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REVIEW

Carers in post-stroke aphasia: a scoping review of interventions and outcomes beyond communication partner training

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ABSTRACT

Purpose: Carers of people with aphasia face unique challenges. Research has demonstrated that these carers have a higher burden of care and more negative stroke-related outcomes in comparison to carers of stroke survivors without aphasia. The aim of this scoping review was to map the range of interventions for carers other than communication partner training and to examine their outcomes.

Materials and methods: We conducted a scoping review on this topic.

Results: Twenty studies were included. Most studies were case series with four randomised control trials. Both quantitative and qualitative approaches were used. Most studies occurred during the long-term phase of care. Two interventions had only carers as participants. Interventions were comprised of different combinations of intervention components including psychoeducation, skill-building, and support. There was high variability on who led the interventions, the format, and the dose/schedule. Twenty-eight different outcome measures for carers and dyads were used across various domains with overall positive outcomes post-intervention.

Conclusions: This review uncovered a wide range of formats, dosages, and outcome measures in interventions for carers. Encouragingly, the majority of these interventions included psychoeducation, skill-building, and support components. While most studies were case series, there are promising interventions that have the potential to enhance carer wellbeing.

IMPLICATIONS FOR REHABILITATION

- Carer targeted interventions play an important role in reducing carer burden and increasing psychological wellbeing for carers of people with aphasia post-stroke.
- A tailored intervention for carers of people with aphasia should include components of psychoeducation, skill-building, and support to meet their needs across the continuum of care.
- Recognising carers as clients has the potential to improve healthcare outcomes for the carer and the person with aphasia.

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Carers; caregivers; aphasia; intervention; wellbeing

Introduction

Carers for stroke survivors are often spouses and other close family members, and the majority of these carers are women [1]. Carers of people with chronic aphasia face unique challenges in caring for someone who has difficulty in their ability to express and understand language in everyday functional tasks and conversation. Aphasia is a stroke sequela that effects an individual's ability to communicate, impacting up to 40% of stroke survivors [2]. Changes to relationships are inevitable following the sudden disruption in communication from post-stroke aphasia [3]. Studies have confirmed carers of people with aphasia have an overall higher burden of care and more negative stroke-related outcomes in comparison to carers of stroke survivors without aphasia [4,5].

After stroke, the dynamics between family members and people with aphasia change, with family members frequently having to assist with communication and take on new roles as a carers, advocates, and therapists [6]. In addition to a deterioration in their relationships, carers have reported a decline in their own physical and psychological health [7]. Research has outlined the negative impacts on the mental health of carers of stroke survivors with increased depression and anxiety [8], yet the incidence of mental health problems of family members of people with aphasia remains unknown [9]. Additionally, carer stress may lead to social isolation, deteriorating health, and an elevated risk of mortality among the carers, potentially impeding the stroke survivor's rehabilitation [10,11]. Spouses of people with aphasia report a lack of information on available psychological support which becomes increasingly apparent during the transition from hospital to home [12]. Participants in one study described their need for practical and emotional support, respite, and recognition of their new roles

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and responsibilities as carers [13]. Carers have identified positive reframing techniques and taking time away from the people with aphasia to enjoy personal activities as strategies that help them cope with the emotional and mental fatigue of caring. [14,15].

The assistance carers need to support themselves and people with aphasia varies across the acute, rehabilitation, and long-term phases. At the onset of aphasia, important needs during hospitalisation are receiving information on the diagnosis and remaining hopeful; however, some carers describe feelings of "being in the dark" and frustration with the format in which information is presented by healthcare workers [16,17]. Cheng and colleagues emphasise the importance of recognising and attending to the emotional and practical requirements of carers while providing prognostic information, as these conversations involve elements of both optimism and sorrow[18]. During the rehabilitation phase, improved communication with the person with aphasia is highlighted as an important need, while some carers report challenges in navigating the healthcare system [19]. Later, in the long-term phase, carers report wanting more community-based information, such as information about support groups and new meaningful activities [17, 20,21]. There is a shift to needing more psychosocial support during the long-term phase, with an increased burden of care and decrease in social support over time [8]. Failure to address the needs of carers across the continuum of care may have repercussions in living successfully with aphasia for both the person with aphasia and the carer.

Healthcare professionals face a significant challenge in providing support to family carers due to the multifaceted nature of carer burden. A previous scoping review explored carers' perceptions of their intervention needs in relation to aphasia that resulted in recommendations categorised as information, support, or training across the continuum of care [22]. These recommendations emphasised the importance of delivering appropriate interventions at the right time. The provision of appropriate information and psychosocial needs are closely linked, in that having more information could reduce anxiety at the point of discharge [23]. Experienced healthcare professionals have the capacity to educate carers about the expected challenges and equip them with tailored resources, which could potentially benefit both the carers and individuals with aphasia [24]. However, in one study, speech pathologists described working with carers as challenging, with workplace environment playing a significant role in shaping this perception. This included time constraints to address both recovery goals and goals of adaptation to aphasia, difficulties in developing new services and acquiring new skills, challenges in maintaining regular interactions with carers and a perception carers were too busy with other responsibilities [25]. Speech pathologists rarely engaged in training carers to use communication strategies with the primary reasons given including lack of time and available resources [26]. When deemed necessary, speech pathologists did collaborate or refer to social workers to address carers' emotional and interpersonal issues. Additionally, speech pathologists with greater experience in aphasia were more likely to provide counselling to family members and individuals with aphasia [25–27].

