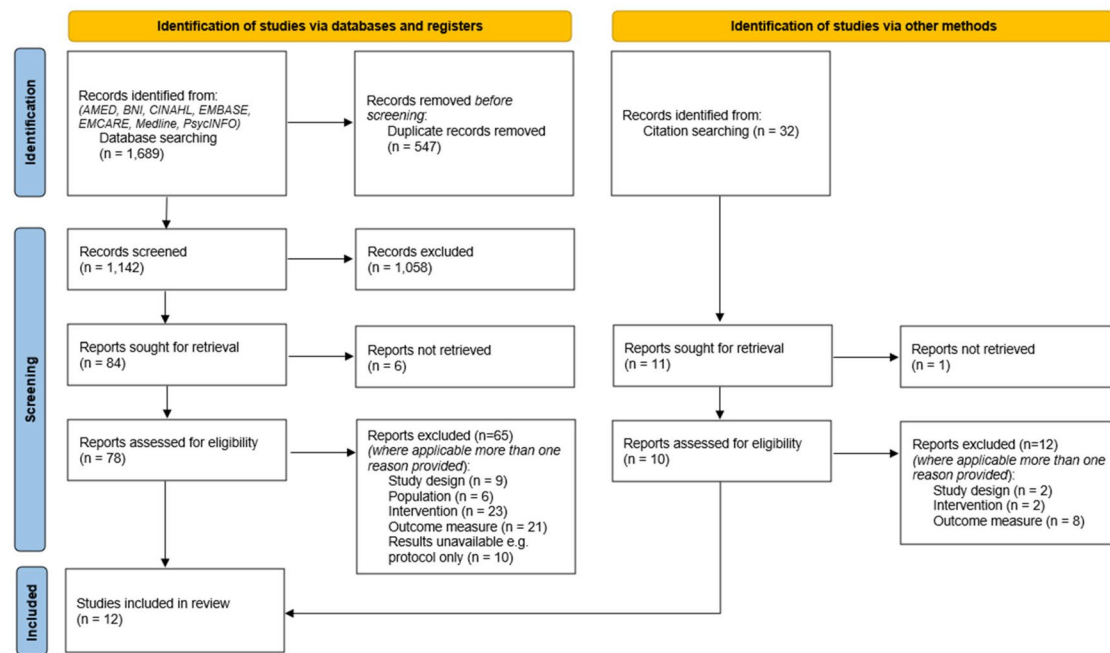


Figure 1. PRISMA flow diagram detailing study screening and selection.

### Data extraction

Two reviewers (AH and DM) extracted data from the included studies. The Template for Intervention Description and Replication (TIDieR) framework (Hoffmann et al., 2014) was used to structure extraction of data related to intervention characteristics.

### Analysis

Meta-analysis was not appropriate due to heterogeneity in study designs, interventions, control groups and outcome measures. Narrative analysis was therefore conducted using the TIDieR framework (Hoffmann et al., 2014) as a structure for data synthesis.

## Results

### Characteristics of included studies

Twelve studies were included (Table 1). Five were conducted in English-speaking countries, with two including at least one UK site. Interventions targeted various dementia diagnoses. Two studies specified mild or mild-moderate stage of dementia. Four included the person with dementia only, and two included informal caregivers only. Six included both the person with dementia and their informal caregiver (dyads). In the studies involving dyads, quality-of-life outcome measurement did not always relate to both the person with dementia and their caregiver. Participant numbers ranged between one individual participant and 255 dyads.

### Risk of bias assessment

Methodological quality was variable across all studies (Appendices 3-4). Of the RCTs, only one study had low risk in three or more domains (Barnes & Markham, 2018). Common

reasons for bias included a lack of true randomisation, lack of blinding, and reporting bias. For the non-RCTs, there were low risk of bias domains due to selection of participants and classification of interventions. However, bias was introduced due to confounding, outcome measurement and selection of the reported result. All studies demonstrated high or questionable risk of bias across several domains. Although at times this was due to the nature of interventions, such as lack of ability to blind participants to intervention group, findings must be interpreted with caution as a result and the results of the included studies are interpreted within this context in the discussion section.

