IntechOpen

The Importance of Aphasia Communication Groups

Marina Charalambous[1,2] and Maria Kambanaros[1]

[1]Rehabilitation Sciences Department, Cyprus University of Technology, Limassol, Cyprus;
maria.kambanaros@cut.ac.cy, https://orcid.org/0000-0002-5857-9460;
marina.charalambous@cut.ac.cy, https://orcid.org/0000-0002-5310-3017
[2] Laboratory of Cognitive and Neurological Sciences, University of Fribourg, Switzerland; marina.charalambous@unifr.ch

Corresponding Author: maria.kambanaros@cut.ac.cy, Professor of Speech Pathology

Abstract

Chronic aphasia is linked to poor functional recovery, depression, and social isolation. In the exploration of the above factors the role of aphasia communication groups has evolved. Aphasia communication groups for stroke survivors with chronic aphasia and their communication buddies are gaining clinical importance. Communication buddies can be family members, friends, carers, health professionals and speech and language therapy students who serve as communication facilitators for each group member. Group members share experiences on stroke and aphasia by using technology/tablets and the total communication approach. The benefits or outcomes of group involvement are measured by assessment of functional communication, individual self-ratings of the impact of aphasia on communication and quality of life after stroke. The use of the communication buddy system, total communication approach and systematic evaluations enables therapists to measure the effectiveness and efficacy of communication groups in terms of functional communication, social inclusion and quality of life.

Keywords: communication buddies, quality of life, aphasia communication groups

1. An introduction to aphasia communication groups

Aphasia is an acquired communication impairment, that impacts the ability to speak, understand, read, write, and carry out mathematical calculations [1]. It is caused by damage to the language networks in the brain usually after stroke but not only [2]. Aphasia is linked to poorer functional recovery [3], return to work [4], activities of daily living [5], depression [6] and social isolation [7].

Functional communication and social participation are impaired in aphasia which brings about reduced confidence in communication [8]. This leads

to reduced interactions with family and friends [9] and smaller social networks [10]. Although maintaining social interactions and friendship networks in the chronic phase of aphasia (greater than 6-months post brain injury) has been identified as an important goal in aphasia rehabilitation, this is not regularly addressed by aphasia clinicians [9].

Historical models of aphasia assessment and treatment have focused mainly on the person's linguistic competence [11]. Even though people with aphasia (PWA) may have successfully achieved their therapeutic goals in individual speech and language therapy sessions, they still struggle to use their new communication skills successfully in natural environments e.g., with family members, close friends, and their therapist outside of the clinic/treatment environment [12]. Contemporary rehabilitation approaches pay increasing attention to the pragmatic competence and the overall functionality of communication of PWA via aphasia communication groups (ACGs) [13].

In the context of the International Classification of Functioning, Disability and Health (ICF) [14], biopsychosocial models of disability, and particularly the Life Participation Approach to Aphasia Project Group [15] interest in ACGs is increasing in both research and clinical settings [16]. ACGs provide psychosocial benefits to PWA, including increasing social participation and peer support [17].

1.1 Defining Aphasia Communication Groups

Aphasia communication groups (ACGs) are defined as small groups of people with aphasia and their communication partners who interact with each other on a regular basis. These groups include PWA who can communicate in any accessible way, are aware of each other's presence and perceive themselves, and are perceived by others, as being members of a group [18]. *ACGs* are described as informal groups meaning that they are more erratic and spontaneous, and less constrained by formal structures and power relationships compared to formal groups (committees, boards etc.) [19].

While ACGs can focus on the impairment-based characteristics of the aphasia, the nature of the group setting tends to elicit functional, naturalistic forms of communication [20]. The actions and subject matter of each communication group varies enormously and depends mainly on the goals and aspirations of the group members. Group members develop close relationships with each other in a natural and supporting environment which promotes meaningful conversations with people who empathize with their difficulties. *ACGs* work on the "barriers" that make communication challenging for the person with aphasia and their communication partners, and on what communication tools members could use to improve communication [21]. The different methodological approaches used in ACGs such as learning events, personal stories and patient narratives foster functional communication, active engagement and mutual support [22, 23, 24].

The primary *aim* of the *ACGs* is to provide support for PWA on learning about aphasia, communication opportunities to promote living well with aphasia and improve quality of life [20]. Another common *goal* is the understanding that aphasia can be a life-long condition, and that aphasia is a 'family issue', impacting not only the person with aphasia [21]. The main *pillar* of ACGs is to

create a supportive and safe environment for meaningful communication and social endeavors that encompass interactive functional communication activities [21]. *ACGs* promote full participation and engagement in activities of interest and are inclusive to all PWA irrespective of degree and severity of aphasia [25]. In fact, ACGs have been likened to a '*rope team'* [26]. The term 'rope team' comes from the sport of mountain climbing. The rope team will tether themselves together for safety to help prevent falls. By establishing a rope team, individuals with aphasia are provided with a positive atmosphere for participation and communication without fear of judgment. In aphasia rehabilitation, a rope team can consist of other healthcare professionals and caregivers, but, more importantly, others with aphasia.

