

# UCSF

## UC San Francisco Previously Published Works

### Title

Designing and Implementing a Community Aphasia Group: An Illustrative Case Study of the Aphasia Group of Middle Tennessee.

### Permalink

<https://escholarship.org/uc/item/77s735ff>

### Journal

Perspectives of the ASHA Special Interest Groups, 7(5)

### ISSN

2381-4764

### Authors

Levy, Deborah F  
Kasdan, Anna V  
Bryan, Katherine M  
et al.

### Publication Date

2022-10-20

### DOI

10.1044/2022\_persp-22-00006

Peer reviewed

**SIG 2****Clinical Focus**

# Designing and Implementing a Community Aphasia Group: An Illustrative Case Study of the Aphasia Group of Middle Tennessee

Deborah F. Levy,<sup>a,b,c</sup>  Anna V. Kasdan,<sup>b,d</sup>  Katherine M. Bryan,<sup>a</sup> Stephen M. Wilson,<sup>a</sup>   
Michael de Riesthal,<sup>a</sup> and Dominique P. Herrington<sup>a</sup>

<sup>a</sup>Department of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, TN <sup>b</sup>Curb Center for Art, Enterprise, and Public Policy, Nashville, TN <sup>c</sup>Department of Neurological Surgery, University of California, San Francisco <sup>d</sup>Vanderbilt Brain Institute, Vanderbilt University, Nashville, TN

**ARTICLE INFO**

## Article History:

Received January 19, 2022

Revision received April 21, 2022

Accepted June 14, 2022

Editor-in-Chief: Mary J. Sandage

Editor: Dallin John Bailey

[https://doi.org/10.1044/2022\\_PERSP-22-00006](https://doi.org/10.1044/2022_PERSP-22-00006)**ABSTRACT**

**Purpose:** Community aphasia groups serve an important purpose in enhancing the quality of life and psychosocial well-being of individuals with chronic aphasia. Here, we describe the Aphasia Group of Middle Tennessee, a community aphasia group with a 17-year (and continuing) history, housed within Vanderbilt University Medical Center in Nashville, Tennessee.

**Method:** We describe in detail the history, philosophy, design, curriculum, and facilitation model of this group. We also present both quantitative and qualitative outcomes from group members and their loved ones.

**Results:** Group members and their loved ones alike indicated highly positive assessments of the format and value of the Aphasia Group of Middle Tennessee.

**Conclusion:** By characterizing in detail the successful Aphasia Group of Middle Tennessee, we hope this can serve as a model for clinicians interested in starting their own community aphasia groups, in addition to reaching individuals living with chronic aphasia and their loved ones through the accessible and aphasia-friendly materials provided with this clinical focus article.

**Supplemental Material:** <https://doi.org/10.23641/asha.20520783>

For an aphasia-friendly version of this article, see Supplemental Material S1.

Aphasia, a communication disorder resulting from damage to language regions of the brain, has a high prevalence, with over 2 million people living with aphasia in the United States alone (National Aphasia Association, 2016). Following the onset of language symptoms, individuals with aphasia can experience loneliness, social isolation, and lack of belonging to the communities of which they were once integral members (Dalemans et al., 2010; Parr, 2007; Spaccavento et al., 2013). While one-on-one speech therapy often results in significant gains in

language function (Breitenstein et al., 2017), therapy often focuses less on addressing the new socio-emotional needs of these individuals, due to limitations imposed by insurance providers that require quantifiable recovery of language functions. Similarly, therapy does not often provide individuals with practice conversing with their peers in more naturalistic group settings (Galletta & Barrett, 2014). Often, speech therapy sessions take an impairment-based approach, focusing on a patient's language deficits and how to improve in those language domains. On the other hand, community aphasia groups tend to focus on empowering individuals to live successfully and autonomously with aphasia (Galletta & Barrett, 2014; Pettigrove et al., 2021). These community groups help to combat feelings of seclusion in individuals with aphasia by providing social support (Elman & Bernstein-Ellis, 1999), education (Attard et al., 2015; Lanyon et al., 2018), opportunities for building relationships (Rotherham et al., 2015; Shadden, 2005), and