A previous systematic review on the effectiveness of psychosocial interventions for carers of stroke survivors revealed the majority of studies used psychoeducation methods, which included psychotherapeutic techniques such as counselling, education, coping strategies, and social support groups [28]. Two studies included in the systematic review suggested carer-directed psychoeducation programs led to a statistically significant decrease in hospital readmission for stroke survivors [29,30]. Research into the interventions for stroke carers have classified intervention components into the categories of psychoeducation, skill-building, and support [31,32]. Additionally, the recommendations for stroke carer interventions have indicated interventions targeted at carers individually are associated with better carer outcomes, while dyad interventions are associated with better outcomes for stroke survivors[31].

Communication partner training or conversation therapy is a skill-building intervention that has been researched for people with aphasia and their communication partner, often their carer, with two systematic reviews completed to date [33,34]. The aim is to train the person with aphasia and their communication partner in how to use effective strategies to enhance communication and interaction. Forty-one of the studies across the two systematic reviews included carers/spouses, or other family members [35–75] and we have included eight of these. The eight included studies employed additional components to communication partner training, such as family counselling and support groups [36–38, 40,41, 46, 48, 57]. The remaining 33 studies investigated communication partner training alone and employed outcome measures related to communication behaviour. One exception employed additional outcome measures and found that communication partner training did not have an impact on self-esteem, anxiety, or depression in carers [44]. Nonetheless, communication partner training can be effective in providing communication access to people with aphasia and should be a skill set all carers are trained in.

Given the unique needs of carers of people with aphasia, ideal interventions may differ from those designed for carers of stroke survivors in general. To date, there appear to be no existing reviews investigating carer interventions in post-stroke aphasia outside of communication partner training; therefore, we conducted a scoping review to address this gap. Our aim was to explore carer interventions beyond communication partner training. Therefore, we did not consider interventions that only focus on communication partner training as there is existing evidence from two systematic reviews that it is effective in enhancing communication.

In carer research, the terms informal carer, family carer, and caregiver are interchangeably used and differ from a paid carer. Informal or family carers are defined as people who take on the main responsibility for caring for someone with a chronic disability [76]. For this review, we focused only on informal carers that may include family members, relatives, or friends.

Aims

We conducted a scoping review investigating carer interventions other than communication partner training for people with post-stroke aphasia. The primary research questions for this review were:

1. What interventions for carers of people with post-stroke aphasia are described in the literature?
2. What are the procedures and targets in the interventions?
3. What are the outcomes of the interventions?

Methods

A scoping review methodology following the Arksey and O'Malley [77], Levac, Colquhoun [78] and Peters, Marnie [79] frameworks was used. Each step is described below.

Step 1: Identifying the research question

We used a broad research question (as stated above) to explore the scope of how intervention approaches for carers of people with aphasia have been described in the literature. The question was relatively broad to encompass the various forms of carer interventions that may run in conjunction with people with aphasia.

Step 2: Identifying relevant studies

A multi-step strategy was utilised, determined through consultations with a library research advisor from La Trobe University. An initial trial search explored appropriate key words and search terms for inclusion and exclusion. The final search strategy was then implemented across the following online databases: Medline, PsycINFO, CINAHL, Cochrane, and Embase. Search terms used were: aphasia* or dysphasia* (abstract) AND carer* or caregiver* or relative* or famil* or spouse* or partner* (abstract) AND intervention* or education* or training* or support* or therapy* or program* or group* or psych* (abstract) AND stroke* or CVA* or cerebrovascular accident* or cerebrovascular event* (keyword). The reference lists of existing scoping reviews or systematic reviews on communication partner training were screened for additional studies [33,34, 80].

Step 3: Study selection

Following the search, retrieved citations were collated and uploaded into Covidence (an online tool used for systematic reviews) with duplicates removed. Titles and abstracts were screened by the first author and author KP. The full text of selected citations was assessed in detail against the inclusion criteria (see below) by the first author and author KM. Reasons for exclusion were recorded. Disagreements in inclusion were resolved by discussion. The results of screening and inclusion are described in the review and represented visually in a PRISMA flowchart [81]. Studies focused only on communication partner training were excluded, given the extensive research that has been conducted through two systematic reviews of this topic [33,34], though the importance of this aspect of carer intervention is acknowledged. However, if the carer intervention included other components beyond communication training (e.g., support groups), they were included to extract outcome measures.

Eligibility criteria

Study inclusion criteria:

- Adult (people over 18 years) carers for people with aphasia following stroke. For the purpose of this review, a carer is defined as someone who provides the majority of unpaid care and support for a person with aphasia.
- Studies with a mixed sample of carers of other aetiologies (e.g., traumatic brain injury) were considered for inclusion only if carers of people with aphasia were clearly identifiable in the study population.
- Intervention directed towards carers.
  - May also include person with aphasia and other family members.
- Includes carer outcome measures (quantitative or qualitative).