1.2 Communication Quality in Aphasia Communication Groups

ACGs should seek to make improvements in the communication quality of PWA. Based on the *Communication Quality Guidelines* of the Royal College of Speech and Language Therapists (RCSLT) [27] this is fostered when groups are EASIER:

1. ***E**ffective*: by delivering group activities that adhere to evidence-based practice and result in improved activity and participation outcomes for PWA, based on individual needs;
2. ***A**ccessible*: by delivering ACGs that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical/ rehabilitation needs;
3. ***S**afe*: by delivering ACGs which minimizes risks and harm to service users;
4. ***I**ndividualized/client-centred*: by delivering ACGs which considers the preferences and aspirations of individual service users and their communities;
5. ***E**quitable*: by delivering ACGs which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status;
6. ***R**esource efficient*: by delivering ACGs in a manner which maximizes resource use

1.3 Why are aphasia communication groups important to people with aphasia?

Loneliness and social inaccessibility in chronic aphasia leads to poor community and public engagement [9]. Aphasia communication groups are an opportunity for social participation [28] that promote community integration, broaden friendship circles, and improve social connectedness [29]. Without prospects for *good communication* PWA struggle to learn about their condition, to achieve personal goals, make friends and interact meaningfully – all fundamental for citizenship and humanity and central to improving quality of life [27]. All these principles are offered to PWA in a communication group setting as they are given opportunities to exercise their human right on how to be involved with decisions about their care, make choices about their daily life, create opportunities to communicate their needs and thoughts, understand and express their necessities in relation to their health and wellbeing whilst being treated with respect and dignity [27].

ACGs are important to PWA as they have a common *purpose*: to become familiar with aphasia symptoms, to share personal experiences, support and encourage each other and training on how to establish successful functional communication [25]. In a review by Attard and colleagues [30] on consumer perspectives on community ACGs the findings revealed that group attendance formed positive relations for PWA with others, gave purpose in life, promoted environmental mastery, autonomy, personal growth, and self-acceptance. According to Lanyon and colleagues [31] PWA perceive community aphasia-group participation to be beneficial to their ability to live well with aphasia. Peer-to-peer communication strategies, shared roles and responsibilities, and consultation regarding group objectives and processes provide group members with the opportunity to become active contributors, demonstrate competence and have positive influence over the group [31]. During the qualitative investigation of the factors impacting participation and integration of PWA in aphasia community groups, Lanyon and colleagues [31] revealed 7 important features:

1. *Balanced interactional patterns*: reflects the balance and equal share in interactions between group members and leaders. It is associated with equal turn taking opportunities and the promotion of the appropriate sensitivity of the group leader towards group members.
2. *An open and non-hierarchical group environment*: relates to the maintenance of an interactional space which provides active consultation between peers and opportunities for the members to share roles and assume responsibilities (such as activities planning, assisting in message transfer and organizing coffee breaks).
3. *Communication awareness and education amongst members*: demonstrates the need for group members to learn communication support strategies and aphasia training to understand and interact respectfully to their fellow members.
4. *Meaningful activity*: shows the constant need of group members for authentic interactions related to day-to-day life situations and life sharing experiences with socially focused activities.
5. *Ritual and structure*: group rituals such as formal welcomes, opportunities for sharing information and involvement in the preparation of a coffee break, are considered the foundation for enabling members, regardless their prior experience with group processes, to intergrade within the group and feel that they participate in a relaxed and non-threatening environment.
6. *Composition and group size*: both size and composition are central to the involvement of PWA within the group and may function as a bridge or barrier to their positive participation experience. ACGs with a mixed composition of people with a range of communication abilities are considered more beneficial for PWA with more severe communication difficulties. Also, smaller group size (3-4 members) fosters the creation of an individual *identity* of each group member and promotes family and friendship like endeavors. On the contrary, large groups (15 members) are challenging for PWA to interact.
7. *Group leadership*: Group organizers and leaders play a crucial role in shaping the pattern of interaction, encourage an engaging space and model effective interaction. ACGs should equalize the power and status between leaders and the members by elevating the position of member peers to group leaders.

Aphasia communication groups positive participation promotes *patient involvement* (PI) and elevates discussions on how aphasia impacts activities of daily living, social integration, and participation [32]. Azios et al (2021) propose a *co-design* model of intervention and research on friendship maintenance within aphasia communication groups, as a means of addressing the issues of social isolation and other personal concerns of PWA. The *Quality of Communication Life Scale* [33] suggests that "the more positive the personal and environmental factors, the more successful the [person's] communication acts, the better the quality of communication life" (p. 2). Taking into consideration the perspectives, needs and experiences of PWA, as service users in ACGs, is critical to use PI approaches and activities that will accelerate translation to real-world activities and promote functional interventions and strategies for living successfully with aphasia (activity and participation levelo [14]. Positive effects of ACGs where PWA are actively involved in decision making, build confidence in PWA to express their needs, whereas research evidence demonstrates positive health benefits of building interpersonal relationships and community while being part of an ACG [20].

2. Setting up an aphasia communication group

2.1 Establishing Ground Rules

Before establishing an ACG, members should discuss and agree on the group's ground rules using a SIMPLE approach. The ACG and each individual group member should be:

Supportive – Ask caring questions; listen attentively to responses/others
Inspirational – Reassure others that life gets better and not to give-up
Motivational – Encourage action and acknowledge improvement
Practical – Offer options, helpful tips, and information and access to resources
Life-affirming – not deny or devalue/trivialize the feelings of others
Educational – Talk about what's worked for them and others; offer guidance/counsel, but without giving prescriptive advice

2.2 Inclusion Criteria

The general inclusion criteria for *ACGs* are that PWA:

- are living in the community
- have been discharged from acute and sub-acute rehabilitation
- are in the chronic stage of aphasia,
- do not need additional medical support while being at group,
- have given written informed consent to participate
- have signed a confidentiality contract so they won't share the personal experiences and narratives of other group members with people outside the group
- present with various types and severities of aphasia

The inclusion criteria are usually adjusted according to the setting and the purpose of each ACG [21].