Correspondence to Deborah F. Levy: [deborah.levy@ucsf.edu](mailto:deborah.levy@ucsf.edu). **Disclosure:** Pi Beta Phi Rehabilitation Institute has been host of AGoMT for 17 years; authors MDR and DPH are affiliated. The authors have declared that no competing financial or nonfinancial interests existed at the time of publication.

restored senses of community and identity (Shadden & Agan, 2004; Shadden, 2005). Additionally, aphasia group participation has been associated with improvements in functional communication (Elman, 2016; Elman & Bernstein-Ellis, 1999) as well as improvements in relationships between people with aphasia and their loved ones (Elman, 2007), though results are mixed (Pettigrove et al., 2021).

Aphasia groups are increasing in prevalence (Fridriksson & Hillis, 2021); however, they still only serve a small percentage of those living with aphasia, in part due to limited resources and trained personnel necessary to facilitate aphasia groups (Rose & Attard, 2015; Simmons-Mackie, 2018). Additionally, community aphasia groups, which vary widely on a number of dimensions (e.g., program duration and frequency, activities, facilitation model; Pettigrove et al., 2021), tend to be affiliated with universities, medical centers, or large aphasia centers (Pettigrove et al., 2021), often limiting access of those who live in rural areas. While the existence of virtual aphasia groups can increase access (Caute et al., 2021; Walker et al., 2018) and the number of virtual groups available is likely to have risen sharply during the COVID-19 pandemic, these virtual formats may introduce new communication challenges (Neate et al., 2021).

Though the benefits of aphasia community groups appear to be numerous and the establishment of these groups is on the rise, the literature outlining the details of existing programs and how an interested clinician might go about implementing an aphasia group is sparse. It is also difficult to tabulate the designs of all of the community aphasia groups in existence due to the “gray literature” nature of this field (e.g., information about aphasia groups on websites and in newsletters, rather than academic studies or book chapters; Pettigrove et al., 2021). The purpose of this clinical focus article is therefore to describe, in detail, the history, philosophy, design, curriculum, and facilitation model of a weekly, day-long aphasia group with a 17-year legacy, Aphasia Group of Middle Tennessee (AGoMT). This group serves individuals across a span of urban and rural areas, with distances travelled to attend the group ranging from 1 to 68 miles. AGoMT not only provides individuals with aphasia with a steadfast, supportive community, but also places them in the role of mentor to aspiring clinicians, thus creating a synergistic relationship between patient empowerment and student education. For these reasons and more (to be described herein), AGoMT is a success story in aphasia group implementation and can serve as a model for fledgling community groups across the field of aphasia rehabilitation.

We first highlight the features of the AGoMT (following categories outlined in a scoping systematic review of these groups; Pettigrove et al., 2021). Second, we quantify the effects of AGoMT on the psychosocial well-being and communication of its members through a survey we administered in the winter of 2020 and spring of 2021 to

both group members and their loved ones, including both quantitative and qualitative results.

Our goal is to make this work accessible not only to the research community but also to individuals living with aphasia and their loved ones. Often, academic literature of this nature is hidden behind expensive paywalls and institutional logins/affiliations, making it inaccessible to some of the people who may benefit from it the most. The aphasia-friendly version of this clinical focus article is meant to serve as an educational resource for individuals with aphasia themselves who want to learn more about aphasia groups, their design, and benefits.

## History

The AGoMT began in 2004 under the leadership of Dominique P. Herrington, Masters of Science, Certificate of Clinical Competence in Speech-Language Pathology (senior author on this clinical focus article). The group has met consistently under Dominique’s leadership since then and is housed within the Pi Beta Phi Rehabilitation Institute at Vanderbilt University Medical Center in Nashville, Tennessee, in the United States. Over the course of its 17-year (and counting) history, AGoMT has seen 140 members, many of whom have been attending consistently for over a decade. AGoMT has maintained a continuously large group size across the 17 years, with an average of about 20 group members attending each semester.