### Intervention characteristics according to the TIDieR checklist (Table 2)

#### Why (goal of intervention)

Three study interventions targeted linguistic or cognitive functioning (Andrade-Calderon, Salvador-Cruz and Soso Ortiz, 2015, La Rue et al., 2015, and Santos et al., 2015). One targeted functional communication of the person with dementia (Cadorio et al., 2019). Three targeted skills/strategies for the person with dementia and the caregiver (Jokel et al., 2017, Judge et al., 2013, and Leroi et al., 2020). The remaining five studies targeted caregiver knowledge.

#### What (intervention type)

Six studies investigated single component (communication-focused) interventions (Andrade-Calderón et al., 2015; Barnes & Markham, 2018; Cadorio et al., 2019; Haberstroh et al., 2011; Jokel et al., 2017; Messemaker et al., 2017). The other six investigated multi-component interventions of which communication was a part. Studies varied in intervention recipient (caregiver, person with dementia, or both); and intervention type (e.g. language training (impairment-based interventions), communication strategies, counselling, social inclusion (functional interventions)).

Table 1. Study characteristics.

Authors, date, and location	Study Design	Quality of life outcome measures used	Participant diagnosis	Participant demographics (N, gender, mean age)
Andrade-Calderón et al. (2015), Mexico	<b>Case study</b> of an individual receiving communication intervention	DEMQOL and DEMQOL proxy. This study only included the final DEMQOL question, relating to overall quality-of-life. WHOOOL-BREF ACQOL	Primary non-fluent aphasia (a sub-type of primary progressive aphasia)	N = 1, male, 84 years
Barnes and Markham (2018), UK	<b>Randomised-controlled trial</b> Intervention programme delivered to informal caregivers of people with dementia	SAQOL-39	Caregivers of people with AD (21), VD (9), mixed etiology (18)	N = 55 <b>Intervention:</b> 28; male 16%; 67 years <b>Control:</b> 27; male 23%; 68 years N = 2; male 50%, female 50%; 57 years
Cadório et al. (2019), Portugal	<b>Pre-post case report</b> of people with primary progressive aphasia receiving a communication intervention	QOL-AD proxy	Caregivers of people with AD (77.8%), VD (16.7%), mixed etiology (5.6%)	N = 24 dyads <b>Intervention:</b> 9, PwD, 33.3% female; 76.8 years. CG, 66.7% female; 72.2 years <b>Control:</b> 13, PwD, 61.5% female; 76.4 years. CG, 46.2% female; 64.9 years N = 101
Haberstroh and Johannes (2011), Germany	<b>Comparison group study (non-randomised)</b> Communication training for informal caregivers of people with a variety of dementia diagnoses	QOL-AD proxy	Informal caregivers of people with mild to moderate dementia <i>Note: sub-types not specified by authors</i>	<b>Simulation-based only:</b> 27; 22.2% male, 77.8% female; 61 years <b>Lecture-based only:</b> 27; 14.8% male, 85.2% female; 59.37 years <b>Combined intervention:</b> 24; 16.7% male, 83.3% female; 62.08 years <b>Control:</b> 23; 17.4% male, 82.6% female; 54.35 years N = 10 dyads <b>Intervention:</b> 5, PwD, 40% female, 60% male; 72.4 years. CG, 70.4 years <b>Control:</b> 5, PwD, 20% female, 80% male; 65.5 years. CG, 63.6 years N = 118 dyads <b>Intervention:</b> 59, PwD, 54.2% female; 78.74 years. CG, 72.9% female; 66.54 years <b>Control:</b> 59, PwD, 57.6% female; 75.65 years. CG, 74.6% female; 64.30 years N = 64; 56.3% female, 43.8% male; <70, 9.4%; 70-79, 29.7%; >80, 60.9%