2.3 Group Features

A successful group requires several features to be efficient: the members, the group, and the tasks/activities, the context [34]:

- The *Members*:
  - → work co-operatively and not competitively
  - → support each other and show empathy
  - → get rewarded collectively and not individually
  - → are aware of the nature of the group process
- The *Group*:
  - → is relatively small (maximum 5 people),
  - → is autonomous to address its activities and tasks
  - → has an effective leader/facilitator
  - → operates in the context of a supportive organization or community
- The *Tasks/Activities*:
  - → are accessible to all members
  - → are designed considering the individual skills of each member
  - → promote the active engagement of all members
  - → have precise objectives
  - → have a beginning and a defined end
  - → have measurable indicators of success
- The *Context*:
  - → Physical environment should be accessible
  - → Time Schedule and Agenda should be defined
  - → Resources should be allocated before enrolment
  - → External factors should be taken into consideration (travelling, financial issues)

2.4 Total Communication

Group members practice total communication skills i.e., gestures, singing, drawing, and writing and/or a combination of all the above [20]. The main topics of discussion are learning about/refreshing knowledge on stroke and aphasia, linking the information to members own experiences, asking questions, and discussing living with stroke and aphasia [21]. It is also important for members to share stories about life before the stroke [35]. Resources for Total Communication such as writing boards, notebooks, tables, communication books, aphasia friendly materials [36] and the Internet should be used to access information online [37].

2.5 Virtual Aphasia Communication Groups

Group meetings can be established with face-to-face contact or digitally. Virtual group meetings and videoconferencing is a growing trend in aphasia rehabilitation with a major impact [38]. Online groups favor the person with mild to moderate aphasia, the member who is well motivated to participate and seeks interaction despite the means. In online ACGs, it is mandatory that members know how to operate a tablet, mobile phone or a laptop independently and understand the ethics and procedures behind video conferencing [39]. Realistically, ACGs via video conferencing compared to face-to-face interaction

needs more time to plan and prepare. When technical problems occur, and they often do occur, they cause anxiety and frustration to the group. Some members become diverted into 'fixing' the problem where others 'switch off' from participating, factors that make the interaction dysfunctional. The experience of engaging in an online meeting is more mentally demanding as members must concentrate simultaneously on the content of the meeting, the visual material, and the constant input from several sources. Additionally, non-verbal cues are not detected easily, and the facilitator must be proactive in giving cues and prepare digital material to promote engagement.

3. Setting Client-Centred Goals in the Aphasia Communication Groups

According to Worrall and colleagues [40] goal setting in ACGs with PWA can be challenging because of members:

- *persisting language impairment* which makes expressing needs and discussion of experiences a long and demanding process
- *cognitive difficulties* that create struggles with decision-making,
- strain in understanding the *abstract concept of aphasia*
- *poor awareness* of their overall condition
- feelings of *disempowerment* that arise when communication is distracted
- *age as* members that are often older expect to be directed in one- on-one therapy rather than group treatment

A further challenge is related to the *setting* that may reinforce a culture in which SLTs focus on the language impairment and are in control.

3.1 SMART short-term goals

At the beginning of each ACG goals are discussed with the members of the group, which are more likely to be their long-term goals for aphasia rehabilitation in general. The facilitator along with the communication buddies needs to support the members of the group to break down these goals into SMART short-term goals that can be addressed in the group. These goals should be SMART: Specific, Measurable, Attainable, Relevant, and Time based.

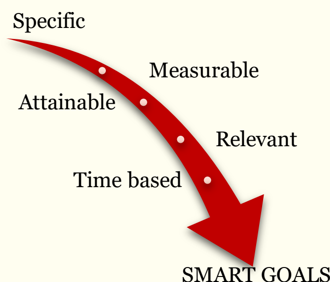

Figure 1. Setting SMART goals in ACGs

3.2 The SMARTER Framework

In combination with the SMART goals, the SMARTER "Shared, Monitored, Accessible, Relevant, Transparent, Evolving, Relationship" framework encourages aphasia rehabilitation specialists engaged into group therapy to share the goal setting process with the person with aphasia [41]. The procedure of setting SMARTER goals should be accomplished in a way that is accessible to the members of the group and ensures that the goals evolve with the needs of the clients. Within this framework, the person with aphasia is actively engaged in monitoring their own progress on the goals and each activity in group ensuring transparency (see Figure 2). All goals are relevant to the person with aphasia, and care is provided in a way that builds rapport within the group. Personalized and qualitative therapeutic objectives enable group members to gain more insight into their communication barriers, individually and within the group.

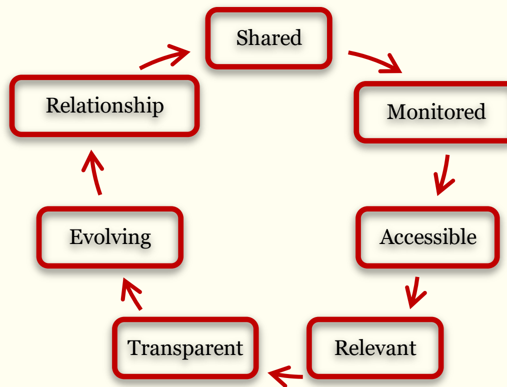

Figure 2. The SMARTER framework based on Hersh et al. (2012).

For ACGs to achieve a SMARTER goal setting, the facilitator must read through the framework extensively and then answer the questions for each domain reported below in Table 1 [41]:

	YES	NO
Shared		
• Has the person with aphasia and their family been able to prepare before attending the session? • Have family members, carers and significant others been involved in goal setting? • Has information been presented in a comprehensible way? • Is the information relevant to the person with aphasia? • Is the relationship between group members a trusting and collaborative one? • Have all people involved in goal setting understood the purpose the procedure? • Have all people involved been able to express their individual needs and personal expectations?		

