COMMUNICATION TRAININGS FOR DEMENTIA CARERS

Informative Title: COMMUNICATION TRAININGS FOR DEMENTIA CARERS

Running title: Communication training programmes for informal caregivers of people living with dementia: A systematic review.

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Authors' Contributions

L. Perkins was principal investigator for the study. L. Perkins designed the study, developed the search protocol and carried out the screening, selection, and data extraction. C. Felstead was the second reviewer for the included papers. L. Perkins wrote all drafts of the article. J. Stott and A. Spector supervised the review and contributed to edits made in each draft of the paper.

Abstract

Aims and Objectives: Current research suggests that communication training programmes for caregivers of people living with dementia can benefit both parties by improving communication, quality of life and stress. Previous reviews in this area focus on mixed samples of formal and informal caregivers. This review aimed to evaluate current research for trainings specifically for informal caregivers, including the research quality and the key training components.

Design and Methods: The review followed the PRISMA research reporting checklist. The electronic databases CINAHL, Embase, Medline and Psychinfo and reference lists of included literature were searched for studies relevant to the aims. Of the 45 identified studies, 36 were excluded based on pre-specified criteria. Nine studies were included in the final review and subject to quality appraisal using the Qualsyst tool.

Results: The included studies' programmes averaged five to six hours in length over four to five sessions, were mostly face to face in both group and individual settings and were developed using various communication and psychological theories. Studies demonstrated variable quality and outcomes, making it difficult to identify optimal components. However, careful consideration of different factors enabled some suggestions for training dose, delivery method, content and outcomes to measure.

Conclusions: Communication training programmes can benefit people living with dementia and their informal caregivers in outcomes such as communication skills and quality of life. Suggestions are made on the training components that optimise these benefits.

Relevance to clinical practice: Given the clear benefits on outcomes such as quality of life, there is a need for communication trainings to be offered in clinical contexts. However, given

the limited pool of variable quality research and lack of accessible manuals, it is unlikely that this is the case. Consolidating and widening the evidence through further research is essential in making these trainings more widely available.

Keywords: communication training; psychosocial interventions; informal caregivers; dementia; Alzheimer's disease; systematic review

Introduction

'Dementia' is 'an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain the activities of daily living' (World Health Organization, 2017). There are an estimated 885,000 people in the UK living with a diagnosis of dementia and rising (Wittenberg et al, 2019). The impact of living with dementia on the individual and their caregivers is huge and can lead to outcomes such as reduced quality of life (Karg et al, 2018). One contributing factor to this impact is the breakdown of communication between people living dementia and their caregivers (Downs & Collins, 2015). Language impairments, such as word finding, naming, and word comprehension difficulties, are common across dementias and occur both at the semantic level (meaning of words) and pragmatic level (the ability to adapt language to the specific social situations) (Banovic et al, 2018, Ferris & Farlow, 2013). These impairments can lead to people with dementia finding it increasingly difficult to express their needs and become cognitively overloaded in conversations with others (Ferris & Farlow, 2013). Not only can this lead to increased psychological distress and reduced QoL for people with dementia but can also reduce the quality of interactions and relationships with others (Eggenberger et al, 2013; Watson et al, 2012). This includes relationships with informal caregivers, who are 'non-professional people (such as a family member, friend or paid caregiver) who provide care…assistance and supervision that are necessary to fulfil the basic needs of people with dementia living in the community' (Chiao et al, 2015).

The most up to date figures report that there are 670,000 unpaid, informal caregivers for people with dementia in the UK, saving the economy £11bilion per year (Alzheimer's Society, 2014). Informal caregivers of people with dementia often report feeling overwhelmed and burnt-out by having to balance the physical and emotional demands of their caregiving role, alongside managing difficult emotions such as loss and grief through their role as a friend or family member (Mattock & McIntyre, 2015). Therefore, supporting

caregivers and people with dementia with these roles and relationships is paramount in reducing stress and the impact of living with dementia on both sides. Young et al (2011) suggested that this can be achieved through improving communication and reducing the use of 'Elderspeak', defined as 'a communication style adopted by a person interacting with an older adult where speech is characterised by a 'simplified speech register' often used with young children and is based on negative stereotypes of older adults being physically frail and cognitively impaired (Kemper, 1994)'. They stated that this relates to Kitwood's (1997) ideas on 'Personhood', which is 'a standing or status that is bestowed upon one human being, by others, that implies recognition, respect and trust', as this can 'initiate and perpetuate a virtuous circle, whereby the recognition of and support of the individuality and agency of people with dementia by caregivers increases both individuals' sense of self and competence, positively changing the nature of the social interaction for all parties'.

Effective communication is necessary for people with dementia to be able to receive high quality care from their caregivers (Nguyen et al, 2018). Increasing effective communication between people with dementia and their caregivers can improve quality of life (QoL) and lessen the impact these symptoms have on mental wellbeing (Eggenberger et al, 2013). It is, therefore, important to be able to offer interventions that support the development of effective communication between people with dementia and their caregivers, as this could improve QoL, reduce the impact on caregivers supporting a person with dementia and reduce costs to the healthcare system (Eggenberger et al, 2013).
A systematic review by Egan et al (2010) investigated different interventions for improving communication between people with dementia and their caregivers and found that memory aids and communication training interventions for caregivers gave the best outcomes. Although they noted that much of the evidence lacked internal validity or was poorly designed, the review demonstrated that communication training packages had the potential to support people with dementia and their caregivers to improve communication with one another. However, reviews such as that done by Fossey et al (2014) found that the majority

of current communication training programmes lacked any theoretical basis, had no evidence base or were developed in poor quality trials. Overall, these findings suggest that although communication training packages seem to be helpful in improving communication between people with dementia and their caregivers, there is little on offer that is based on theory and evidence. These reviews also seem to suggest that most of the training that does exist is aimed at care staff of people with dementia rather than informal caregivers.