## Philosophy

The AGoMT adopts the Life Participation Approach to Aphasia (Chapey et al., 2000) under the context of a biopsychosocial model of health, aiming to maximize re-engagement in life and foster functional communication for individuals with aphasia. Individuals of all ages, with aphasia of all etiologies, are welcome at AGoMT. Though the majority of group members are stroke survivors, individuals with traumatic brain injury, post-operative aphasia, and primary progressive aphasia also regularly attend the group. AGoMT benefits these individuals despite differences in long-term language prognosis (i.e., in neurodegenerative forms such as primary progressive aphasia vs. traumatic etiologies), based on continued attendance and enjoyment of group activities. AGoMT serves individuals with aphasia both by providing them with a platform in which to communicate, as well as by providing them with opportunities to educate loved ones, caretakers, and future clinicians on how to best communicate with them. Graduate student clinicians are formally trained as “Partners in Communication” (PIC) at the beginning of the semester and taught how to work with individuals with aphasia toward a shared goal of revealing communicator competence and arriving at mutual understandings. To

this point, a key element of AGoMT is the training it offers to student clinicians. At the start of each semester, a new group of students from Vanderbilt's master's program in speech-language pathology participate in a multiday aphasia group training. Throughout the semester, these graduate student clinicians gain clinical experience, as well as clinical hours that fulfill graduation and licensure requirements, by working with individuals in the group. This serves to mutually benefit the students and the group members: students gain the opportunity to work first-hand with individuals with aphasia (something many budding speech-language pathologists do not have experience with—see the work of Finch et al., 2013), while group members gain the opportunity to mentor student clinicians and train them to treat individuals with aphasia as equal partners in communication (discussed in more detail in the Facilitation Model and Training section below). As the group is sustained by nominal contributions and does not require insurance, it is more affordable than many other aphasia treatments (Ellis et al., 2012; Jacobs et al., 2021). Throughout the day, AGoMT activities target specific communication skills including verbal expression (i.e., speech), written expression, speech comprehension, reading, and effective use of technology. Information on the specific methods by which these skills are addressed are described in detail below.

## Facilitation Model and Training

A core tenet of AGoMT is the reciprocal training it provides between student clinicians and aphasia group members. In a typical semester, anywhere from six to eight speech-language pathology masters students are assigned to AGoMT as their clinical placement. Students may request this placement and may also be placed in Aphasia Group due to academic and clinical needs for hours and experience. At the beginning of each semester, author D.H., the director of AGoMT, hosts supported conversation training sessions for students. This training consists of (a) watching a series of training modules and podcasts released by Aphasia Access (Aphasia Access, 2022), (b) participating in group discussions centered around the social model of aphasia, and (c) completing the Supported Conversation Partner Training, a program provided by the Aphasia Institute in Ontario, Canada (Aphasia Institute, 2022). The latter involves students role-playing as individuals with aphasia and clinicians. In addition to this training, D.H. meets with all students as a group before the start of the day's program and also meets weekly with each student individually to provide them with feedback on communication strategies with their PIC partner (more details below) and the group as a whole.

In addition to speech-language pathology Masters students, PhD students and other speech-language pathologists sometimes facilitate specific activities or offer additional support when needed. For example, these individuals may provide enrichment to group members with the highest levels of communicative functioning. Group members are encouraged to participate in the day's activities without their loved ones so that they may focus on functional communication with their peers. However, loved ones can remain nearby and join particular sessions/activities and are especially encouraged to attend in the first weeks of a group member's participation. Loved ones also often participate in the lunch block as well as special events (e.g., holiday and birthday celebrations).