Relationship Centered		
• Have the established goals been client-centered? • Has good rapport and trust been developed between the group members and facilitators?		
Relevant		
• Do the goals take into account the client's everyday life? • Has the client's family members and carers been involved in the goal setting process?		
Accessible		
• Are goals written in an accessible aphasia-friendly format? • Can extra support been provided to ensure understanding? • Do PWA understand that they can change their goals if they wish to?		
Transparent		
• Are PWA and their carers aware about which goals will be worked and how these will be assessed? • Is it clear how their personalized goals and the processes used to achieve these are linked? • Have they been able to assess what they will learn about during the group based on their current needs and goals?		
Monitored		
• Have the goals been written in a way that allow for ongoing evaluation? • Have the goals been written in a way that allow modifications? • Can these goals be used to review improvements or no improvements?		
Evolving		
• Are PWA and their carers aware that they can review the goals? • Are PWA and their carers aware that they can change the focus of the activities if they like?		

Table 1. Specific questions involved in SMARTER goal setting framework as adapted from Hersh et al., (2012)

4. The Communication Buddy System

A Communication buddy is a communication and conversation partner assigned for each individual person with aphasia within the group. Their main goal is to facilitate the understanding and output (not necessarily verbal) for PWA within the group. Communication buddies should establish mutual support, promote learning about aphasia, facilitate communication and promote communication skills enhancement [21]. Pairing in groups is based on Bion's theory of 'containment' or 'container and contained'. According to Bion (1961) the *theory of containment* is the capacity of one individual to receive in himself projections from another individual, which he then can sense and use as communications (from him), transform them, and finally give them back (or convey back) to the subject in a modified form (see Figure 3) [42].

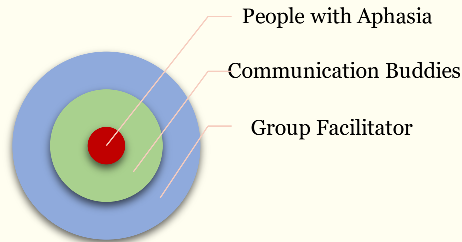

Figure 3. The 'essential' people that make up *ACGs*

Communication buddies can be:

- health care professionals
- allied health rehabilitation students e.g., speech and language therapy students
- the client's carer, a family member or friend
- volunteers from aphasia and stroke support organizations

Communication buddies should be identified and assigned by the person with aphasia or by the setting where the group is taking place e.g., students in a university setting. Communication access, social contact and active participation are crucial elements in aphasia groupwork. The person with aphasia, the group facilitator, and the communication buddy must collaborate to find the means and strategies that are most useful for the particular client during communication breakdowns. These may include gestures, drawing, picture support, simplified text, writing keywords, clarification statements, verification questions, eliminating environmental distractors and summarizing (see Table 2). It is mandatory to work closely as a team to identify and tailor these strategies to the person with aphasia.

Means and Strategies	***Description***
Gestures	Hand and body movements to express a meaning
Drawing	A picture or a diagram to represent a word or a meaning
Picture Support	The use of a picture that can support understanding of the topic
Simplified Text	A process to simplify a written message's content by paraphrasing

Writing Keywords	The use of important/ concept words to promote understanding
Clarification Statements	To explain something in more detail to clarify the meaning
Verification Questions	To ask yes/no or simple questions so to confirm understanding
Environmental Distractors	Things in the environment that move, make noise or vibrate
Summarizing	To give a brief statement of the main points

Table 2. The means and strategies for communication recovery

4.1 Communication Partners Training

It is crucial that communication buddies, prior to their involvement with the group [41]:

- receive *education* on group therapy principles
- *practice* scenarios via role play and home assignments
- watch videos and work on communication repair (i.e., how to modify, repeat or revise a message when the first communication attempt has failed) and facilitation strategies (i.e., active listening, good preparation, prompting, visual and verbal cues).
- receive *training* on feedback techniques, problem solving, conversation skills and self-reflection.

It is mandatory that communication partners learn how to implement the communication strategies within the group, communicate their message in simplified and accessible ways and assist the person with aphasia to get their message across [43].

5. Peer-led aphasia communication groups

Peer-led support groups for PWA are run by a person with aphasia and/or family member, with the assistance of their communication buddies which aim to increase social interaction and peer support [44]. Peer-led models in aphasia communication groups provide access to constant peer support and may address some of the limitations of professionally led support groups that may use formal agendas and have a strict group structure [45].

Studies examining peer led support groups in other chronic conditions, that is, cancer survivors, have shown peer-led support groups (72.1%) are greater in the community than professionally led support groups (27.9%) [46], and there is a larger preference for peer than professional health care leaders [47]. For example, by reducing professional resources and interventions, peer led ACGs can provide extensive, long-term opportunities for functional communication, social contact, friendship, and peer support [48]. Aphasia Connect has successfully expanded the range of services available for PWA across the UK by utilising PWA as service providers (group leaders) as well as receivers (group members) [49]. Additionally, members of peer led ACGs share a greater sense of empowerment and ownership as they provide *and* receive support [45]. In most UK aphasia peer led groups, PWA receive training and ongoing support from speech-language therapists and trained volunteers to co-facilitate and co-design

support groups [48]. Similarly in other community based ACGs such as Speakability UK, professional facilitators support the initial development of self-assisted groups for PWA, for example by suggesting resources and tips, and provide additional support upon request from group members [47].