Han et al. (2020), South Korea	<b>2 x 2 Factorial randomised-controlled trial</b> A multi-component simulation-based and/or lecture-based educational programme delivered to informal caregivers of people with dementia	Care-related Quality of Life Instrument	People with primary progressive aphasia and their caregivers	N = 19 dyads, PwD, 63% male; 76 years. CG, 68% male; 67 years
Jokel and Meltzer (2017), USA	<b>Comparison-group study</b> A communication focused intervention for people with primary progressive aphasia and their informal caregivers	ASHA quality of communication life scale (QCL)	People with AD (50%), VD (5.1%), mixed etiology (0.8%), dementia (24.6%), MCI (5.9%), other (13.6), and their caregivers	N = 19 dyads, PwD, 63% male; 76 years. CG, 68% male; 67 years
Judge et al. (2013), USA	<b>Randomised-controlled trial</b> An educational skills programme for people with dementia and their informal caregivers	QOL-AD proxy	People with AD (50%), VD (5.1%), mixed etiology (0.8%), dementia (24.6%), MCI (5.9%), other (13.6), and their caregivers	N = 19 dyads, PwD, 63% male; 76 years. CG, 68% male; 67 years
La Rue et al. (2015), USA	<b>Pre and post intervention study</b> A community-based intervention for people with mild dementia	QOL-AD self-reported	People with AD (65.6%), dementia unspecified/other (26.6%), MCI (6.3%), pending (1.6%)	N = 49 <b>PwD:</b> 10; 60% female, 40% male; 75.4 years <b>CG:</b> 39; 69.2% female, 30.8% male; 62.7 years N = 89 <b>Mild AD group:</b> 62 <b>Intervention:</b> 46; 41.3% male, 58.7% female; 57.7 years <b>Control:</b> 16; 37.5% male, 62.5% female; 74.8 years <b>Moderate AD group:</b> 13; 77% female; 77 years <b>CIWD:</b> 14; 71.4% female; 72.2 years
Leroi et al. (2020), France, UK and Cyprus	<b>Nested-case series within a single arm open label field study</b> A communication intervention for informal caregivers of people with dementia, who also have adult acquired mild/moderate hearing and/or vision impairment	DEMQOL and DEMQOL proxy	People with AD (47.4%), VD (47.4%), mixed etiology (5.3%) (with vision/hearing impairment) and their caregivers	N = 19 dyads, PwD, 63% male; 76 years. CG, 68% male; 67 years
Messemaker et al. (2017), Germany	<b>Pre-post intervention study</b> A multi-component training programme for people with dementia and their caregivers	QOL-AD self-reported	People with AD (50%), VD (20%), mixed etiology (10%), other (20%) and/or their caregivers	N = 49 <b>PwD:</b> 10; 60% female, 40% male; 75.4 years <b>CG:</b> 39; 69.2% female, 30.8% male; 62.7 years N = 89 <b>Mild AD group:</b> 62 <b>Intervention:</b> 46; 41.3% male, 58.7% female; 57.7 years <b>Control:</b> 16; 37.5% male, 62.5% female; 74.8 years <b>Moderate AD group:</b> 13; 77% female; 77 years <b>CIWD:</b> 14; 71.4% female; 72.2 years
Santos et al. (2015), Brazil	<b>Comparison-group study</b> A multi-component programme, including a speech and language therapy module, for people with mild or moderate Alzheimer's disease (AD), and people with Cognitive Impairment without Dementia (CIWD). <i>Note: Only people with mild AD had an experimental and a control group. All groups had Quality of Life outcome measures.</i>	QOL-AD self-reported and proxy	People with mild AD (69.7%), moderate AD (14.6%), CIWD (15.7%)	N = 255 dyads, PwD, 49.0% female; 81.3 years. CG, 74.5% female; 68.7 years
Teri et al. (2018), USA	<b>Staggered multiple baseline</b> A treatment manual including communication strategies for people with dementia and their informal caregivers	QOL-AD self-reported <sup>a</sup>	People with dementia and their caregivers <i>Note: sub-types not specified by authors</i>	N = 255 dyads, PwD, 49.0% female; 81.3 years. CG, 74.5% female; 68.7 years