Exclusion criteria:

- Texts not available in English.
- Other aetiologies of aphasia (e.g., dementia and traumatic brain injury).
- Studies investigating communication partner training as the only intervention for carers.
- Studies investigating an intervention directed towards the person with aphasia and not the carer.

Step 4: Charting the data

Data from included studies were collated into a table. Data extracted included: author name, year, title, country, aims, study design, sample size, methodology, phase of stroke, intervention type (including procedures and targets), outcome measures for carers, and outcome measures for people with aphasia.

Step 5: Collating, summarising, and reporting results

Studies were analysed in relation to research design, outcome measures, outcomes, participant groups, and intervention type.

Results

Literature search results

Initial literature search completed in December 2022 returned 2024 studies. After removal of duplicates, 974 studies were screened by title and abstract. Full-text screening was performed on 81 studies. A total of 12 studies were included in the initial search yield (see Figure 1). An additional 48 studies were identified from references within studies and five additional study met criteria. The first updated search was completed in July 2023. The literature search returned 189 studies, after removal of duplicates, 112 studies were screened by title and abstract. Full-text screening was performed on two studies. One additional study met criteria for a total of 18 studies. The second updated search was completed in June 2024. The literature search returned 317 studies, after duplicates, 278 were screened by title and abstract. Full-text screening performed on ten studies. Two additional studies met criteria for a total of 20 studies. Nine studies originated from North America, seven studies from Europe, and four from Australia. Analysis of the studies according to study characteristics is detailed below.

Year of publication

Year of publication ranged from 1987 to 2023. Three studies were published in the 1980s, four studies in the 1990s, five studies from 2001-2010, and eight studies were published from 2011-2023.

Sample

In total, studies reported results separately for 653 carers and 656 people with stroke and/or aphasia, with dyad outcomes reported for 132 couples. Most studies had fewer than 20 participants, though one randomised control trial included 87 carers and 83 people with aphasia in the treatment group [82]. Mean carer age reported across studies ranged from 34.7 to 65.7 years, and the majority of carers were female spouses. Reported mean ages for participants with aphasia ranged from 54.7 to 64.3 years and the majority were male. Time post-onset since stroke ranged from 1 month to 20 years (See Supplementary Table 1).

Study design

Following the National Health and Medical Research Council (NHMRC) levels of evidence guidelines [83] the studies were categorised as: Level II, randomised controlled trial (RCT) ($n = 2$), Level III-1, pseudorandomised RCT ($n = 2$), Level III-3, comparative study with concurrent controls ($n = 1$), Level IV, case series ($n = 15$).

Timing of intervention

There were no interventions that occurred solely in the acute phase (early hospitalisation). Interventions that occurred across

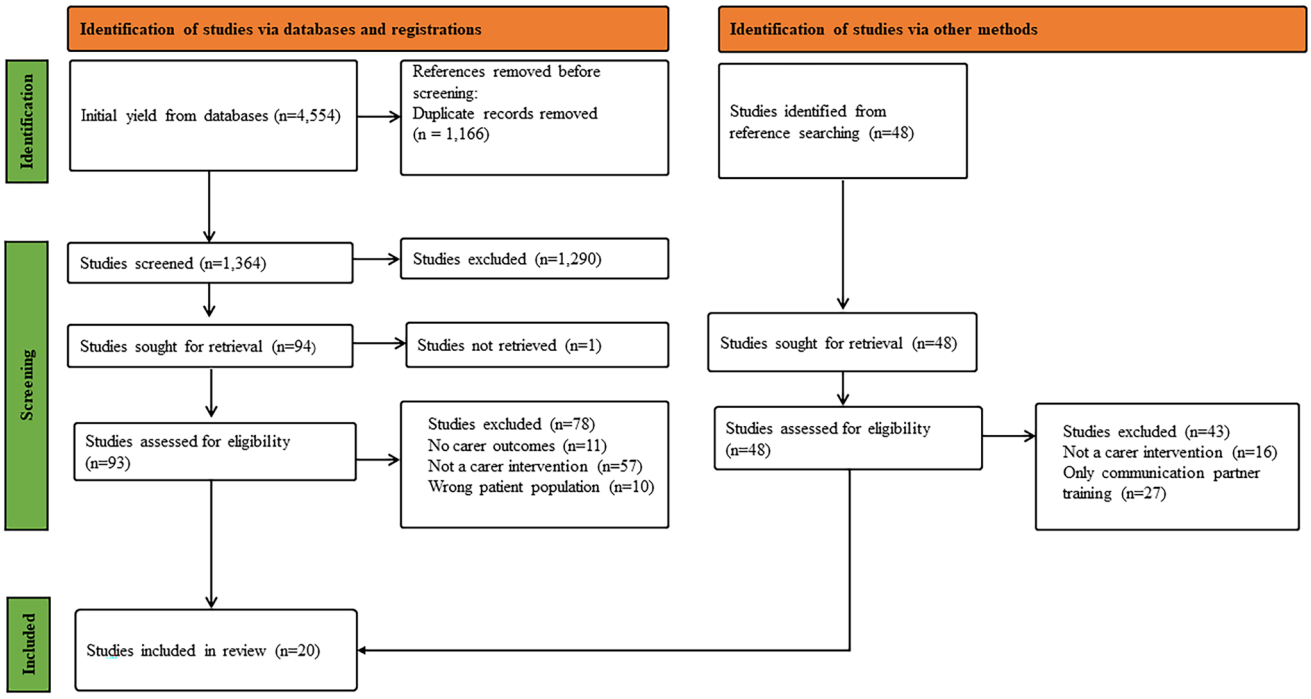

Figure 1. PRISMA flowchart of literature searching, screening, and inclusion.