## Curriculum

### In-Person Meetings: Pre-COVID-19 Pandemic (2004–2020)

During the academic year, AGoMT meets weekly from 9:30 a.m. to 4:00 p.m. at Pi Beta Phi Rehabilitation Institute at Vanderbilt University Medical Center in Nashville, Tennessee. The year is organized into "semesters" that typically last 10–12 weeks. A representative group day proceeds as follows:

*9:30–10:00: "Coffee Talk."* All group members and students gather in the lunchroom to drink coffee and chat in an unstructured manner. Students are encouraged to use Supported Conversation for Adults with Aphasia (SCA). This time targets verbal expression.

*10:00–11:00: "PIC Session."* Group members split off into groups organized largely by aphasia severity; most group members work one-on-one with their graduate student clinician or PIC partner. This time is often used to create a Current Events slide, describing a recent news article or item of interest, to be presented to a larger group in the afternoon. Group members with more mild aphasia create Current Events slides in a group setting in the main conference room where the group member to student ratio is approximately 2:1 or 3:1 (rather than one-on-one for individuals with more severe aphasia). Creating Current Events slides targets technology use, reading, and writing by requiring individuals with aphasia to access online news sources, read and comprehend their chosen article, and transfer/summarize that information to a written form on a PowerPoint slide (targeting the use of technology once more).

*11:00–11:55: "Executive Group."* Group members in one-on-one partnerships continue to work with their PIC partners on exercises they have identified to meet their functional communication goals; higher level individuals transition to "Executive Group," in which decisions about group outings, budget usage, special events, and general group business are discussed. Additionally, a subgroup of

the Executive Group, entitled the “Sunshine Committee,” monitors birthdays and life events of the group members and organizes the signing and delivery of appropriate greeting cards. The specific skills this session targets depend on the desires of the individual group members, allowing them to advocate for themselves and work on developing the skill sets that are most important to them.

*11:55–12:50: Lunch.* All group members and students come together in the lunchroom and eat; group members may play a large group game such as trivia. Students are again encouraged to use SCA. This time targets verbal expression.

*1:00–1:45: “Book Club.”* Group members split into groups, organized either by aphasia severity/reading level or selected book, and, with the aid of speech pathology students, discuss assigned chapters of a book they read at home throughout the preceding week. Reading Ramps materials from the Aphasia Center of California’s Book Connection (Elman & Bernstein-Ellis, 2006; see <http://www.aphasiacenter.net/the-book-connection/>) and/or audiobooks are used by multiple members as supplements to their assigned reading. Books are generally selected by group members at the beginning of the semester. Favorite book choices among group members in the past have included *My Stroke of Luck* (author: Kirk Douglas), *The Five People You Meet in Heaven* (author: Mitch Albom), and *Marley and Me* (author: John Grogan), to name a few. Skills targeted during this time include reading and verbal expression.

*1:45–2:45: “Current Events.”* Group members convene in two large groups, organized by aphasia severity. Each group member presents the Current Events slide they created in the morning to this larger Current Events group, with the support of their assigned student. Conversation about these news stories is encouraged and facilitated by student leaders. This session targets verbal expression, use of technology, and retention of reading material.

*2:45–4:00: “Big Group.”* All group members reconvene in the main conference room at Pi Beta Phi Rehabilitation Institute, and a selected topic for the semester is discussed by the group at large. Previous Big Group topics have included “History of Music and Fashion,” “Hometowns,” “Research on Aphasia,” and “Continental Travel.” Discussions are interactive and multimodal and may be led by a student or by a group member; all group members are encouraged to participate in the discussion throughout, promoting verbal expression.

### **Virtual Meetings: During COVID-19 Pandemic (2020 to Present)**

Since the COVID-19 pandemic, health and safety took precedence over the many benefits of the in-person Aphasia Group. The importance of the communication environment created by AGoMT was evident in the

group’s enthusiasm to continue by any means necessary despite the challenging circumstances, and a virtual Zoom Aphasia Group was established in the spring of 2020. The day begins with all group members participating in current events and then proceeds via breakout groups that replicate the in-person book club, executive group, and so forth. The nature of the schedule has evolved throughout the pandemic, but in general, it mirrors the structure of the in-person schedule, except that rather than all activities occupying one full day, shorter activity blocks are dispersed throughout the week. Group facilitators screen-share slides with aphasia-friendly supports, including key words and pictorial supports, to aid comprehension. Student clinicians also maintain one-on-one Zoom chats with group members to prompt participation and facilitate understanding of the topics at hand.