<sup>a</sup>Note: PwD, person with dementia; CG, caregiver; CIWD, cognitive impairment without dementia; DEMQOL, dementia quality of life measure (Smith et al., 2007); WHOOOL-BREF, World Health Organisation quality of life scale in brief (The WHOQOL Group, 1998); ACQOL, adult carers quality of life questionnaire (Joseph et al., 2012); SAQOL-39, stroke and aphasia quality of life scale (Hilari et al., 2003); QOL-AD, quality of life in Alzheimer's disease (Logsdon et al., 1999); ASHA, American speech-language-hearing association; ASHA quality of communication life scale (Paul et al., 2004) SD, standard deviation



Table 2. Intervention characteristics.

Authors	Brief name	Intervention goals: Why	Summary of intervention: What (Materials, Procedures) & Tailoring	Mode of Delivery: Who provided, How & Where	Frequency: When & How much	Deviation from original design: Modifications & How well
Andrade-Calderón et al. (2015)	Intensive speech therapy intervention	To maintain or improve linguistic functioning, quality of life and activities of daily living for the person with dementia, and family environment.	<i>Single-component intervention:</i> Intensive, tailored speech therapy involving stimulation strategies relating to various components of linguistic processing (i.e. phonological, lexical, and syntactic). <i>Tailoring:</i> Tailored topic selection.	Neuropsychologist Individual face-to-face sessions Dementia Clinic	50 1-h sessions over 12 months	No
Barnes and Markham (2018)	The Talking Sense programme: an individualised cognitive behavioural communication intervention for informal carers of people with dementia	Using self-efficacy theory to reduce carer anxiety and depression through addressing thinking, knowledge, skills (e.g. with role play) and behaviour.	<i>Single-component intervention:</i> Three sessions with carers and the author to discuss the topics and training materials. Carers encouraged to trial the communication strategies discussed between the sessions. Written individual strategies and recommendations provided. <i>Tailoring:</i> Nine mandatory steps, but topics were slightly flexible within each step.	Speech and Language Therapist (SLT) Individual face-to-face sessions Community visits	3 1-h visits over 8 wk	No
Cadório et al. (2019)	Combined restorative and compensatory treatment for primary progressive aphasia (PPA)	To improve and maintain linguistic deficits through language tasks, and to improve the person with dementia's ability to participate in daily life activities through developing communication strategies.	<i>Single-component intervention:</i> Restorative naming activities and communication strategies for people with dementia. <i>Tailoring:</i> Tailored target words and education for spouses around individual needs.	Speech and Language Therapist (SLT) Individual face-to-face sessions Clinical visits	12 1-h weekly sessions	No
Haberstroh et al. (2011)	TANDEM: Communication training for informal caregivers of people with dementia	To increase caregivers' use of strategies for maintaining communication in order to increase care receivers' QoL and to reduce caregivers' burden.	<i>Single-component intervention:</i> Training for caregivers, development of individual communication strategies. Topics included attention, comprehension, remembering, and self-help. <i>Tailoring:</i> Development of individual strategies.	Multi-disciplinary professionals Group sessions (implied face-to-face) Location not specified	Five 2.5-h weekly sessions	No
Han et al. (2020)	A lecture-based education program on family caregivers of people with dementia	To teach caregivers to identify and assess contributing factors, person-centred and strengths-based care strategies including communication strategies	<i>Multi-component intervention:</i> A lecture for informal caregivers, including communication strategies. <i>Tailoring:</i> none.	Psychiatrist Face-to-face group sessions University hospital	1-h lecture	No
Jokel et al. (2017)	Group intervention for individuals with primary progressive aphasia (PPA) and their spouses	To provide PPA-relevant education, teach communication strategies, and problem-solve experiences.	<i>Single-component intervention:</i> intervention program comprising language activities, communication strategies, counselling, and education on individual needs.	Speech and language students and multi-disciplinary professionals Face-to-face group sessions Clinical visits	10-week intervention programme	Orthographic cue added as prompt during language exercises. No deviations reported.