Tregea and Brown [45] found that the features that are important for the successful functioning of a peer-led aphasia support group are:

- *Friendship*: instant bonds, feelings of belonging and close friendships that resulted from shared experiences and mutual understanding.
- *Informality*: the sense of casualness, a relaxed environment with no pressure to communicate and no formal agenda.
- *A supportive communication environment*: mutual support to participate, the need for patience and encouragement to communicate.
- *Providing support*: a support base for PWA and their families to feel accepted, provision of resources and information about aphasia.

Additional factors that facilitated peer leaders to start and run groups include informational support, practical support, attracting new members, time, venue and organization, and a pleasant communicative personality [45].

6. The role of the facilitator

Aphasia communication group facilitators should not necessarily be qualified SLTs but individuals who have been trained by professional SLTs and/or the research team, in case the group is part of a randomised controlled trial (RCT), ahead of the intervention or trial, with a particular focus on meaningful and effective communication with PWA [49]. Facilitators should be provided the National Aphasia Guidelines [50] for communication with PWA and be trained on partner conversation skills [43]. Facilitators should assist PWA to co-facilitate the group, and complete checklists at the end of each group session to evaluate fidelity to group content [49]. In a recent pilot feasibility RCT by Tarrant et al [51] examining group signing intervention in PWA, the facilitators identified several benefits which they attributed to the intervention, starting with the prospect for PWA to meet peers and share personal experiences and the development of warm, empathetic friendships.

In contemporary clinical aphasiology, facilitated conversation in aphasia communication groups are a popular exercise but only a small number of published studies have documented how interactions occur in such group settings [51, 52]. One aspect of ACGs that has been mentioned in the recent literature, but that has not yet been the focus of intensive study, is participation management [51]. Facilitators report that finding ways to help people with limited expressive language participate in conversation and the group in general is one of the central challenges faced by the clinicians and volunteers who lead these groups [51, 52, 53].

The study of Archer and colleagues [52] documents common approaches to assisting PWA to participate meaningfully within the group discussions. Results revealed a set of conversational practices used by facilitators and by group members with verbal output difficulties. Archer et al [52] stated that 'these practices took the form of two sequences viz. floor transfers and question-answer series' (p.15). The identified sequences contributed to promoting meaningful conversational participation by group members with non-fluent aphasia.

After a national survey of third sector ACGs facilitators in the UK by VandenBerg and colleagues (2018, p.25) [54] results revealed that the factors described as important to supporting members' attendance in aphasia support groups were as follows:

- A kind induction (29%);
- Members' confidence in their communication skills (24%); and
- Positive group dynamics (23%).

Also, in the same study [54] (p.25) facilitators indicated that motivators for PWA's attendance were prioritized by their communication needs:

- "To get better at communicating"(16%);
- "To feel confident talking"(13%);
- "Meeting other people with aphasia" (18%)
- "Over peer support" (10%)
- or "Emotional support" (8%)

7. Evaluating the benefits of aphasia communication groups

Aphasia communication groups offers many advantages over traditional individual therapy models in the chronic stage [55]:

- *Provides naturalistic communication opportunities and practice*: the group setting facilitates provides a safe non-judgmental environment for participants to practice and improve pragmatic skills, such as turn-taking, topic initiation and maintenance [56]. Conversation practice and the use of spontaneous utterances may assist with generalization of language skills to everyday interactions rather than the use of overlearned therapy targets [57].
- *Is cost effective:* the session cost for each individual member can be reduced while maintaining a per-hour reimbursement that is similar one to one session.
- *Has positive psycho-social outcomes*: PWA experience social isolation and reduced meaningful social engagements [42].

Group evaluation has three fundamental purposes [57]:

1. *To validate* and gain approval and acceptance of the status of the group. This process gains justification both for the choice of activities of the group and the continuing of its actions.
2. *To improve* by recognizing the importance of identifying any weak areas and how to improve these.
3. *To condemn* the weak practices of the group and to highlight the group inadequacies.

To proceed with an evaluation process of the ACG one could choose to evaluate all or any of the following areas [19]:

- *The process*: How were activities prepared and conducted? How was the method processed from formation of the group to disbandment?
- *The members*: How did the members perform, either as individuals or within the group?
- *The resources*: Was the allocated venue, resources, room equipment and time allocated sufficient?

- *The organization*: Did the group structure, context, content, and communication strategies, hinder or promote members involvement?
- The objectives: Were the goals appropriate to the needs of the group? Were the goals sufficiently adapted to the individual needs of the group members?

8. The Aphasia Communication Team (TACT): a university affiliated aphasia communication group

The TACT is a university affiliated ACG in the Republic of Cyprus. The number of strokes in Cyprus range between 1,200 - 1,400 yearly [58]. If one considers a third of all stroke survivors have aphasia this means, there are roughly 400 new cases of aphasia each year. 61% continue to experience communication problems 1 year after stroke leading to fewer friendships and smaller social networks [59]. In the exploration of all the above factors influenced by aphasia, the idea of The Aphasia Communication Team – TACT emerged. TACT delivers benefits to PWA, families, and speech-language therapy trainees. TACT aims to provide stroke survivors support for learning and communication opportunities to promote living well with aphasia. TACT works on the barriers (areas of weakness of the person with aphasia and conversation partners that make communication difficult) and on what communication tools members could use to improve communication. TACT has a broad outlook for living well with aphasia and to improve quality of life. Another goal targeted is the understanding that aphasia can be a long-term condition and that aphasia is a 'family issue'—not just for the person with aphasia [60]. TACT promotes full participation and engagement in activities of interest. TACT encourages a safe, positive, environment, and is inclusive to all.