## **Method**

### **Outcomes Survey**

#### **Participants**

Ten group members with aphasia (five male, five female;  $M_{\text{age}} = 53.5$ , range: 22–72) participated in the survey. These individuals volunteered after two virtual presentations describing the study were given to the entire group (15 group members) in November 2020 and March 2021. Group members who participated in the survey ranged in the severity of their aphasia from mild to severe per clinical impression by author D.H. (2 = mild, 1 = mild–moderate, 4 = moderate–severe, 3 = severe). Average time attending group for surveyed group members was 5.4 years (range: 1.5–11.6 years). Two members regularly attended other support or community groups, two other members did so only briefly, and the other remaining six members did not attend any other support or community groups. Six participants received speech-language therapy, ranging in total duration from 3 to 41 months, concurrently with group attendance; the other four participants did not receive speech-language therapy while attending group.

For each of the individuals with aphasia who participated, one of their loved ones was also surveyed if willing and available. This resulted in a total of 17 individuals surveyed—10 with aphasia and seven loved ones (three male, four female). The loved ones we surveyed included three husbands, two wives, and two mothers of surveyed group members; other personal information (e.g., age) was not collected for these loved ones.

For individuals with aphasia, we provided aphasia-friendly aids to consent to ensure understanding of the terms of consent (see Supplemental Material S2). These aids were used in concert with supported conversation techniques by graduate students and clinicians during the consent

process. All materials were approved by the institutional review board at Vanderbilt University Medical Center.

### Consent and Survey Process

Questions were designed to reflect stated goals of aphasia groups as indicated by both group members and clinicians. The majority of questions were framed in terms of an adapted Likert scale and were displayed with pictorial aids, bolding of key concepts, reduced question length, and large font, as has been shown to be effective in aphasia-friendly survey material in prior work (Dalemans et al., 2009). Questions required (a) reflecting on the experience of group (e.g., responding “yes,” “no,” or “maybe” to statements like “I feel connected to people in Aphasia Group”; “Aphasia Group helps me feel like myself”), (b) comparing emotions before and after joining group (e.g., selecting among options such as “lonely,” “sad,” “hopeful,” “supported” in response to statements like “BEFORE group I felt. . .”), and (c) selecting preferred activities (e.g., selecting among options in response to questions like “My favorite activities in Aphasia Group are. . .”). While some questions were initially designed to elicit single responses (e.g., “What is BEST about Aphasia Group is. . .”), group members were enthusiastic about selecting multiple options and all responses were therefore accepted. A link to the survey slide deck is provided in the Supplemental Material S3.

Both consent and surveys for group members were administered over Zoom by the first three authors between December 2020 and March 2021 in a single session for each participant and were audiovisually recorded when the participant consented to this. Questions were shared in a Google Slides document, with responses highlighted in real time (via a movable green rectangle) by the researchers to ensure that their understanding of the participants’ response was correct. Consent and surveys of loved ones were conducted via mail; these surveys reflected similar content to the group member surveys, but required the loved one to reflect on their impression of the group members’ experiences with group as well as their own (e.g., using a Likert scale to respond to statements such as “Aphasia Group has had a positive impact on my loved one with aphasia”; “Aphasia Group has had a positive impact on me,” etc.).

Survey results are plotted in Figures 1–6. Note that for many questions, more than one response was permitted.

## Results

### Survey Results: Group Members

Overall, survey results demonstrated that the AGoMT is extremely valuable to both group members and their loved ones alike. All 10 group members surveyed indicated that AGoMT helped them feel like themselves, and nearly all of

them (9/10) reported that AGoMT made them feel very good (the highest possible rating; see Figure 1). When asked about their feelings before and after joining AGoMT, fewer group members reported feelings of loneliness, sadness, and isolation after participating in the group, with no surveyed member reporting loneliness or isolation after joining AGoMT (see Figure 2).