Judge et al. (2013)	ANSWERS: Acquiring New Skills While Enhancing Remaining Strengths	To address care issues and needs through providing educational skills (for caregivers) and cognitive rehabilitation skills (for people with dementia) training	<i>Multi-component intervention:</i> A training programme including a session on effective communication strategies. <i>Tailoring:</i> Tailored to each dyad with individualised goal setting.	Trained counsellor Individual face-to-face sessions Community visits	6 90-minute sessions plus preparation activities	No
La Rue et al. (2015)	LEEPS: A Language-Enriched Exercise Plus Socialization Programme	To improve cognitive performance, physical fitness, and well-being through individualised exercise and language training.	<i>Multi-component intervention:</i> A training manual of physical exercises, with imbedded language stimulation exercises and socialising. <i>Tailoring:</i> Outings tailored to preferences and availability.	Trained volunteers (non-specific > 18) Individual face-to-face sessions Community settings	Twice 1.5-h weekly sessions	No modifications reported. Outings occurred less frequently than proposed.
Leroi et al. (2020)	SENSE-Cog: sensory intervention to support hearing and vision in people with dementia	Individual participants receiving the extended programme set their own goals related to device use, device care, communication, function, and social inclusion	<i>Multi-component intervention:</i> A vision and/or hearing assessment +/- fitting and advice around glasses/hearing aids/sensory aids. Individualised adherence support, communication training with caregiver, and social inclusion support. <i>Tailoring:</i> Tailored to each dyad's individual needs.	Research sensory support therapist Individual face-to-face sessions Community visits	3-4 sessions over 3-4 wk, plus one 2-h session per week for up to 12 wk	No
Messemaker et al. (2017)	MULTITANDEM: Modified communication training for caregivers of people with dementia	To improve dementia caregivers' communication skills through acquiring new knowledge.	<i>Multi-component intervention:</i> A training programme for professional and family caregivers, including a module on social and communication skills. <i>Tailoring:</i> Training tailored to individual needs and individual counselling sessions offered.	Outpatient nursing professionals Face-to-face group sessions counselling sessions Location not specified	5 weekly sessions lasting 2.5h	No
Santos et al. (2015)	Multidisciplinary rehabilitation programme	To maintain cognitive function and community independence. To reduce depression symptoms and improve the quality of life of the person with dementia and caregiver through memory, language and physical training.	<i>Multi-component intervention:</i> A programme including a module with a speech and language professional. Activities to enhance general communication, and communication strategies. <i>Tailoring:</i> None, though sharing of individual experience was encouraged in sessions.	Face-to-face group sessions Clinical visits	People with dementia: two 5-h sessions a week for 12 wk Caregivers: two 1.5-h workshops a week for 12 wk	No
Teri et al. (2018)	ROAD-NW: Reducing Disability in Alzheimer's Disease-Northwest intervention	To reduce excess disability, improve physical functioning and train caregivers to cope effectively with behaviour difficulties.	<i>Multi-component intervention:</i> A detailed treatment manual, including exercise, behavioural/psychosocial support, and education in communication strategies. <i>Tailoring:</i> Individualised goal setting.	Multi-disciplinary professional Individual face-to-face sessions Community visits	Between 6-9 one-hour sessions Coach adherence to ROAD-NW protocol content across sessions averaged 82%-94%.	No modifications reported. Coach adherence to ROAD-NW protocol content across sessions averaged 82%-94%.

### **Who (intervention provider)**

Interventions were delivered by a variety of individuals including psychiatrists, psychologists, SLTs, SLT students, other multi-disciplinary clinicians, and trained volunteers.