The Cyprus Stroke Association recruits stroke survivors and TACT is held at the premises of the Rehabilitation Clinic of the Cyprus University of Technology once a week, for two hours. Two groups have been established so far, with 5 stroke survivors with chronic aphasia and 5 communication buddies, for each group. Communication buddies are speech and language therapy students who serve as communication facilitators of each group member. The groups are supervised and coordinated by academic and scientific staff from the Department of Rehabilitation Sciences.

The Inclusion Criteria for participating in TACT is that PWA:

1) are discharged from formal rehabilitation [53]
2) have terminated individual speech and language therapy sessions [34]
3) aphasia is a predominant communication difficulty in relation to possible apraxia of speech or dysarthric symptoms [20]
4) can sustain approximately 2-hour participation with the group
5) present with different severities of aphasia [18]
6) do not need additional medical support while being at group [55]
7) should manage toileting or have additional support from a carer [34]
8) have given written consent to participate and sign a confidentiality contract with the clinic and CSA.

Group members are assessed on psychometric measures (language, cognition, and quality of life) at the beginning and at the end of each block of therapy. Therapy consists of a 12-week block of weekly sessions. The assessment

procedure is based on the International Population Registry for Aphasia after Stroke (I-PRAISE) protocol [61] in combination with the Attard et al [53] ICF based assessment protocol. This is deemed necessary to measure improvement or change in behaviors post-therapy (see Table 3).

ICF Domain- Outcome Measures	
Aphasia impairment	• Aphasia Severity Rating Scale; ASRS by the shortened version of the Boston Diagnostic Aphasia Examination; BDAE • Western Aphasia Battery–Revised Aphasia Quotient; WAB–R AQ
Activity & participation	• Amsterdam Nijmegen Everyday Language Test; ANELT • Scenario Test • Communicative Effectiveness Index; CETI
Contextual Factors	• Therapy Outcome Measure; TOM • Subjective Index of Physical and Social Outcome; SIPSO
Quality of life	• Stroke and Aphasia Quality of Life Score; SAQOL-39g • Assessment of Living with Aphasia; ALA
Psychological health	• General Health Questionnaire-12; GHQ-12 • Perception of Patient-Centeredness/Consultation Care Measure

Table 3. ACGs Outcome measures

Group members are encouraged to share experiences by using technology and tablets. They also practice total communication skills i.e., adding gesture, drawing, and writing to speech. The main topics of discussion are acquiring new knowledge on stroke and aphasia, linking the data to members personal experiences, clarifying questions and misunderstandings about their condition, and sharing stories about their life before stroke, the incidence itself and living with aphasia (see Figure 4).

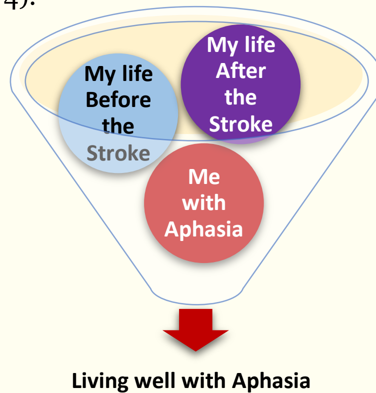

Figure 4. The main conversation 'topics' for TACT members

Group member's outcomes consist of change or improvement in measures of functional communication, overall severity of language impairment, auditory comprehension, spoken language (including naming), reading, and writing from baseline, overall communication self-rating and quality of life after stroke. Data gathered via assessment procedures are digitalized for each individual member on a data base using the RELEASE protocol [61]. The use of the communication buddy

system, the involvement of the total communication approach, the systematic assessment, and the collection of individual patient data (IPD) sets enable the TACT team to measure the effectiveness and efficacy of group therapy interventions for people with chronic aphasia in terms of use of functional communication, social inclusion [14] and quality of life [31].

Conclusion

There is no doubt that Aphasia Communication Groups (ACGs) are of great benefit for people with chronic aphasia. ACGs are associated overall with improvement in communication, social networks, and community access. To achieve this, ACGs facilitators, participating members and communication buddies should have equal involvement in the realization of the group.

Conflict of Interest

The authors declare no conflict of interest

References

1. Mitchell C, Gittins M, Tyson SF, Vail A, Conroy P, Paley L, et al. Prevalence of aphasia and dysarthria among inpatient stroke survivors: describing the population, therapy provision and outcomes on discharge. Aphasiology. 2020;(4):1–11.

2. Berg K, Isaksen J, Wallace S, Cruice M, Simmons-Mackie N, Worrall L. Establishing consensus on a definition of aphasia: an e-Delphi study of international aphasia researchers. Aphasiology. 2020;1–16.

3. Ali M, Lyden P, Brady M; VISTA Collaboration. Aphasia and Dysarthria in Acute Stroke: Recovery and Functional Outcome. Int J Stroke. 2015 Apr;10(3):400–6.

4. Burfein P, Roxbury T, de Silva N, Copland D. (2016). Return to work for stroke survivors with aphasia: Preliminary findings of a scoping review. The Inaugural Herston Health Precinct Symposium, 7-11 Dec 2020. Royal Brisbane and Women's Hospital.

5. Manning M, MacFarlane A, Hickey A, Franklin S. Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis. PLoS One. 2019 Mar;14(3):e0214200.

6. Laures-Gore JS, Dotson VM, Belagaje S. Depression in Poststroke Aphasia. Am J Speech Lang Pathol. 2020 Nov;29(4):1798–810.

7. Hoover E, McFee A, DeDe G. Efficacy of Group Conversation Intervention in Individuals with Severe Profiles of Aphasia. Semin Speech Lang. 2020 Jan;41(1):71–82.

8. Doedens W, Meteyard L. Measures of functional, real-world communication for aphasia: a critical review. Aphasiology. 2020;34(4):492–514.