A more recent review by Nguyen et al (2018) sought to not only evaluate the communication training packages on offer to caregivers of people with dementia, but also to investigate the potential benefits of these on caregivers and the people they care for. The most significant effects identified in caregivers were in outcomes relating to communication skills, knowledge and attitudes, with these effects seemingly being sustained post intervention. Through meta-analysis of the included studies, Nguyen et al (2018) also identified a significant reduction in psycho-physiological symptoms in caregivers and neuropsychiatric symptoms in people with dementia at follow up. This is further evidence that communication trainings for caregivers of people with dementia can lead to a variety of positive outcomes for both caregivers and they people they care for. However, most of the evidence identified in the review was from formal, paid caregivers of people with dementia and the evidence for informal caregivers was less clear.

Aims

Despite the number of published papers reviewing the evidence base of multi and single component communication training packages for both formal and informal caregivers of people with dementia (i.e. Egan et al 2010; Eggenberger et al, 2013; Fossey et al, 2014; Nguyen et al, 2018), there is currently no review specifically investigating training that prioritises communication skills over other components and focuses solely on informal, unpaid caregivers. The aim of the current review is therefore to synthesise the research

base for communication training programmes in this specific area. The two research questions that this review will address are:

1. What are the current evidence-based communication training programmes on offer for informal caregivers of dementia? This includes the quality of the research and the key features such as optimal dose, method of training and content of sessions.

2. What is the current evidence base for communication training programmes for informal caregivers of dementia and what are the benefits for informal caregivers and the people they care for? This includes the main outcome measures used to assess change, which outcomes are significant and which are not significant.

Method

This review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist for research reporting (Page et al, 2021) (Supplementary File 1).

Search strategy

Initial searches were conducted on electronic databases CINAHL, Embase, Medline and Psychinfo to identify relevant studies published from January 2000 until April 2020. Three umbrella search term categories with additional search terms were identified from key words in existing literature (see table 1.) Searches were conducted using free-text keywords similar to previous reviews (I.e. Eggenberger et al, 2013). Terms were initially entered separately and then combined. Results were limited to studies written in English that were published in peer-reviewed journals. A further search was conducted by hand on the

reference lists of the included studies and in other related review papers to identify any additional studies not picked up in the electronic search.

Inclusion and exclusion criteria

The inclusion and exclusion criteria were guided by the research questions and previous review papers that focused on communication training for caregivers of people with dementia. A flow diagram is provided to demonstrate how studies were eliminated from the final literature pool (see Figure 1).

Inclusion and exclusion of studies were based on the following criteria:

- *Study design:* Studies were included if outcome measures were administered both before and after participation in the intervention. This included randomised controlled trials and non-randomised, non-controlled pre-posttest designs. Studies that only administered measures at one time point were excluded, for example posttest only designs.

- *Participants*: Studies were included if the sample consisted solely of informal caregivers of a person living with a diagnosis of any type of dementia. Informal caregivers were defined as 'non-professional people (such as a family member, friend or paid caregiver) who provide care…assistance and supervision that are necessary to fulfil the basic needs of people with dementia living in the community' (Chiao et al, 2015). The definition of 'dementia' was intentionally kept broad to increase the likelihood of including appropriate studies. This included all types of known dementia diagnoses, such as Alzheimer's Disease, Vascular Dementia, Posterior Cortical Atrophy and Frontotemporal Dementia. Studies were excluded if

the sample included informal caregivers of people who did not have a dementia diagnosis. Studies were also excluded if the sample included formal caregivers of people with dementia.

- *Intervention Content:* Both group and individual interventions that primarily focused on communication training were included in the review. To be included, at least 50% of the intervention content need to be focused on communication problems and strategies. Studies were excluded if this content formed less than 50% of the overall intervention, for example one session out of four.

- *Measures:* Studies were included if they used any form of quantitative measure as part of the data collection that assessed outcomes relating to potential benefits of communication training programmes for people living with dementia and their caregivers. This included studies using solely descriptive statistics and those who created outcome measures for the purposes of the study. However, studies that solely reported outcomes relating to feasibility and/or acceptability but no other quantitative outcomes were excluded. Studies that included both quantitative and qualitative measures were included but only the quantitative data were reviewed. Studies that used only qualitative measures were excluded.

Data collection and extraction

All studies were downloaded to the reference management software Endnote X9.3.3 (Clarivate Analytics, 2019) and duplicates were removed using the 'remove duplicates' function. The titles and abstracts of all remaining studies were screened for relevance to the review question by one reviewer. Studies that referenced communication training for informal caregivers of people with dementia and appeared to use quantitative measures were subject

to a full text review to assess whether they met the inclusion criteria. The remaining articles were then subject to data extraction based on the questions of the current review and a full quality appraisal. A data extraction form was created based on the research questions and the key characteristics that were being analysed, such as the type of study, the intervention content and the quantitative outcome measures used. Once the data from each study was extracted in this way, this was amalgamated and synthesised into the table shown in the results (see Table 2.). The information was then synthesised by comparing similarities and differences of the key characteristics of the studies, taking into account the quality of the research, in order to weight the strengths and weakness in the studies and make suggestions based on this.

Quality appraisal

The Qualsyst critical appraisal tool (Kmet at al, 2004) was chosen to screen for quality in the final study pool as it had been used in literature on similar topics (i.e., Scerri et al, 2017). The tool helps to compare studies with diverse designs in a 'systematic, reproducible and quantitative' manner (Kmet et al, 2004). The Qualsyst tool comprises of a checklist of 14 criteria for which papers received a score based on the degree to which each quality criterion is met. These are scored as zero (criterion not met), one (criterion partially met), two (criterion fully met) or N/A if the criterion was not relevant. Quality scores are then calculated by adding up these scores and dividing by the maximum score that can be achieved by that particular paper, removing any criteria that were not relevant. This allows direct comparison on papers that may have different relevant criteria. All papers were quality appraised by the main reviewer. A second reviewer (CF) quality appraised a third of the included papers to check for reliability of the final quality ratings. All initial disagreements between reviewers in relation to quality ratings were resolved through discussions until an agreement was reached.