the acute and the rehabilitation phase (first 12 months since stroke) were delivered in four studies (two studies reported on the same cohort). Interventions that occurred across the rehabilitation and long-term phase (post 12 months since stroke) were delivered in three studies. Intervention that occurred during the long-term phase were reported in 13 studies.

Dose and schedule of interventions

Intervention dose was variable across duration, frequency, and total amount. Duration was highly variable with the shortest occurring during a 2-day seminar and the longest occurring over a three-year period. Frequency ranged from once per week to five times per week. Session length varied from one to three hours (see Table 1).

Format of interventions

Formats of interventions delivery varied. Two studies were carer-only interventions conducted in group sessions [36, 40]. Other formats included carer-only support groups [36, 48, 84–91], mixed support groups[57, 84, 87, 90], family and/or general counselling, [35, 40,41, 57, 82], marriage counselling[92,93], camps[48, 87–89], and seminars[37,38].

Categorisation of included studies by intervention approach

Within the categorisation framework utilised in previous systematic reviews of carer and dyad interventions for stroke survivors [31,32], the studies fell across three main categories of psychoeducation, support, and skill-building.

Eighteen studies included psychoeducation as a component of the intervention. The psychoeducation included knowledge relating to stroke, aphasia, communication impairment, prognosis, therapy approaches, psychosocial issues related to living with aphasia, vocational and avocational pursuits, and other support services (e.g., respite care).

Eighteen studies included support as a component of the intervention. The support included peer-led carer support groups or psychological/psychosocial support for the carer and/or family *via* counsellors, speech pathologists, and neurologists. Specific counselling services were designed to support adjustment to, and acceptance of, aphasia.

Fourteen studies included skill-building as component of the intervention. These studies variously aimed to promote problem solving skills, coping skills, goal setting, stress management, intimacy, assistance with activities of daily living, and communication partner training.

Twelve studies included all three components of psychoeducation, support, and skill-building. These programs varied in format such as camps, support groups, or couple/family counselling sessions (see Table 1 and Figure 2)

Outcome measures and timepoints

Generally, outcomes were measured by means of quantitative data ($n = 14$) arising from standardised assessments, questionnaires, and self-rating scales. Other studies collected qualitative data ($n = 6$) through semi-structured interviews, questionnaires with open-ended questions, and feedback evaluations. The majority of studies measured outcomes for carers and people with aphasia separately with two studies measuring them as a dyad. For the purpose of this review we will only focus on carer or dyad outcomes. There were 28 different outcome measures for carers and the dyad utilised across the studies. The most used outcome measure was a variant of the General Health Questionnaire across four studies. Post-intervention follow-up timepoints varied from 4 weeks to 12 months. Only two studies reported effect sizes for carers relating to general health and marriage satisfaction. For the purpose of this review, we will only discuss carer-specific and dyad outcomes. The supplementary table includes outcome measurers specific to people with aphasia (See Supplementary Table 1)

Carer outcomes

Across the included studies, carer outcomes were measured and reported across seven domains: carer burden and stress,

Table 1. Description of interventions.