### **How (mode of delivery) and where (location of intervention)**

All interventions involved face-to-face contact; this was implied and not explicit in Haberstroh et al.'s (2011) paper. Four included group interventions, one included group and individual sessions, and seven comprised individual sessions. Locations included: domiciliary settings; community spaces; hospital out-patient settings; and service settings that promote independent living. Two did not specify location.

### **When and how much (duration, number of sessions)**

Interventions varied significantly in their duration and intensity, from a one-off hour-long lecture (Han et al., 2020) to 50 sessions over a 12-month period (Andrade-Calderón et al., 2015).

### **Tailoring (e.g. individualised to client)**

Five interventions were tailored to individual needs. Han et al.'s (2020) intervention involved a lecture which could not be tailored. Six interventions had set themes or topics, but involved some flexibility, for example encouraging identification of individual strategies or goals, or teaching individualised skills.

### **Modifications/how well (attrition, compliance)**

Only Jokel et al. (2017) reported an intervention modification following study commencement (the addition of an orthographic prompt). La Rue et al. (2015) reported limitations in volunteer availability resulting in fewer outings for some participants. Other studies did not report protocol deviations.

## **Outcomes**

### **Outcome measure used and timing of outcome assessment**

Seven quality-of-life outcome measures were utilised in the studies with either the person with dementia or the caregiver (Table 1). All the studies completed outcome assessments prior to intervention and soon after intervention completion. Five studies incorporated second follow-ups, the timing of which varied considerably (Appendix 5).

### **Patient quality-of-life (self-reported or proxy)**

Ten studies investigated patient quality-of-life (patient-reported or proxy). Three reported no change in patient quality-of-life (Andrade-Calderón et al., 2015; Judge et al., 2013; Messemaker et al., 2017). One reported a statistically significant decrease in quality-of-life (La Rue et al., 2015:  $p=0.048$ , 95% CI =  $-0.40$  to  $-5.15$ ). Leroi et al (2020) documented increased patient-reported quality-of-life, but decreased proxy scores, however, these were based on raw scores so statistical significance could not be ascertained. Four studies reported statistically significant increased quality-of-life (Haberstroh et al., 2011:  $p < 0.01$ ; Jokel et al., 2017:  $p < 0.05$ ; Teri et al., 2018:  $p < .001$ , 95% CI =  $0.50$  to  $1.56$ ); with Santos et al. (2015) reporting significant increase in patient-reported scores in the mild Alzheimer's Disease group ( $p=0.003$ ) but no change for the moderate Alzheimer's Disease group or any group's proxy scores.

Of the four studies reporting statistically significant improvement in patient-reported quality-of-life, none were RCTs, but three involved non-randomised comparison group studies. The fourth (Teri et al., 2018) demonstrated statistically significant positive changes in pre-post treatment comparisons in a staggered multiple baseline design. These four studies varied considerably in: methodology; participant numbers; intervention types and recipients. All four studies included communication strategy training for caregivers and/or people with dementia and involved face-to-face group or individual sessions.

### **Caregiver quality-of-life**

Three studies reported on caregiver quality-of-life. Han et al. (2020) identified a decrease in caregiver quality-of-life following intervention ( $p=0.004$ ). Barnes and Markham (2018) and Andrade-Calderón et al. (2015) did not find an overall increase in caregiver quality-of-life scores, however the former reported statistically significant improvement in one caregiver quality-of-life sub-score, value ( $p=0.046$ , 95% CI =  $-2.3$  to  $-0.02$ ).

## **Discussion**

This systematic review has examined the evidence relating to quality-of-life outcomes of interventions which target communication for people with dementia and their families. Twelve studies met the eligibility criteria and were heterogeneous in their methodological designs and outcome measures. Conclusions should be made with caution due to the limited number of RCTs, as well as study heterogeneity and risk of bias identified. However, this review highlights several considerations.

### **Interventions**

Several studies included communication as a subsection within more general multi-component interventions. In the present systematic review, some single-component (Haberstroh et al., 2011; Jokel et al., 2017) and some multi-component interventions (Santos et al., 2015; Teri et al., 2018) reported positive effects on quality-of-life.