Results

Included Studies

A total of 2680 studies were initially identified by database and manual searches. A total of nine papers were included in the final review based on the inclusion criteria. Six of these were randomised controlled trials (RCTS) and three were non-randomised feasibility studies.

Review Question 1: What are the current evidence-based communication training programmes on offer for informal caregivers of dementia, including the quality of the research and the key features?

Quality of studies

Overall, study ratings ranged from 0.43 to 1.00 indicating a wide variation in quality (see Table 3.). To facilitate comparison, the studies were divided into three categories depending on the score they achieved using Kmet et al's (2004) Qualsyst tool; high quality (0.8-1.0), medium quality (0.6-0.79) or low quality (0.0-0.59). These categories were created to reflect how the study ratings clustered together following analysis. Barnes & Markham (2018) scored the highest quality rating (1.00) as they managed to fully meet each of the criteria that applied to their study, including a full description of their randomisation procedure, use of robust outcome measures and an outline of their power analysis. Two other studies fell within the high-quality category, scoring 0.92 (Klodnicka Kouri et al, 2011) and 0.88 (Liddle et al, 2012). These generally showed strengths in study design, use of control groups, descriptions of sample characteristics and confounds and blinding were appropriate. Four studies were of medium quality, scoring between 0.64 - 0.69 (Haberstroh et al 2011; Williams et al, 2018; Done & Thomas, 2001; Troche et al, 2019). Although generally demonstrating clear objectives, robust designs and appropriate outcomes, these

studies tended to use small sample sizes, have insufficient use of a control group and not consider or control for confounds. Chesneau et al (2019) scored the lowest quality rating (0.43) as the sample size was very small, the participant characteristics were not sufficiently described and the objectives were not clearly stated. One other study fell into the low-quality category for scoring 0.50 (Silvestri et al, 2004) for similar reasons.

Study characteristics

Table 2. outlines the full details of each study. All studies demonstrated some benefits of communication training but varied greatly in dose, method of delivery, content and outcome measures used. These are examined below.

Dose

For the purposes of the review, treatment dose includes the number of sessions offered to participants, the length of each session and the total duration of the training. The number of sessions ranged from two to ten, with the mean number of sessions being 4.44. The duration of each session ranged from 45 to 150 minutes, with the mean duration being 77.86 minutes. The total duration of the intervention ranged from 1.5 hours to 12.5 hours, with the mean duration being 5.86 hours. Two low quality studies did not include information on session length so were not included in the data for session duration and total duration (Chesnau et al, 2019; Silvestri et al 2004).

Method of Delivery

All studies delivered training face to face except for one high quality study which used a training DVD for participants to watch at home by themselves (Liddle et al, 2012). Out of the eight studies delivering face to face training, interventions were delivered by

Speech and Language therapists in one high quality and two medium quality studies (Barnes & Markham, 2018; Done & Thomas, 2001; Troche et al, 2019), by a nurse and PHD student in one medium quality study (Williams et al, 2018) and by a geriatric specialist, psychologist and neuropsychologist in one low quality study (Silvestri et al, 2004). The remaining three studies did not state who delivered the interventions. Three medium quality studies (Done & Thomas, 2001; Haberstroh et al 2011; Troche et al, 2019) and one low quality study (Chesnau et al, 2019) delivered training in a group format, three high quality studies (Barnes & Markham, 2018; Klodnicka Kouri et al, 2011; Liddle et al, 2012) and one medium quality study (Williams et al, 2018) delivered training in an individual format and one low quality study (Silvestri et al, 2004) used a mix of individual and group sessions. Only one medium quality study (Williams et al, 2018) included the person with dementia in the training. The other eight studies only delivered training to caregivers and did not include people with dementia in the training process.

Content of Sessions

Each of the studies developed their training programme using a wide variety of theoretical frameworks. Most were based on basic models of dyadic communication and interactions, however two high quality studies (Barnes & Markham, 2018; Klodnicka Kouri et al, 2011) used the psychological models of Cognitive Behavioural Therapy and Social Cognitive Theory on which to base their trainings. The key elements of the trainings that were present across all studies were providing psychoeducation into the nature of dementia, its impact on communication and strategies to reduce the impact of these difficulties. Strategies included simplifying communication, using yes/no questions, giving time to answer, encouraging engagement in conversation, speaking in a natural voice and using non-verbal communication. One medium quality study (Done & Thomas, 2001) and one low quality study (Chesnau et al, 2019) additionally used videos depicting caregiver and care receiver dyads demonstrating helpful and unhelpful interactions to encourage discussion

about communication between group participants. One medium quality study (Williams et al, 2018) used role play and observations of interactions between dyads to practice new strategies.

Research question 2: What is the current evidence base for communication training programmes for informal caregivers of dementia and what are the benefits for informal caregivers and the people they care for?

Outcome measures used

A total of 32 different quantitative measures were used across the studies, assessing a variety of different domains. Of these, ten were created for the purposes of the study as researchers were unable to find pre-existing measures for the constructs under investigation. The only two measures used more than once across the nine studies were the Revised Memory and Behaviour Problems Checklist (RMBPC) (Teri et al, 1992) and the short version of the Zarit Burden Inventory (ZBI) (Bédard et al, 2001), both of which were used in higher quality studies. No other measure was used more than once across the nine studies. The most common construct that was assessed with outcome measures was communication skills and knowledge, assessed in every study except one. Other common constructs that were assessed with outcome measures in three to four of the studies were dementia related communication or behavioural symptoms, caregiver stress, the impact of supporting a person with dementia, depression and anxiety. Less common constructs that were assessed with outcome measures in only one or two studies were QoL, self-efficacy, activities of daily living (ADLs) and therapeutic engagement.

Significant outcomes for caregivers

All eight studies that assessed caregivers' knowledge, skills and self-efficacy in communication strategies reported improvements in these outcomes. This was reported in both higher quality studies that demonstrated significant or near significant outcomes in these constructs and in the lower quality studies that relied solely on descriptive statistics. However, the outcome measures that demonstrated the biggest improvements were developed as part of the study and had therefore not been subject to the rigours of validity testing that well established measures have undergone. This is because the authors of these studies state that they were unable to find validated measures for the constructs that they wished to assess. When taking study quality and significance into account, the most established and validated communication outcome measure that demonstrated the most change was the Verbal and Non-verbal Interaction Scale for Caregivers (VNVIS- CG) (Williams & Parker, 2012).