Author and design/ NHMRC level of evidence	Sample	Intervention components	Dose	Provider	Dyad, family, carer group, or mixed group	Acute, rehab, or long-term	Findings
Armour, Brady, & Sayyad, 2019 Case series Level IV	$n = 40$ carers $n = 41$ people with aphasia	Carer support group, book club, technology club, game club, maths club, cooking club, fitness club (clubs were only for people with aphasia)	1x a month for 11 weeks for support group	Speech pathologists, certified personal trainers, recreational therapists, music therapists	Carer group	Rehab, long-term	Carers reported a statistically significant lower level of carer burden post intervention.
Attard et al. 2018* Case series Level IV	$n = 8$ dyads	Communication therapy for people with aphasia, carer support group, conversation practice, psychological support, information on stroke/aphasia, meaningful activities	2-hour sessions per week for 12 weeks	Speech pathologist, social worker, peer aide with aphasia, and an aide	Mixed group, carer group	Long-term	Supported communication skills did not statistically improve post intervention. Perceived carer burden improved post intervention and maintained at follow-up. Psychological health had no statistically significant change post intervention.
Attard et al. 2020* Case series Level IV	$n = 8$ dyads	Communication therapy for people with aphasia, carer support groups, conversation practice, psychological support, information on stroke/aphasia, meaningful activities	2-hour sessions per week for 12 weeks	Speech pathologist, social worker, peer aide with aphasia, and an aide	Mixed group, carer group	Long-term	Carers reported positive feedback on the spouse-only sessions with some recommendations that included: more support-related information, reducing the focus on the stroke/aphasia experience, and more open discussions.
Borenstein et al. 1987 Case series Level IV	$n = 6$ carers $n = 9$ people with aphasia	Information on cause, treatment and prognosis of aphasia and psychological counselling	5-day intensive course	Speech pathologist, psychologist, and neurologist	Mixed group, dyad	Long-term	Carers learned how to identify and manage their psychological problems in a more constructive way.
Draper et al. 2007 Randomised controlled trial Level II	$n = 19$ cares immediate treatment $n = 20$ waitlist controlled	Information on relaxation and stress management, managing emotions and existing resources, carer support group, and communication skills training	2-hour sessions once a week for 4 weeks	Speech pathologist and clinical psychologist	Carer group	Acute and rehab	Improvement on psychological wellbeing post intervention and not maintained at follow-up. Supported conversation skills and carer burden did not significantly change.
Fitzgerald-DeJean, 2008 Case series Level IV	$n = 6$ carers	Carer support group	1x week for 5 weeks	Psychologist	Carer group	Long-term	Quality of life scores had a significant positive improvement. Not all carers were for people with aphasia, thus results are inconclusive for this review as there were only group-level outcomes reported.
Fox et al. 2004 Case series level IV	$n = 19$ carers	Carer support group	2-hour sessions for 2 days per year	Unknown	Carer group	Long-term	Carers reported a renewed sense of hope, improved ability to access their social support resources, improved ability to monitor their wellbeing, greater acceptance of the family's altered state, and emergence of a new social support network.
Hinkley et al. 1995 Case series Level IV	$n = 60$ dyads	Lecture, small group discussions, and hands on workshops	2 days once per year	Speech pathologist, social worker, recreational therapist, and art therapist	Mixed group	Long-term	Positive effect for the dyad on independence and participation in leisure and social activities.
Hinckley & Packard, 2001 Comparative study with concurrent controls Level III-2	$n = 21$ dyads participants $n = 15$ dyads nonparticipants	Lecture, small group discussions, and hands on workshops	2 days once per year	Speech pathologist	Mixed group	Long-term	Significant improvement for the dyad in functional activity level, improved knowledge of aphasia, and improve family relationships. Nonparticipant pairs did not demonstrate any changes over the same period.
Hoen et al. 1997 Case series Level IV	$n = 12$ carers and $n = 35$ people with aphasia	Carer support group and aphasia communication group	Half days 2 times a week long-term	Communication disorder assistant, social worker, and trained volunteers	Carer group	Long-term	Significant positive changes on five out of the six scales on a measure of psychological wellbeing (positive relations with others, increased sense of personal growth, purpose of life, and self-acceptance).

(*Continued*)

Table 1. Continued.

Author and design/ NHMRC level of evidence	Sample	Intervention components	Dose	Provider	Dyad, family, carer group, or mixed group	Acute, rehab, or long-term	Findings
Kim et al. 2017 Case series Level IV	*n* = 4 carers *n* = 9 people with aphasia	Carer support group, aphasia communication group, and recreational activities	3 days once per year	Speech pathologist and psychologist specialising in stroke	Carer group, mixed group	Long-term	Carers reported benefits in increased resources on living with aphasia, new friendships, respite, newfound confidence observed in their person with aphasia, and opportunities to participate in new activities.
Nichols et al. 1996 Case series Level IV	*n* = 14 family members *n* = 5 people with aphasia	Joint speech and language therapy and family counselling sessions.	90-minute 5 sessions across 12 weeks	Family therapist and speech pathologist	Family	Rehab	Family members showed positive significant changes across the intervention in their overall observed symptoms that were reported in a personal questionnaire.
Orlowska et al. 2018* Pseudorandomised controlled trial Level III-1	*n* = 80 dyads participants *n* = 80 nonparticipants	Social support group and psychoeducation program	90-minute sessions once a week for 10 weeks	Unknown	Mixed group	Acute to rehab	There was not a statistically significant effect but there was a positive influence on communication in marriage, with couples adjusting to non-fluent aphasia receiving the most benefit.
Rasmus & Orlowska, 2020* Pseudorandomised controlled trial Level III-1	*n* = 80 dyads participants *n* = 80 nonparticipants	Social support group and psychoeducation program	90-minute sessions once a week for 10 weeks	Unknown	Mixed group	Acute to rehab	There was not a statistically significant change in quality of marriage post intervention. However, there was a positive effect on preventing decline of marriage quality. Marital relationship decline was worse amongst control subjects, who were not involved in any kind of psychological support.
Rice et al. 1987 Case series Level IV	*n* = 10 carers	Information on aphasia and the roles of clinicians, counselling and training in strategies to improve communication	2-hour sessions once a week for 12 weeks	Two Speech pathologists and psychologist	Carer group	Rehab and long-term	Good attenders showed significant improvement across measures of social dysfunction, somatic symptoms, anxiety, and psychological wellbeing.
Ryan et al. 2023 Randomised controlled trial Level II	*n* = 47 carers/family members control group *n* = 87 treatment group *n* = 88 people with aphasia control group *n* = 83 treatment group	Aphasia Action Success Knowledge (ASK) intervention, uses multimodal individualised goal setting and counselling	1x week for 1 h until 3 modules were completed (3h) plus four 2-hr phone calls	Speech pathologist	Dyad	Acute- rehab	There was no significant improvement in psychological wellbeing within groups for carers/family members.
Stead and White, 2019 Case series Level IV	*n* = 22 dyads	Information on relationship and intimacy, small and large group counselling sessions, and carers counselling group	3 days once per year	Occupation therapist students, speech pathologist students, neuropsychologists, nurses, and aphasia network staff	Carer group, mixed group, dyad	Long-term	Carer reported they felt they had strengthened the connection with their partner and "feeling like they are not alone."
Schwertfeger et al. 2023 Case series Level IV	*n* = 24 carers (almost half reported caring for someone with aphasia) *n* = 40 people with stroke	Support groups for stroke survivors and carers separately, recreational activities, and healthcare classes	3 days once per year	Music therapist and a nurse	Carer group, mixed group	Long-term	Statistically significant decrease in stress levels among stroke survivors and their carers. However, results are inconclusive since the study only looked at group-level outcomes and not all carers were for people with aphasia.
Van der Gaag et al. 2005 Case series Level IV	*n* = 22 carers *n* = 38 people with aphasia	Information on self-advocacy, counselling, and group-based therapy	1.4-hour sessions once per week for 17 weeks	Co-facilitated by people with aphasia and trained counsellors with aphasia	Mixed group, carer group	Long-term	There was not a statistically significant change on the coping with care measure, though the direction of change was positive post intervention. Carers reported the support groups was a good source for advice and information from others in a similar situation.
Wahrborg & Borenstein, 1989 Case series Level IV	*n* = 37 family members *n* = 22 people with aphasia	Family counselling sessions	2 to 6 sessions	Family therapist	Family	Long-term	After therapy, family members noticed improvements in the person with aphasia across 5 of the 18 items on a questionnaire that included tendency towards irritation, impatience, decreased quality and quantity in communication and lack of knowledge about the handicap. People with aphasia noticed improvements in family members across 3 of the 18 items that included irritation, decreased quality and quantity in communication.