The range of professionals providing communication-related interventions in this review demonstrates the roles of professionals other than SLTs in delivering communication-related interventions. This suggests a value in multidisciplinary approaches. Integrated multidisciplinary approaches to dementia care are beneficial, as no single professional body has the expertise to address the complex range of physical, cognitive, and psychological changes that occur with dementia (Grand et al., 2011). However, only four of the 12 studies included in this review had SLT involvement in the communication intervention. As SLTs have particular expertise in communication disorders, their limited representation within this review suggests a need for the SLT profession to develop its evidence-base relating to quality-of-life and communication interventions in dementia. This could include research into current SLT clinical practice, with possible future recommendations for training or more specific clinical guidance.

Many of the interventions involved a family member of the person with dementia, highlighting the important roles of these individuals in the delivery of communication interventions. Brodaty et al.'s (2003) systematic review of psychosocial interventions for caregivers of people with dementia found

that caregiver involvement often led to positive outcomes and study success. Of the four studies that demonstrated a statistically significant improvement in quality-of-life, all involved caregivers. This may suggest that dyadic or caregiver interventions for communication can have a positive impact on the quality-of-life of people with dementia; further research is needed in this area.

All the studies that showed statistically significant improvements in quality-of-life focused on functional communication strategies and education, as opposed to impairment-based interventions targeting linguistic abilities. Research suggests that cognitive stimulation therapy, an impairment-based intervention focused on maintaining cognitive function, can lead to improved quality-of-life for people with dementia (Spector et al., 2003); it is unclear why the impairment-based intervention approaches in this review did not influence quality-of-life. This could be due to small sample sizes, or that people with dementia experiencing more significant communication difficulties may be at a later stage of disease progression, resulting in difficulty engaging in impairment-based interventions.

Many of the interventions were tailored to the individual needs of participants, and an element of intervention tailoring was found in all studies that showed improvements in quality-of-life. Individual tailoring is likely to be necessary due to the heterogeneity of this population. All studies that demonstrated improvements in quality-of-life involved a block of at least weekly sessions over a 5–12-week period. Research suggests that intensive SLT positively influences outcomes in the stroke population (Breitenstein et al., 2017). However, given service limitations for this client group, particularly with prevalence increasing, the delivery of higher-intensity programmes may not be feasible in current service delivery models. All interventions consisted of face-to-face sessions. Further research into the efficacy of remote input for this population would be valuable, given the development of technology in recent years and the increase in remote interventions following the COVID-19 pandemic.

### **Outcome measures**

Seven quality-of-life outcome measures were used across the 12 studies. This decreased study comparability, which contributed to the authors' inability to meta-analyse the results. Additionally, these outcome measures make minimal reference to communication, which may reduce their sensitivity for this communication-focused review. Communication-related quality-of-life measurement tools have been standardised for the post-stroke aphasic population (e.g. ASHA QCL (Paul et al., 2004), SAQOL (Hilari et al., 2003)) but have not been standardised for use with the dementia population despite growing evidence of the association between communication difficulties and quality-of-life for this population (Banerjee et al., 2010; Brod et al., 1999; Martyr et al., 2018; Olthof-Nefkens et al., 2023; Savundranayagam et al., 2005; Stadle et al., 2014). The identification and standardised use of a dementia-specific quality-of-life tool that includes communication-related items would be beneficial. This would facilitate effective and quantifiable measurement of the quality-of-life impact of communication interventions, and increase comparability of studies, which would support future reviews. It is increasingly recognised that quality-of-life is a valuable health outcome measure for this population, due to a lack of a cure for dementia to date, so an

effective measure for this population would be valuable (Department of Health, 2020; Perneczky, 2019).

A further limitation of the included studies is that only two of them completed a follow-up after a period without study intervention. This limits the conclusions that can be drawn relating to the maintenance of intervention gains.