One high quality study suggested that communication training could improve QoL in caregivers as Barnes & Markham (2018) found a significant improvement in the 'values' subsection of the Adult Carers Quality of Life questionnaire (ACQOL) (Joseph et al, 2012) from caregivers in the treatment groups compared to controls. However, caregiver QoL was only measured in one study where significant changes were only observed within some of the QoL sub-categories. Reported significant outcomes that self-efficacy can be improved through communication training was mixed. Klodnicka Kouri et al (2011) reported a significant improvement in caregivers' communication specific self-efficacy using the Carer Self-efficacy Scale (CSS) (Bandura, 1997), whereas Barnes & Markham (2018) reported no significant improvement in either general or communication specific self-efficacy using the General Self-Efficacy Scale (GSES) (Schwarzer & Jerusalem, 1995) and a measure developed and validated during the study called the Communication Self-Efficacy Scale (CSES). However, Barnes & Markham (2018) did find a significant result in the 'happens' subsection of the CSES.

None of studies reported a significant change in caregiver stress or the impact of supporting a person with dementia, although Liddle et al (2012) reported a near significant improvement in the positive aspects of the caregiving experience in the treatment group using used the Positive Aspects of Caregiving scale (PAC) (Tarlow et al, 2004). Troche et al (2019) reported a reduction in the impact on caregivers supporting a person with dementia using the short version of the Zarit Burden Inventory (ZBI) (Bédard et al, 2001), however the study only used descriptive statistics due to a very low sample size so these results are not reliable. No significant improvements in mood or anxiety were found in caregivers. However, Haberstroh et al (2011) found that caregivers reporting a significantly higher mood rating on training days compared to non-training days using a subjective Likert scale mood rating.

Significant outcomes for people with dementia

All outcomes for people with dementia were completed by the researchers or the caregivers, with the exception of the Face Scale for Wellbeing in the study by Liddle et al (2012) and the Mini Mental State Examination (MMSE) (Folstein et al, 1975) in the studies by Silvestri et al (2004) and Williams et al (2018). Two of the studies reported that caregivers' participation in communication training could support improvement in the communication skills of people they care for, although this was from medium quality studies with small sample sizes (Troche et al, 2019; Williams et al, 2018). The Verbal and Non-verbal Interaction Scale for Care Receivers (VNVIS- CR) (Williams et al, 2017) has the strongest clinical implication as an outcome measure used to measure this construct as it was the only validated measure used that demonstrated significant outcomes in the reviewed literature. However, it should be noted that significant change was only detected using this measure when cognition was controlled for using the MMSE (Folstein et al, 1975) as the communication skills of people with dementia are less likely to improve as their dementia grows more severe. All four studies that measured communication and behavioural symptoms presenting in people with dementia demonstrated significant or near

significant improvements in the treatment group following training when compared to controls. Based on the reviewed literature, the Revised Memory and Behaviour Problems Checklist (RMBPC) (Teri et al, 1992) has the strongest clinical implication as an outcome measure to use to measure this construct as it is well established and showed significant or near significant change in two high quality studies.

One medium quality study reported a significant improvement in the QoL of people living with dementia following communication training (Haberstroh et al, 2011). However, this was measured using the Quality of Life Alzheimer's Dementia (QoL-AD) (Logsdon et al, 1999) which was completed by the caregiver rather than by the person with dementia themselves. One low quality study reported significantly worsened ability by the person with dementia to independently carry out activities of daily living in the control group than the treatment group following caregiver participation in training. This was measured using the Activities of Daily Living (ADL) (Katz et al, 1963) and Instrumental Activities of Daily Living (IADL) (Lawton & Brody, 1969) measures. There were no reported improvements in mood or anxiety in people with dementia following caregiver participation in communication training.

Discussion

Summary of findings

Overall, the findings of the current literature suggest that informal caregivers' participation in communication training programmes can benefit both caregivers and the people with dementia that they care for. However, research in this particular area was found to be limited and of variable quality so these findings should be looked at with caution. An extensive literature search found only nine papers that met the inclusion criteria for the review. Only three of these were high quality studies, whilst four were of medium quality and two were of low quality. A large number of different outcome measures were used across the

studies with variable degrees of significance in findings. However, these outcomes demonstrated some clear benefits of communication training for both caregivers and people with dementia. Although this review was able to identify some optimal features and benefits of communication trainings with informal caregivers, significantly more high-quality research is needed to support this as current research is generally limited and of poor quality.

In relation to outcomes, there was strong indication that training can improve communication skills and knowledge for caregivers and slightly weaker indication that it can improve self-efficacy and QoL. The measures with the strongest clinical implications to use for these outcomes were the VNVIS- CG to measure communication skills and knowledge, the ACQOL to measure caregiver QoL and the CSS and GSES to measure self-efficacy. There was little to no indication that training could improve caregivers stress, the impact of supporting a person with dementia, mood or anxiety. For people with dementia, there was strong indication that their dementia related communication and behavioural symptoms can be improved when their caregivers participated in communication training and weaker indication for improvement in communication skills, QoL and maintence of ADLs. There was little to no indication that training can improve mood and anxiety in people with dementia. The measures with the strongest clinical implications to use for these outcomes were the RMBPC for dementia related communication and behavioural symptoms, the VNVIS-CR for communication skills, the QoL-AD for QoL and the ADL or IADL to measure ADLs. Based on the findings, it is suggested to use measures for people with dementia that can be completed by caregivers or the researchers. However, this suggestion should be taken with caution as none of the studies attempted to use validated measures that could be completed directly by the person with dementia, and so future research is required to investigate whether using these types of measures is feasible.