*Same data set.

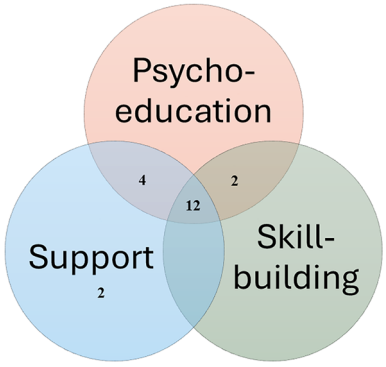

Figure 2. Venn diagram of number of studies with different intervention components.

psychological wellbeing, family functioning, knowledge of communication disorder and communication skills, social well-being, marital relationships, and carer's experience of the intervention.

Psychological wellbeing (n = 6)

Two studies reported significant improvements across domains of social dysfunction, somatic symptoms, and anxiety following a carer-only intervention [36, 40]. Two studies reported significant improvements in general wellbeing [85,86]. However, one of these reported on a carer support group that was a part of an Intensive and Comprehensive Aphasia Program (ICAP) [85], where not all participants were carers for people with aphasia post-stroke. Thus, results are inconclusive for this study as there were only group-level outcomes reported. Non-significant positive changes to wellbeing were reported by a community aphasia support group [84] and by a low intensity psychological counselling session (Aphasia Action Success Knowledge (ASK) intervention) [82].

Carer burden and stress (n = 5)

Two studies reported significant improvements in carer burden and stress following a community aphasia support group (mixed and carer-only groups) [84, 91] and a three-day therapeutic and recreational camp [89]. However, results are inconclusive for the latter since the study only reported group-level outcomes and not all carers were for people with aphasia. Non-significant positive changes in carer burden and stress were found in a carer-focused intervention [36] and in a community support group [90].

Social wellbeing (n = 4)

Two studies reported a positive effect on independence and participation in leisure and social activities for the dyad following a 2-day seminar [37,38]. One study reported carers in an aphasia camp making new friendships through opportunities of respite, and participation in new activities [87]. One study reported non-significant results on social participation in the carers-only intervention [36].

Family functioning (n = 5)

One study reported significant improvements in family functioning that included areas of problem solving, roles, behaviour control, and responsiveness by the carer and person with aphasia [37]. Another study reported family members showed positive significant change in their overall observed symptoms described in a personal questionnaire across the intervention [46]. Three studies reported on common themes that included being able to identify and deal with psychological problems in a more constructive way, greater acceptance of the family's altered state, a renewed sense of hope, improved ability to access social support resources, and emergence of a new social support network following a family-intervention [41, 48, 57].

Supported communication skills (n = 4)

One study reported statistically significant improvements on use of supported communication skills [40]. Whereas two studies reported non-significant results on improved use of supported communication skills [36, 84]. In another study family members and people with aphasia reported a positive change in quality and quantity in communication [41].