The best thing about AGoMT according to the majority of group member responses was meeting other people with aphasia (9/10), followed by learning to use technology (5/10), improving language (5/10), and getting out of the house (5/10; see Figure 3). The most reported favorite activity was Book Club (7/10), followed by Current Events (5/10), and Coffee Talk (5/10; see Figure 3). The most-reported areas of improvement since joining AGoMT were talking (9/10), use of technology (8/10), and understanding (7/10).

When surveyed about their experiences participating in the virtual Zoom Aphasia Group during the COVID-19 pandemic, all group members reported enjoying Zoom Aphasia Group (10/10), and most reported that it helped them to stay connected (9/10 “yes,” 1/10 “maybe”). When asked whether Zoom Aphasia Group helped their communication, responses were somewhat mixed, though all individuals indicated at least some utility of the Zoom group for language (7/10 “yes,” 3/10 “maybe”; see Figure 6).

### Selected Quotes From Group Members

“I needed all of it...I used it everywhere.... For me to be able to talk, that was a big deal for me.”

“Really, it...wow, amazing. Joyful, happy. All the time.”

“It gets me out of the house. I come home and feel really good. I love it...just being around there talking, there’s not people that are looking at you because you can’t get the words out. There’s nobody looking at you funny.”

### Survey Results: Loved Ones of Group Members

Loved ones unanimously reported that AGoMT had a positive impact on their loved one with aphasia (7/7 strongly agree). All surveyed loved ones also agreed that AGoMT had a positive impact on them personally (6/7 strongly agree, 1/7 agree), made it easier to care for their loved one with aphasia (5/7 strongly agree, 2/7 agree), and positively impacted their relationship with their loved one with aphasia (6/7 strongly agree, 1/7 agree; see Figure 4).

The most frequently reported perceived areas of improvement in group members by their loved ones were speech production (7/7), speech comprehension (7/7), mood (7/7), motivation (7/7), and socialization (7/7; see

**Figure 1.** Group members’ experiences of aphasia group. x-axis shows the number of participants who selected a given answer.