There was a range of differences in key features between the nine studies, making it difficult to assess which features were optimal. However, this review was able to preliminarily

identify optimal features when considering factors such as study quality and significance of findings. In relation to optimal dose, the intervention used in Klodnicka Kouri et al's (2011) study appeared most optimal when taking quality of research and the significance of the data into account and consisted of five sessions lasting 90 – 120 minutes each, totalling 7.5 – 10 hours across the whole intervention. The other high-quality studies (Barnes & Markahm, 2018; Liddle et al, 2012) offered lower doses at around two to three hours for the whole intervention, however the change in outcomes measured in these studies was not as apparent.

There was no clear indication whether individual or group sessions were superior, however higher quality studies opted for individual sessions making this method more suggested. There was also no clear indication as to who should deliver the trainings. Speech and Language therapists delivered three of the trainings in high and medium quality studies, however it was unclear whether the facilitator's profession had a significant impact on the outcomes of the study due to sample sizes and a mixture of significant and non-significant results. Only one medium quality study included the person with dementia in the training process, however there was no indication that people with dementia should be excluded from caregiver trainings in communication. This suggests that there may be a lack of sensitivity to including people with dementia in the training process and, so, more needs to be done to include them in caregiver communication trainings as much as their mental capacity will allow.

In terms of session content, interventions that used psychological models such as Cognitive Behavioural therapy or Social Cognitive theory appeared most optimal and thus interventions should, at a minimum, consist of psychoeducation into the nature of dementia, communication related difficulties and specific communication strategies based these theories. These interventions can be didactic in nature as there was no indication that use of role plays or videos were superior. However, this may be due to the lack of use as evidence

from learning theory suggests that role plays are one of the best methods of enhancing learning (Petracchi, 1999; Berkhof et al, 2011).

Methodological limitations of the literature

Through the quality appraisal process, a number of different methodological issues were found within the studies included in this review. One of the most common issues identified was small sample sizes, ranging from four to 55 participants across studies. There is no general consensus as to what the 'rule of thumb' should be for sample sizes in pilot studies, with the literature suggesting a minimum of anywhere between 12 per treatment group to 70 in total (Julious, 2005; Teare et al, 2014). Even with this suggested range, three of the nine included studies failed to reach any of these numbers, making the validity of the data questionable. Although the remaining six studies sample sizes fall within this suggested range, they are unlikely to be sufficiently powered to detect small to medium effect sizes and, therefore, increase the risk of type II errors (Leon, 2008; Biau et al, 2008).

Another common issue across many of the studies is that little to no follow up was conducted post intervention. Researching outcomes at follow up is important as it can highlight long term benefits of interventions and strengthen the validity of the data (Llewellyn-Bennett et al, 2016). Even though the included studies all showed some benefits of communication training immediately post-intervention, the lack of follow up means that it is impossible to assess any long-term benefits or sustained use of learnt strategies from the intervention. As the review conducted by Nguyen et al (2018) demonstrated, potential benefits for both formal and informal caregivers that were not identified immediately post-intervention only became apparent when assessed at follow up. Therefore, the studies identified in the current review could demonstrate different outcomes if subjected to follow up assessment.

The high number of outcome measures used across the nine studies, a third of which were developed as part of the study due to a lack of suitable established measures, was another common limitation as it made cross-comparisons of outcomes difficult. Studies should to try to use well established outcome measures that have faced rigorous testing in order to ensure reproducibility and valid measurement the constructs and populations that they claim to measure (Jerosch-Herold, 2005). The newly developed measures used across the nine studies are unlikely to have faced these rigorous tests, making the validity and reliability of the data relatively unknown.

One final, common issue identified across the literature was in relation to blinding. Blinding occurs when participants or assessors do not know which groups participants are allocated to and is important in research as it helps to reduce performance bias, ascertainment bias and can improve the validity of the data (Renjith, 2007). Although it would have been very difficult for participants and researchers to remain blind to group allocation in the studies included in the current review, it is still worth highlighting that the data is likely to been subject to the biases described.

Strengths and limitations of the review

Despite the lack of high-quality studies found within this subject area, this review was able to identify clear benefits and suggestions through rigorous analysis. The results were limited to studies written in English that were published in peer-reviewed journals in order to increase the likelihood of only including high quality data. However, it should be acknowledged that this may have introduced publication bias. Despite these strengths, there were some limitations to this review that have been identified.

The review makes inferences on significance of outcome data based on the information in the included papers, however no further statistical analysis was conducted on

these data as they were not amenable to meta-analysis. As the studies used a plethora of methods, design and outcome measures, this makes it difficult to infer direct comparisons between the data. The review conducted by Nguyen et al (2018) demonstrated that effects not identified in initial analyses, could become apparent if data was further subjected to meta-analysis. Also, it is recognised that the use of Kmet et al's (2004) Quality Appraisal tool has its own limitations. For example, quality appraisal tools are designed subjectively as there is always variability in the criteria chosen to define what dictates quality in research design. The tool does not include guidance on what scores should be considered 'high, medium and low' quality, so it is inevitable that different authors conducting similar reviews using this tool will define these cut offs differently. The authors of the tool also state that it has limited assessment of inter-rater reliability and small sample size on which is it has been tested. Despite this, it was felt to be an appropriate tool in which to assess quality in the current review.

There were further limitations that may have introduced bias to the results and suggestions given in this review. Despite developing a methical system for paper inclusion and exclusion, the review protocol was not formally registered and no second reviewer was used throughout the paper selection process. It is recognised that using these in the review process may have reduced unnecessary bias and strengthened the findings. Limited resources meant that only studies published in English were reviewed, however this is also likely to have introduced bias to the data.

Recommendations for Future Research

Future research is recommended to build on the initial findings identified in this review by attempting larger scale randomised controlled trials using the training models developed in current research. This will enable more rigorous investigation of the efficacy and efficiency of these interventions. Given the wide variety of outcome measures used, it is

important for this research to narrow down and focus on specific measures so that closer comparisons can be made across the literature. Doing this will enable more comparison between the interventions to investigate which training models are more efficacious and demonstrate the greatest benefits to participants and the people they cared for, using larger sample sizes that can detect smaller effects. Future research should consider using the outcome measures suggested in this review, subject newly developed measures to validity testing or to search for other established communication measures. It is also important for future research to routinely incorporate post intervention follow up to allow investigation on the longer-term effects of these training packages, as well as test out the feasibility of using measures that can be completed directly by the person with dementia. Finally, further research is required to investigate whether including the person with dementia in the training process could provide further benefits and whether the facilitator's profession has any impact on how much participants can benefit from the training.