### **Quality-of-life**

There is some evidence relating to the expected trajectory of quality-of-life for people with dementia and their families. Lyketsos et al. (2003) found a small reduction in quality-of-life ratings in long-term care residents with dementia over a two-year period. However, quality-of-life ratings stayed the same or improved for nearly half of these residents. Clare et al. (2022a) found that quality-of-life of people with mild-moderate dementia on average remained stable over a two-year period but with individual differences in particular sub-groups. They found that the quality-of-life of caregivers of people with mild-moderate dementia decreased slightly over a year period (Clare et al. 2022b). Quality-of-life outcomes of the interventions under discussion should be interpreted within the context of these varying trajectories and, for example, for some members of the caregiving population in particular, either stabilising or slowing the decline in quality-of-life would be a positive intervention effect. To best analyse the intervention effects within the context of varied quality-of-life trajectories for this population, studies should include large participant numbers and control groups. Nearly half of the studies in this review had under 10 participants and only six studies had control groups; three were RCTs, but none of these demonstrated statistically significant improvements. Furthermore, the risk of bias assessments highlighted several areas for concern, primarily in the lack of true randomisation and blinding within the RCTs. This demonstrates a need for further high-quality research in this area, considering designs that are appropriate to the complex nature of the interventions and that are sensitive to outcomes meaningful to people with dementia and their families. Realist approaches considering the contexts, mechanisms and outcomes of communication interventions may be useful to allow future studies to consider not only 'what works', but 'what works for who, how, in what circumstances and to what extent' (Pawson et al., 2005, p.32).

### **Strengths and limitations of this review**

Four reviewers were involved in the screening process. Reviewers resolved disagreements through discussion and reference to inclusion and exclusion criteria, as advised by Siddaway et al. (2019) best practice guide for systematic reviews. A patient and public involvement group discussed the plan for this systematic review and provided feedback considering lived experiences of dementia-related communication difficulties. This project was also discussed with a group of third-sector dementia professionals, who highlighted challenges in advising clients about the effectiveness of dementia-focused communication interventions.

This study includes English-language papers only, limiting the transferability of findings and potentially excluding important findings from non-English language papers. Additionally, this paper only involves studies with quantitative outcome measurements; qualitative exploration of this topic could



provide a broader perspective of communication-related quality-of-life for this population.

Several methodological factors and limitations of the included papers, as well as their heterogeneity, has meant that robust conclusions cannot be drawn about the association between communication interventions and quality-of-life outcomes for this population. These include the variation in (and limitations of) the quality-of-life outcome measures used, and the complex and multi-factorial nature of quality-of-life. This means that non-controlled or non-measured aspects of participants' lives can impact quality-of-life scores, and improvement in one element of quality-of-life might not be strong enough to affect overall quality-of-life scores. This review highlights considerations for future studies, such as the development and implementation of communication-focused quality-of-life outcome measures across studies exploring interventions targeting communication. Furthermore, it is important that future research measures communication changes as well as quality-of-life in order to establish whether intervention effects relating to quality-of-life are associated with communication changes. It is hoped that this will support the development of further robust and comparable research studies in on this topic, which would result in future systematic reviews drawing firmer conclusions about the link between communication interventions and quality-of-life.

## Conclusion

This review has highlighted considerations relating to communication interventions for people with dementia and their families. However, these should be interpreted with caution due to the limited number of studies within this review, as well as the heterogeneity of the studies which limits their comparability. This review suggests the value of multi-disciplinary approaches to communication interventions which involve the families of people with dementia and focus on functional communication strategies. There is a need for further research into the quality-of-life impact of communication interventions for people with dementia, and especially into remote interventions, as these delivery models are becoming more prevalent as technology advances. This review has also highlighted the need for a more standardised approach to outcome measurement for research studies considering the quality-of-life of people with dementia, and the possibility of developing a communication-focused quality-of-life measurement for this population. Future research should also comprehensively study both the intervention and its influencing factors, considering the complex nature of these interventions. Approaches such as realist or process evaluation may be appropriate.

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