9. Azios JH, Strong KA, Archer B, Douglas NF, Simmons-Mackie N, Worrall L. Friendship matters: a research agenda for aphasia. Aphasiology. 2021;1–20.

10. Koleck M, Gana K, Lucot C, Darrigrand B, Mazaux JM, Glize B. Quality of life in aphasic patients 1 year after a first stroke. Qual Life Res. 2017 Jan;26(1):45–54.

11. Tippett DC, Hillis AE. Where are aphasia theory and management "headed"? F1000 Res. 2017 Jul;6:6.

12. Harmon TG, Lin ML, Scronce G, Jacks A. Supporting Confidence and Participation for People with Aphasia Through Student Interaction: A Descriptive Study on the Effects of an Interdisciplinary Campus Program. J Allied Health. 2019;48(4):e107–12.

13. Lee JB, Azios JH. Facilitator Behaviors Leading to Engagement and Disengagement in Aphasia Conversation Groups. Am J Speech Lang Pathol. 2020 Feb;29 1S:393–411.

14. World Health Organization. International Classification for Functioning, Disability and Health (ICF): Short version. Geneva, Switzerland: Author; 2001.

15. LPAA Project Group. Chapey, R., Duchan, J., Elman, R., Garcia, L., Lyon, J. G., & Simmons-Mackie, N. (2001). Life participation approach to aphasia: A statement of values for the future. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (pp. 279–289). Baltimore, MD: Lippincott Williams & Wilkins

16. Pettigrove, K. (2020). *Scoping Review Protocol: Characteristics and Impacts of Community Aphasia Group Facilitation*. https://doi.org/10.13140/RG.2.2.13592.01285..

17. Elman RJ. Introduction to group treatment of neurogenic communication disorders. In: Elman RJ, editor. Group Treatment of Neurogenic Communication Disorders: The Expert Clinician's Approach. 2nd ed. San Diego: Plural Publishing, Inc.; 2007.

18. Elman RJ, Bernstein-Ellis E. The efficacy of group communication treatment in adults with chronic aphasia. J Speech Lang Hear Res. 1999 Apr;42(2):411–9.

19. Elwyn G, Macfarlane F, Greenhalgh T. Groups: A Guide to Small Group Work in Healthcare, Management, Education and Research. 1st ed. CRC Press; 2001. https://doi.org/10.1201/9781315384375.

20. Elman RJ. Group Treatment of Neurogenic Communication Disorders: the Expert Clinician's Approach. 2nd ed. San Diego (CA): Plural Pub.; 2007.

21. Charalambous M, Kambanaros M. Aphasia Communication Groups in Cyprus: The Aphasia Communication Team (TACT). Joined e-Conference of the European Stroke Organization (ESO) and the World Stroke Organization (WSO). Int J Stroke. 2020;15(1 SUPPL):724–724.

22. Bronken BA, Kirkevold M, Martinsen R, Kvigne K. The aphasic storyteller: coconstructing stories to promote psychosocial well-being after stroke. Qual Health Res. 2012 Oct;22(10):1303–16.

23. Kambanaros M. Evaluating Personal Stroke Narratives from Bilingual Greek-English Immigrants with Aphasia. Folia Phoniatr Logop. 2019;71(2-3):101–15.

24. Cruice M, Aujla S, Bannister S, Botting N, Boyle M, Charles N, et al. Creating a novel approach to discourse treatment through coproduction with people with aphasia and speech and language therapists. Aphasiology. 2021;1–23.

25. Fama ME, Baron CR, Hatfield B, Turkeltaub PE. Group therapy as a social context for aphasia recovery: a pilot, observational study in an acute rehabilitation hospital. Top Stroke Rehabil. 2016 Aug;23(4):276–83.

26. Worall L. The Seven Habits of highly effective aphasia therapists: The perspective of people living with aphasia. International Journal of Speech-Language Pathology, 21(5): 438-447. Doi:10.1080/17549507.2019.1660804

27. Royal College of Speech and Language Therapists. The Five Good Communication Standards. London, UK: Royal College of Speech and Language Therapists; 2016.

28. Lanyon L, Worrall L, Rose M. "It's not really worth my while": understanding contextual factors contributing to decisions to participate in community aphasia groups. Disabil Rehabil. 2019 May;41(9):1024–36.

29. Simmons-Mackie N, Savage MC, Worrall L. Conversation therapy for aphasia: a qualitative review of the literature. Int J Lang Commun Disord. 2014 Sep-Oct;49(5):511–26.

30. Attard M, Lanyon L, Togher L, Rose M. Consumer perspectives on community aphasia groups: A narrative literature review in the context of psychological well-being. Aphasiology. 2015;29(8):983–1019.

31. Lanyon L, Worrall L, Rose M. What really matters to people with aphasia when it comes to group work? A qualitative investigation of factors impacting participation and integration. Int J Lang Commun Disord. 2018 May;53(3):526–41.

32. Charalambous M, Kambanaros M, Annoni JM. Are People with Aphasia (PWA) Involved in the Creation of Quality of Life and Aphasia Impact-Related Questionnaires? A Scoping Review. Brain Sci. 2020 Sep;10(10):688.

33. Paul DR, Frattali CM, Holland AL, Thompson CK, Caperton CJ, Slater SC. The American Speech-Language-Hearing Association Quality of Communication Life Scale (QCL): Manual. Rockville, MD, USA: American Speech-Language-Hearing Association; 2004.

34. Hunt J. (1992). Groups organizations. In: *Managing People at Work* (3e). McCraw- Hill: New York.

35. Hersh D. "From the Ground Up": The Talkback Group Program in South Australia. In: Elman RJ, editor. Group Treatment of Neurogenic Communication Disorders: The Expert Clinician's Approach. 2nd ed. San Diego: Plural Publishing, Inc.; 2007.