Relevance to Practice

As this review has identified benefits from caregivers' participation in communication training programmes, there is a clear need for these interventions to be offered in various health and social care contexts. This is especially important given previous evidence for links between communication, QoL and financial costs (Eggenberger et al, 2013). However, given the very limited pool of research found in this review, it is unlikely that dementia services are currently offering programmes that are evidence based. This is further compounded by the lack of availability of manuals and protocols from existing evidence-based interventions, as an online search for these by the primary reviewer found that they were either not easily accessible or not published. Not only is there a need for further research to explore the evidence for these interventions, but there is also a need to ensure that manuals and protocols for these are more readily available to increase the likelihood of these programmes being offered in a clinical setting. Those delivering trainings should be aware of the findings

and suggested made in this review on the key components of such programmes and guidance in relation to outcome measures, keeping in mind the need for further research. Finally, as these trainings have been shown to be beneficial to caregivers, it is important to ensure that services link caregivers to these trainings in order to support them with their caring roles.

Conclusions

Although current research is limited, there are clear benefits of offering communication training programmes to informal caregivers of people with dementia. This review has looked at individual elements of current evidence-based programmes and used this to make suggestions on the key components that trainings should comprise of, the ways in which these trainings can benefit caregivers and the people they care for and which outcome measures should be used to demonstrate these benefits. However, given the limited pool and varying quality of current research, suggestions have also been given as to the direction that further research should take in order to build on the existing literature and continue to demonstrate the need for offering communication training programmes to this population.

Word Count – 6290

What does this paper contribute to the wider global clinical community?
- The review identified papers that showed clear benefits for communication trainings in a variety of countries and therefore demonstrated the need for these trainings in clinical contexts at an international level.
- However, given the limited pool of research identified, it is essential that further research is conducted to build on this and develop programmes that feature the optimal components suggested in this review.

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Table 1. Electronic search strategy

Search Term Category	Terms Applied	Combined with
Informal Caregivers	Informal care* Unpaid care* Carer* Caregiver*	OR
Dementia	Dementia* Alzheimer*	OR
Communication Training	Communication train* Communication interven* Communication skill* Training in Communicat* Communicat*	OR

(Informal Caregivers OR) AND (Dementia OR) → AND (Communication Training OR)

Notes: *Denotes truncation, looks for variants of words such as carer and carers

Table 2: Summary of studies included in the review

Authors	Design, setting and intervention	N	Training Duration	Content of sessions	Outcome, domains measures and time points	Results (follow-up results)	Qual. rating	Comments
Barnes & Markham 2018 (UK)	RCT – face to face, individual sessions Intervention – CBT based communication training Control – 1 hour individual generic information giving session Study – 8 weeks Supervision – none Intervention Facilitator – Speech and Language Therapist	Total – 55 Caregivers Treatment – 28 Control - 27	3 x 1-hour individual sessions Total Duration – 3 hours	CBT based intervention following 9 steps – 1. Knowledge (of dementia & communication difficulties), 2. Insight (into communication difficulties) 3. Thoughts & feelings, 4. Environment, 5. The person 6. How to be the carer 7. Reminders & encouraging conversation, 8. Communication & activities, 9. Challenging behaviours	*Caregiver* Depression & Anxiety – HADS Quality of Life – ACQOL Communication Self-Efficacy – CSES General Self-efficacy – GSES Experience/belief in people with dementia's communication skills – CCS Therapy engagement and readiness – TEI HADS, ACQOL, CSES, GCES & CCS completed as pre/post measures within 12 weeks following consent and within 2 weeks of intervention completion. TEI completed after every session	*Caregiver* No significant differences except for specific domains in ACQOL, CSES and TEI, suggesting significantly higher sense of value and less difficulties from the person with dementia perceived by the caregiver in treatment group. Significantly more readiness for therapy in the control group. Near significant improvement in belief/experience of people with dementia's communication skills in treatment group	1.00	Pos: Randomisation method described, Robust outcome measures, power analysis Neg: No follow up
Chesneau et al, 2019 (Canada)	Non-randomised, non-controlled pre-posttest study – face to face group sessions Intervention- AID-COM programme communication training Control - none Study – 6 weeks Supervision – none	Total – 5 Caregivers	3 sessions Total Duration – Not stated	Sessions divided into psychoeducation, practical application and discussion. Psychoeducation – stages of Alzheimer's Disease, impact on communication and strategies. Focus on memory, lexical access, discourse comprehension, and expression.	*Caregiver* Use and effectiveness of strategies questionnaire (developed for the purposes of the study) Impact of communication strategies questionnaire (developed for the purposes of the study) Both questionnaires were given pre/post intervention	*Caregiver* No formal statistical analysis conducted, only descriptive statistics. All participants reported increase in frequency and effectiveness of communication strategies and greater impact on the person with dementia.	0.43	Pos: Qualitative interviews conducted Neg: Small sample size, no follow up, no control group