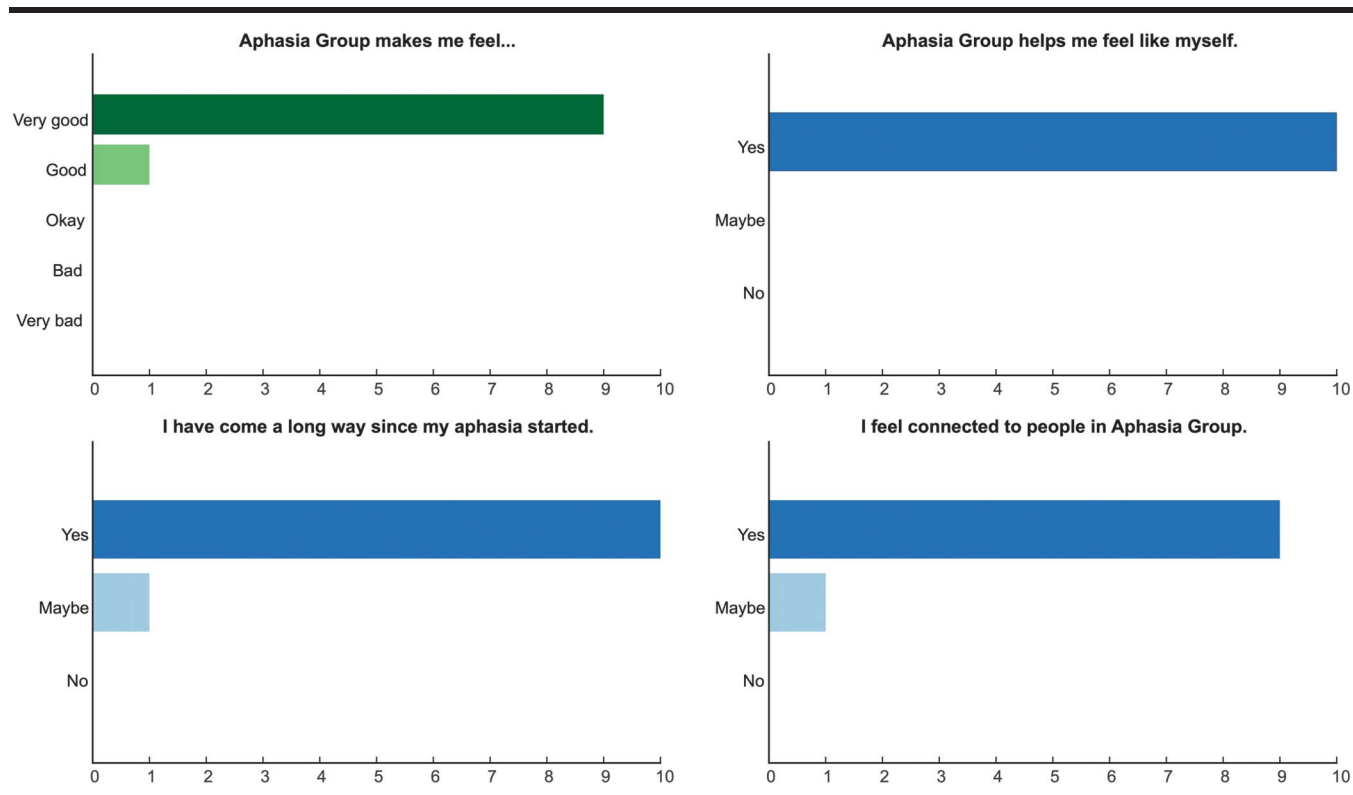


Figure 5). Loved ones reported the most valuable activities in AGoMT were Current Events (7/7), PIC (6/7), Book Club (6/7), and Big Group (6/7; see Figure 5). When asked about Zoom Aphasia Group, all loved ones reported that the Zoom Aphasia Group during the COVID-19 pandemic was helpful (5/7 strongly agree, 2/7 agree; see Figure 6).

**Selected Quotes From Loved Ones**

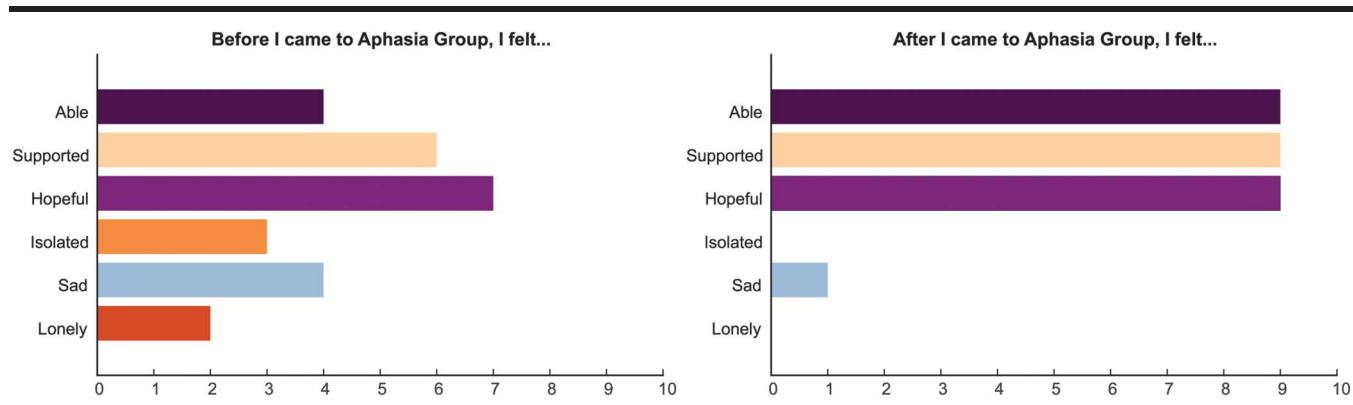
“He saw how others with the same deficits made progress and [it] gave him hope for himself.”