36. Wallace, S. E., Donoso, E. V., Saylor, B. A., Lapp, E. & Eskanderb, J. (2020). Designing Occupational Therapy Home Programs for People With Aphasia: Aphasia-Friendly Modifications. *Perspectives of the ASHA Special Interest*

Groups, 5, 425–434. Copyright © 2020 American Speech-Language-Hearing Association 425.

37. Rose ML, Attard MC. Practices and challenges in community aphasia groups in Australia: results of a national survey. Int J Speech Lang Pathol. 2015 Jun;17(3):241–51.

38. Pitt R, Theodoros D, Hill AJ, Russell T. The development and feasibility of an online aphasia group intervention and networking program - TeleGAIN. Int J Speech Lang Pathol. 2019a Feb;21(1):23–36.

39. Pitt R, Theodoros D, Hill AJ, Russell T. The impact of the telerehabilitation group aphasia intervention and networking programme on communication, participation, and quality of life in people with aphasia. Int J Speech Lang Pathol. 2019b Oct;21(5):513–23.

40. Worrall L, Sherratt S, Rogers P, Howe T, Hersh D, Ferguson A, et al. What people with aphasia want: their goals according to the ICF. Aphasiology. 2011;25(3):309–22.

41. Hersh D, Worrall L, Howe T, Sherratt S, Davidson B. SMARTER goal setting in aphasia rehabilitation. Aphasiology. 2012;26(2):220–33.

42. Bion W. Experiences in Groups and Other Papers. London: William Heinemann; 1961.

43. Mueller AI. (2020). The Effects of Communication Partner Training on People with Aphasia and their Communication Partners. *Speech-Language Pathology Posters*. 10. https://griffinshare.fontbonne.edu/slp-posters/10

44. Simmons-Mackie N, Raymer A, Cherney LR. Communication Partner Training in Aphasia: An Updated Systematic Review. Arch Phys Med Rehabil. 2016 Dec;97(12):2202–2221.e8.

45. Tregea S, Brown K. What makes a successful peer-led aphasia support group? Aphasiology. 2013;27(5):581–98.

46. Stevinson C, Lydon A, Amir Z. Characteristics of professionally-led and peer-led cancer support groups in the United Kingdom. J Cancer Surviv. 2010 Dec;4(4):331–8.

47. Butow PN, Kirsten LT, Ussher JM, Wain GV, Sandoval M, Hobbs KM, et al. What is the ideal support group? Views of Australian people with cancer and their carers. Psychooncology. 2007 Nov;16(11):1039–45.

48. Code, Chris & Eales, Chris & Pearl, Gill & Conan, Margaret & Cowin, Kate & Hickin, Julie. (2003). Supported Self-Help Groups for Aphasic People. https://doi.org/10.1016/B978-008044073-6/50014-6..

49. Pound C, Duchan J, Penman T, Hewitt A, Parr S. Communication access to organisations: inclusionary practices for people with aphasia. Aphasiology. 2007;21(1):23–38.

50. National Health and Medical Research Council (NHMRC) Centre for Clinical Research Excellence. (CCRE) in Aphasia Rehabilitation. (2014). *Australian Aphasia Rehabilitation Pathway (AARP)*. Retrieved June 7, 2021, from http://www.aphasiapathway.com.au

51. Tarrant M, Carter M, Dean SG, Taylor R, Warren FC, Spencer A, et al. Singing for people with aphasia (SPA): results of a pilot feasibility randomised controlled trial of a group singing intervention investigating acceptability and feasibility. BMJ Open. 2021 Jan;11(1):e040544.

52. Archer B, Azios JH, Gulick N, Tetnowski J. Facilitating participation in conversation groups for aphasia. Aphasiology. 2020:1–19.

53. Attard MC, Loupis Y, Togher L, Rose ML. The efficacy of an inter-disciplinary community aphasia group for living well with aphasia. Aphasiology. 2018;32(2):105–38.

54. VandenBerg, K., Ali, M., Cruice, M., & Brady, M. C. (2018). *Support groups for people with aphasia: a national survey of third sector group facilitators in the UK*. Aphasiology, 32(sup1), 233–236. https://doi.org/10.1080/02687038.2018.1487016.

55. Layfield CA, Ballard KJ, Robin DA. Evaluating group therapy for aphasia: what is the evidence? [Bloomington, MN: Pearson.]. EBP Briefs. 2013;7(5):1–17.

56. Elman RJ. The importance of aphasia group treatment for rebuilding community and health. Top Lang Disord. 2007;27(4):300–8.

57. Breakwell G, Millard L. Basic Evaluation Methods: Analysing Performance, Procedure and Practice. Leicester: British Phycologist Society; 1995.

58. Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, et al. Action Plan for Stroke in Europe 2018-2030. Eur Stroke J. 2018 Dec;3(4):309–36.

59. Georgiou A, Konstantinou N, Phinikettos I, Kambanaros M. Neuronavigated theta burst stimulation for chronic aphasia: two exploratory case studies. Clin Linguist Phon. 2019;33(6):532–46.

60. Matos LM, Cruice M. Consequences of stroke and aphasia according to the ICF domains: views of Portuguese people with aphasia, family members and professionals. Aphasiology. 2014;28(7):771–96.

61. Brady MC, Ali M, VandenBerg K, Williams LJ, Williams LR, Abo M, et al. RELEASE: a protocol for a systematic review based, individual participant data, meta-and network meta-analysis, of complex speech-language therapy interventions for stroke-related aphasia. Aphasiology. 2020;34(2):137–57.