	Intervention Facilitator – Not stated			*Practical component – video scenarios encouraging discussion to identify problems and solutions*				
Done & Thomas, 2001 (UK)	*CRCT - face to face group sessions Intervention – Speech and language video and discussion-based communication training Control – information booklet to read Study – 2 weeks Supervision – none Intervention Facilitator – Speech and language therapist*	*Total – 45 Caregivers Treatment – 30 Control - 15*	*2 x 1-hour sessions Total Duration – 2 hours*	*Video of communication breakdown presented to participants to support discussion of communication difficulties and solutions, followed by video of same scenario using successful communication strategies Control group booklet contained cartoon drawings similar to the videos in intervention group and advice on how to manage communication problems*	*Caregiver Caregiver Stress - RSS Frequency of communication problems – TACI Awareness of communication strategies – AACS (developed for the purposes of the study) Consumer evaluation – Likert Scales All measures were given pre/post intervention*	*Caregiver Both groups' awareness of strategies significantly increased but significantly higher for treatment group. No significant differences in caregiver stress between or within groups or in frequency of communication problems between groups but both groups reported significant reduction in frequency of communication problems post intervention.*	*0.68*	*Pos: Randomisation method described, controlled for confounds, blinding of researchers Neg: No blinding of participants, no power analysis, outcome measure not standardised*
Haberstroh et al, 2011 (Germany)	*RCT - face to face group sessions Intervention – TANDEM programme communication training Control – no treatment, waiting list to receive*	*Total – 22 Caregivers Treatment – 9 Control - 13*	*5 x 2.5-hour sessions Total Duration – 12.5 hours*	*Psychoeducation on concepts and skills of TANDEM model: sender presentation, receiver attention, receiver comprehension and receiver remembering. Session format: 1. Review previous session, 2. Exchange experiences from the week, 3. Intro to topic*	*Caregiver Mood – Likert scale every day using diaries during intervention Frequency of strategy use – Number recorded every day using diaries Impact of supporting a person with dementia- HPS Person with dementia QoL – QoL-AD (completed by caregivers pre/post intervention)*	*Caregiver Frequency of strategy use increased significantly throughout training and caregiver mood was significantly improved on training days. No significant change in impact of*	*0.69*	*Pos: Use of observational measures, robust outcome measures, attrition described Neg: Small sample size, no power analysis, true*

Study	Design/Intervention	Participants	Sessions/Duration	Intervention description	Outcome measures	Results		Positive/Negative
	group after post measures Study – 5 weeks Supervision – none Intervention Facilitator – Trainer (Profession not stated)			with case studies, 4. Relate to individual experiences, 5. Use to highlight strengths and weaknesses of topic, 6. Case studies and experiences used to find communication strategies, 7. New skills role played, 8. Set objectives for the week	Mood and frequency of strategy use was measured each session. QoL and impact of supporting a person with dementia were measures pre/post	supporting a person with dementia between groups *Person with dementia* *QoL significantly improved in intervention group*		*randomisation not possible*
Klodnicka Kouri et al, 2011 (Canada)	RCT – face to face individual sessions Intervention – Social Cognitive theory-based communication training Control – Booklet on memory and communication problems Study – 5 weeks Supervision – none Intervention Facilitator – Not stated	Total – 50 Caregivers Treatment – 25 Control - 25	5 x 90-120-minute sessions Total Duration – 7.5 - 10 hours	Psychoeducational approach consisting of five modules related to specific communication related subjects. Four self-efficacy strengthening skills incorporated – 1. Learner given opportunity to master communication skills, 2. Effective models shared with learner, 3. Learner persuaded to perform skills, 4. Diverse action-approaches used to reduce learner's anxieties.	*Caregiver* *Self-efficacy – CSS* *Perceived communication-related behavioural symptoms – RMPBC* *Communication knowledge – The Knowledge Measure (developed for the purposes of the study)* *Communication Skills – The Communication Skills Measure (developed for the purposes of the study)* *All measures were conducted pre/post intervention*	*Caregiver* *Significant increase in communication knowledge, skills and self-efficacy and significant decrease in perceived communication-related behavioural symptoms in treatment group compared to control. However, there was no significant difference for perceived communication difficulties.*	0.92	*Pos: 6 week follow up, robust measures, blinding of assessors* *Neg: small sample size, randomisation method not described*
Liddle et al, 2012 (Australia)	RCT – DVD training Intervention – RECAPS and MESSAGE communication and memory training programme Control – TAU Study – 1 weeks Supervision – None	Total – 29 Caregivers Treatment – 13 Control - 16	2 x 45-minute sessions Total Duration – 1.5 hours	Psychoeducational strategies for communication and memory delivered in a didactic approach. Each letter of RECAPS and MESSAGE representing a different strategy. RECAPS = Reminders, Environment, Consistent routines, Attention, Practice, Simple steps. MESSAGE = Maximise	*Caregiver* *Knowledge of support strategies – Communication and Memory Support in Dementia (developed for the purposes of the study)* *Impact of supporting a person with dementia – Short ZBI* *Positive aspects of caring – PAC* *Perceived communication-related behavioural symptoms – RMPBC* *Person with dementia*	*Caregiver* *Significant improvement in knowledge of strategies and near significant improvement in positive aspects of caring and perceived communication-related behavioural symptoms in treatment group. No*	0.88	*Pos: Power analysis, 3 month follow up* *Neg: Outcome measures vulnerable to bias, small sample size*

	Intervention Facilitator – None (Training delivered by DVD)			*attention, Expression and body language, keep it Simple, Support conversations, Assist with visual aids, Get their message, Encourage and engage in conversation.*	*Depression – CSDD (completed by caregiver) General mood – Faces scale for wellbeing (developed for the purposes of the study) (completed by person with dementia)* *All measures were complete pre/post except the MMSE which was complete pre intervention and the Faces scale which was completed post*	*significant difference found in impact of supporting a person with dementia* <u>*Person with dementia*</u> *No significant differences found for depression or general mood*		
Silvestri et al, 2004 (Italy)	*RCT – Individual and group face to face sessions Treatment – Communication strategies in Alzheimer's disease Control – No training Study - 6 weeks Supervision – none Intervention Facilitator – A geriatric specialist, a psychologist and a neuropsychologist*	*Total – 35 Caregivers Treatment – 18 Control - 17*	*4 x group sessions 2 x individual sessions* *Total Duration – Not stated*	*Psychoeducation on different communication problems at different stages of disease progression and verbal and non-verbal strategies to support communication at each stage. Strategies included speaking in familiar places, using present tense, use more concrete ideas and use of non-verbal communication.*	<u>*Person with dementia*</u> *Cognition – MMSE (completed by person with dementia Activities of Daily Living – ADL & IADL (rated by researchers) Alzheimer's Disease related behaviours - E-Behave-AD (rated by researchers)* *Al measures were completed pre/post intervention*	<u>*Person with dementia*</u> *Significant improvement in Cognition and AD related behaviours in treatment group compared to control group. No significant change in ADLs in treatment group but control group significantly worse.*	*0.50*	*Pos: Robust and appropriate outcome measures Neg: No power analysis, randomisation not described, no follow up, small sample size*
Troche et al, 2019 (USA)	*Non-randomised, non-controlled pre-posttest study – Group face to face sessions Treatment – Supported conversations for Adults (SCA) with*	*Total – 4 Caregivers*	*4 x 1-hour sessions* *Total Duration – 4 hours*	*Psychoeducational didactic training. Session 1. Dementia education and acknowledging competence, i.e., speaking in a natural voice and avoiding quizzing. Session 2. 'Getting the message in',*	<u>*Caregiver*</u> *Skills in engaging people with dementia using SCA principles – MSC (rated by researchers) Impact of supporting a person with dementia – Short ZBI* <u>*Person with dementia*</u>	*Descriptive statistics only due to small sample size.* <u>*Caregiver*</u> *Skills in engaging people with dementia using SCA principles increased*	*0.64*	*Pos: blinding of assessors, robust outcome measures, observational outcome measures used*