Marital relationships (n = 3)

One study reported non-significant positive results on a measure of marriage communication, although the change was more positive for couples adjusting to non-fluent aphasia following a marital relationship focused intervention [92]. The follow-up study looked further into the relationships between aphasia types, therapy attendance, and time factors with *post hoc* comparisons not indicating a significant difference between fluent and non-fluent aphasia groups [93]. Another study reported on surveys that indicated a positive change in perception of intimacy in the relationship post-stroke, with more carers indicating substantial impact than those with aphasia following an aphasia couples retreat [88].

Carers experience of the intervention (n = 1)

One study reported on participants' perceptions of a community aphasia group *via* semi-structured interviews, with carers offering mostly positive feedback about the spouse-only sessions [94]. Some recommendations for modifying the intervention included reducing the focus on the stroke/aphasia experience, introducing more opportunities for open discussions, and providing additional supplementary resources from the social worker.

Discussion

Post-stroke aphasia affects the entire family, with carers facing distinct challenges as they assume new roles within the family dynamic. The aim of this review was to identify and describe interventions for carers of people with post-stroke aphasia (other than interventions solely focused on communication partner training) and summarise the outcomes. To our knowledge, this is the first review to investigate the delivery and outcomes of carer interventions in this population.

Although only 20 studies were eligible for inclusion, a broad range of carer intervention formats were described including camps, seminars, support groups, family counselling, and marriage counselling sessions. Most interventions included people with aphasia and their carers in separate support group sessions [36, 48, 84–87, 89, 91]. Dyadic interventions were delivered in camps and counselling sessions with a focus on the relationship [57, 88]. Family interventions were delivered in private sessions with a focus on psychoeducation on aphasia and new family dynamics mostly led by trained psychologists [41, 46, 57]. However, one intervention trained speech pathologists in stepped psychological care, a structured approach to deliver "low intensity" psychological counselling to the person with aphasia and their carer/family members [82]. Only two interventions exclusively targeted the

carer in group sessions, but the location in which these interventions took place is unclear [36, 40]. The small number of carer-only interventions may be due to carers not being recognised as individual clients in current healthcare systems and the resulting challenge in funding and staffing carer-specific programs.

Most interventions focused on all three components of psychoeducation, skill-building, and support [36, 40, 57, 82, 84, 86–88, 92,93]. This is encouraging since the American Heart Association's Guideline recommends carer programs should contain a combination of skill-building and psychoeducation, stating that interventions for carers of stroke survivors focused solely on support or psychoeducation lack robust evidence [32]. Interestingly, a previous meta-analysis study looking at mental health in stroke carers revealed that psychoeducation interventions had a more significant effect when compared to support programs [95]. This may be in part due to psychoeducation interventions can be more precisely customised to meet the specific needs of carers, whereas support groups tend to cover broader topics and perhaps are explored from a group rather than individual perspective. There were five studies that did not include all three components of intervention, in part due to the format in which they were delivered [37,38, 48, 85, 89]. An ideal intervention program should include all three components as the needs of carers evolve across the continuum of care and each component contributes a distinct element to the program while also complementing one another.

The dose and timing varied considerably from an ongoing, one-day-a-week support group to a once-a-year weekend camp intervention. The high variability in dose would make it difficult to compare the effectiveness of the interventions. In the reviews of interventions for stroke carers, evidence suggests that psychoeducation and skill-building interventions typically involve five to nine sessions across three months [28, 31,32]. However, the majority of these stroke carer intervention studies do not state whether carers of people with aphasia have been included or specifically excluded. This is problematic and unfortunately reflects broader stroke research where a systematic exclusion of people with aphasia has been clearly documented [96]. Most interventions occurred during the long-term phase of aphasia, which is promising as it aligns with previous studies that have reported an increase in carer burden over the long-term phase of caring for someone with aphasia [7, 12]. However, there is a lack of evidence for carer interventions in the acute and rehabilitation phases despite documented carer needs during these phases [6].

Carers' needs differ across the continuum of care and healthcare professionals report barriers to providing ongoing support; for example, limited resources, organisational constraints, and motivation of carers [26]. During the acute and rehabilitation phases, information on aphasia and available resources are at the forefront of carers' needs [19]. During the long-term phase, this focus may shift towards psychosocial needs, with carers reporting having insufficient support in their personal lives and a lack of community resources. This can be attributed to the current model of service delivery that emphasises acute and sub-acute healthcare, with little funding focused on long-term and community services for people with chronic aphasia and their carers [97]. As reported in the carer-only interventions, the wellbeing of the carer can be improved during the rehab and long-term phase with a program that includes elements of psychoeducation, skill-building, and support such as information on aphasia management and wellbeing, stress management, and psychological support [36, 40]. This is an important factor to consider in the implementation of intervention programs for carers across healthcare systems and non-profit organisations.

There was variation in who led or facilitated the intervention programs, including speech pathologists, psychologists, psychiatrists, counsellors, and trained volunteers with or without aphasia. It will be a challenge to create a sustainable and affordable program led only by healthcare professionals due to factors such as staff shortages for funded services, lack of funded positions across the continuum of care, and rising healthcare costs. In addition to traditional face-to-face interventions, the use of online intervention and/or self-managed programs could potentially be cost effective, sustainable, and reach more carers. We found no examples of these in the retrieved studies.