	dementia communication Control – none Study – 6 weeks Intervention Facilitator – Speech and language therapist			*i.e., writing keywords, using yes/no questions. Session 3. 'Getting the message out', i.e., ask one question at a time, give time to answer. Session 4. 'Getting verification of message', i.e., summarising.*	*Skills in participating in conversation – MPC (rated by researchers)* *All measures completed pre/post intervention*	*and impact of supporting a person with dementia decreased post intervention* *Person with dementia Skills in participating increased post intervention*	*Neg: no control group, small sample size. No follow up*
Williams et al, 2018 (USA)	*Non-randomised, non-controlled pre-posttest study - Individual face to face sessions at home Treatment – CARE communication training programme Control – none Study – 12 weeks Supervision – Yes Intervention Facilitator – Lead author (Nurse) and PHD student*	*Total – 15 dyads*	*10 x 50-minute sessions* *Total Duration – 8 hours*	*Observations and role play to tailor 10 modules including psychoeducation on dementia and communication difficulties, empathy, simplifying communication, using questions, responding to conflict, nonverbals, adaptation, challenges, compassion and strengthening relationships. Session format: assess the person with dementia's needs, discuss and role play new strategies with the caregiver, caregiver and person with dementia coached together, caregiver and person with dementia observed.*	*Caregiver Effective communication – VNVIS-CG (rated by the researchers)* *Person with dementia Effective communication – VNVIS – CR (rated by the researchers) Cognition – MMSE (completed by person with dementia)* *All measures were taken pre/post intervention except for the MMSE which was complete pre intervention only.*	*Caregiver Significant improvement in effective communication* *Person with dementia No significant improvement in effective communication post intervention, however a significant improvement was found post intervention when controlled for cognition (using MMSE scores).*	*0.68*
							Pos: robust and appropriate outcome measures, observational outcome measures used Neg: no control group, small sample size, no follow up

Questionnaire Acronyms – AACS = Assessment of Awareness about Communication Strategies, ACQOL = Adult Carers Quality of Life questionnaire, CSDD = Cornell Scale of Depression in Dementia, CCS = Communication Competence Scale, CSES = Communication Self-Efficacy Scale, CSS = Carer Self-efficacy Scale, GSES = General Self-Efficacy Scale, HADS = Hospital Anxiety and Depression Scale, HPS - Häusliche-Pflege-Skala (Home Care Scale), MMSE – Mini Mental State Examination, MPC – Measure of Participation in Conversation, MSC – Measure of Skill in Supported Conversation, PAC = Positive Aspects of Caregiving questionnaire, QoL-AD = Quality of Life Alzheimer's Dementia, RSS = Relative Stress Scale, RMBPC – Revised Memory and Behaviour Problems Checklist TACI = Thomas Assessment of Communication Inadequacy, VNVIS- CG = The Verbal and Non-verbal Interaction Scale for Caregivers, VNVIS- CR = The Verbal and Non-verbal Interaction Scale for Care Receivers, ZBI = Zarit Burden Inventory

Table 3: Results of quality appraisal

** = criteria fulfilled; * = criteria partially fulfilled; () = criteria not fulfilled; - = not applicable for study type.

Quality rating criteria and scores (Kmet et al, 2004)

	Question/Objective sufficiently described?	Study design evident and appropriate?	Method of subject/comparison group selection described and appropriate?	Subject and comparison group characteristics sufficiently described?	Was random allocation described?	Was blinding of investigators reported?	Was blinding of subjects reported?	Outcome measures well defined and robust?	Sample size appropriate?	Analytic methods described and appropriate?	Some estimate of variance reported for the main results?	Controlled for confounding?	Results reported in sufficient detail?	Conclusions supported by the results?	Quality rating (total sum/total possible sum)
Barnes & Markham (2018)	**	**	**	**	**	-	-	**	**	**	**	**	**	**	1.00
Klodnicka Kouri et al (2011)	**	**	**	**	*	**		**	*	**	**	**	**	**	0.92
Liddle et al (2012)	**	**	**	**	*	**	-	*	*	**	**	**	**	**	0.88
Haberstroh et al (2011)	**	**	**	**	*		-	**	*	**	*	*	*	*	0.69
Williams et al (2018)	**	**	*	**	-	-	-	**		*	*	*	*	**	0.68
Done & Thomas (2001)	**	**	*		**	*		*	*	*	**	**	**	**	0.68
Troche et al (2019)	**	*	*	*	-	**	-	**		**	**	-	**	**	0.64
Silvestri et al (2004)	*	**	*	*			-	*	*	**		*	*	**	0.50
Chesneau et al (2019)	*	**	-		-	-	-	*	-	-	-		*	*	0.43

Figure Legend

Figure 1: Flow diagram illustrating the inclusion of studies in the review