All interventions targeted components of quality of life, including specific areas such as wellbeing, carer burden, activities/participation, family dynamics, and relationships. The assessments used to measure these domains were highly variable making it difficult to compare outcomes. For example, there were three different assessments measuring the same construct of carer burden and three different assessments measuring stress levels [36, 84, 89,90]. Carers in this population are far more susceptible to depression and anxiety in comparison to carers of stroke survivors without aphasia, but interestingly, only three studies included a general health questionnaire that screened for mood disorders [36, 40, 84]. As previous studies have highlighted, aphasia negatively impacts marital relationships with spouses having more negative views on their relationship post-stroke [98]. Relationships were targeted in three studies with a focus on improving marriage and intimacy and in four studies with a focus on improving the family dynamic [35, 41, 46, 57, 88, 92,93].

Overall, the studies demonstrated promising outcomes post-intervention across various domains of quality of life, with a focus on various components of psychological wellbeing immediately post-intervention. In some studies, a qualitative approach was taken through interviews and questionnaires at immediate post-intervention and at follow-up, where carers reported a positive change in overall psychological wellbeing and social support. Most studies that reported on follow-up outcomes lacked statistically significant changes, however direction of change tended to be positive. It is important to note that most measures of psychological wellbeing are self-reported and rely on factors such as respondents' perception and truthfulness. Therefore, it is important researchers use consistent validated questionnaires and interview techniques to gather comprehensive data on psychological wellbeing. Although the outcome measures used in quantitative studies varied, there was a consistent focus on improving the psychological wellbeing and psychosocial needs of carers. This is a positive finding, considering the frequent increase in depression and anxiety arising from responsibility of an unfamiliar role [8]. Notably, most studies had limited sample sizes thus requiring a careful interpretation of the outcomes.

Most studies were early proof of concept studies and case series with only three including control groups [36, 92,93]. This underscores the preliminary stage of the current research and emphasises the necessity for additional high-quality studies in aphasia carer intervention research to bridge the current gap. Future studies need to scale up and focus on rigorous study designs to examine the efficacy and effectiveness of various carer programs across healthcare and community-based settings. Research teams should include consumers, and healthcare and community service staff to enhance program development and implementation once programs are found to be efficacious [99].

Carers assume varying roles to help fill in the gaps in services or to facilitate the recovery of their partners and themselves [6]. A systemic change in the healthcare model is warranted, with each carer being seen as a client alongside the person with aphasia. In some countries, there are guidelines that help implement policies that recognise carers as a client. For example, the National

Clinical Guideline for Stroke for the United Kingdom and Ireland provides recommendations on how to work with carers, such as involving them in the planning and delivery of care and involving them in significant decisions [100]. However, these recommendations are focused on the care of the person with stroke and do not incorporate the personal needs of the carer. Additionally, there are no specific recommendations outlined in providing additional support to carers of people with aphasia. The Stroke Foundation in Australia created an online platform, Enableme.org.au, that has multiple resources and services for carers [101]. These include carer support resources to help connect carers with support networks and practical advice on emotional support. However, there are few resources specifically tailored for carers of people with aphasia. Healthcare policies and procedures will need adapting for systemic implementation of evidence-based carer programs, and this will require an investment of time and attention from healthcare providers. Carers have the right to receive appropriate support addressing the impacts of aphasia on their wellbeing, and providing this support for carers will also ultimately improve wellbeing and quality of life for their family member with aphasia.

Limitations

One potential limitation of this review is the inclusion of two studies with a mixed sample of carers, involving both those for stroke survivors without aphasia and those for individuals with traumatic brain injury [85, 89]. The results from these interventions need to be interpreted with caution as they pertain to group-level outcomes. There is a possibility that the outcome results for carers of people with aphasia could reveal distinct findings, deviating from the group level. Another potential limitation was the exclusion of studies solely centred on communication partner training. Two systematic reviews in communication partner training recommended educating partners in strategies that offer environmental support and enhance communication access for individuals with aphasia [31,32]. While the overall number of studies in this review could have been higher, including an analysis of outcomes in supported communication skills would have been redundant. Additionally, five out of 20 studies were discovered through manual searching of study references rather than through database searches. The keywords in four out of these five studies did not include "stroke" or similar terms. Therefore, it is possible that there may be additional studies not accounted for due to the absence of stroke-related keywords.

Conclusion

This review investigated interventions for carers of people with post-stroke aphasia, revealing a diversity of formats, dosage, and outcome measures, with most interventions jointly involving the carer and person with aphasia. Encouragingly, most interventions encompassed psychoeducation, skill-building, and support components, aligning with recommendations for stroke carer interventions. However, evidence gaps persist in the acute and rehabilitation phases, even though there are documented carer needs during these phases[6]. The needs of carers change over time and the current healthcare model limits services during the long-term phase. Additionally, only two interventions were exclusively targeted towards the carer, even though the stroke literature indicates carer-directed interventions have the best outcomes for carers' wellbeing [31]. Overall, studies reported positive carer outcomes following interventions, although the levels of evidence are low. Future studies could consider the efficacy of online and self-management programs, along with the long-term effects of interventions on carers' quality of life. Despite these limitations, there are promising interventions that have the potential to improve different aspects of quality of life for carers.

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