“Aphasia Group is a place [my loved one] can be included and understood. He’s welcomed as he is and for that we are all grateful!”

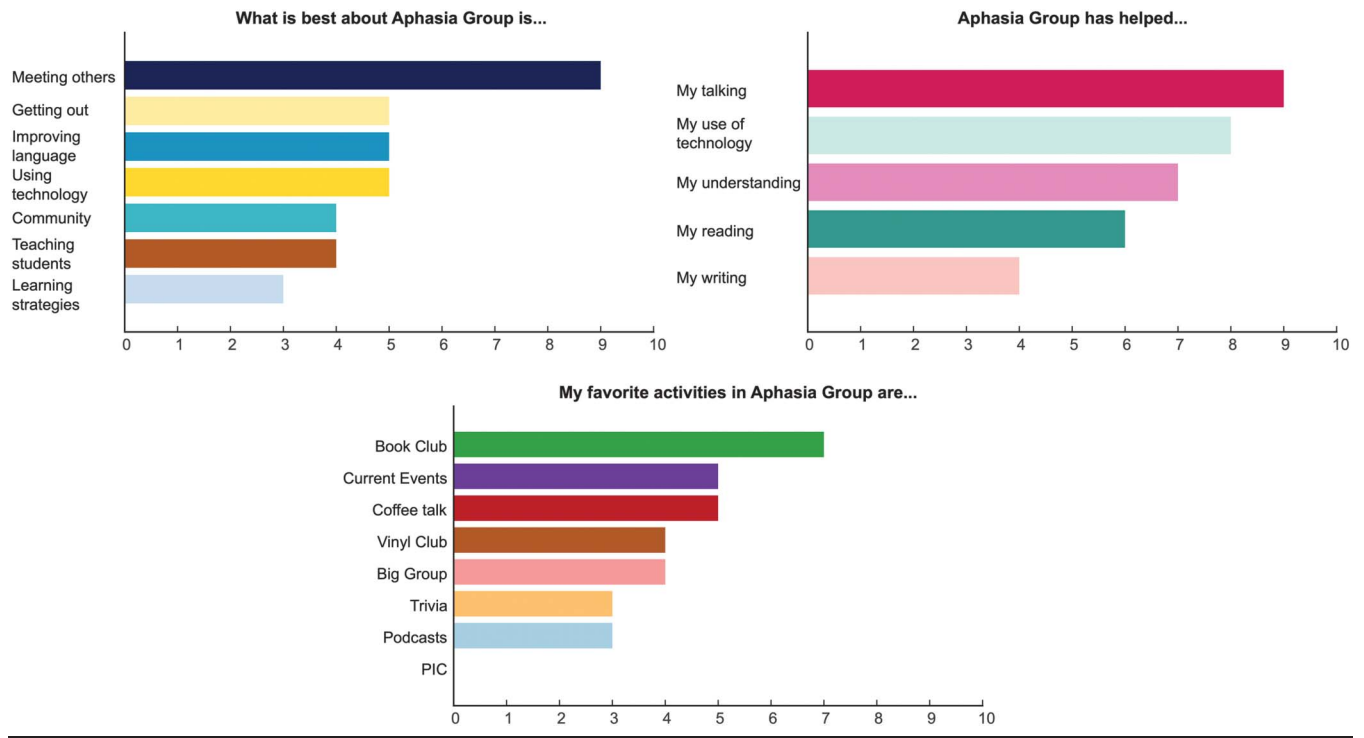
“Aphasia Group helped my loved one become more confident in trying to communicate, helped with his socialization, and improved his mood and outlook on life.”

“I have learned SO much! First we’re not on this journey alone. Dominique and ALL the students we’ve met have been very gracious in explaining the

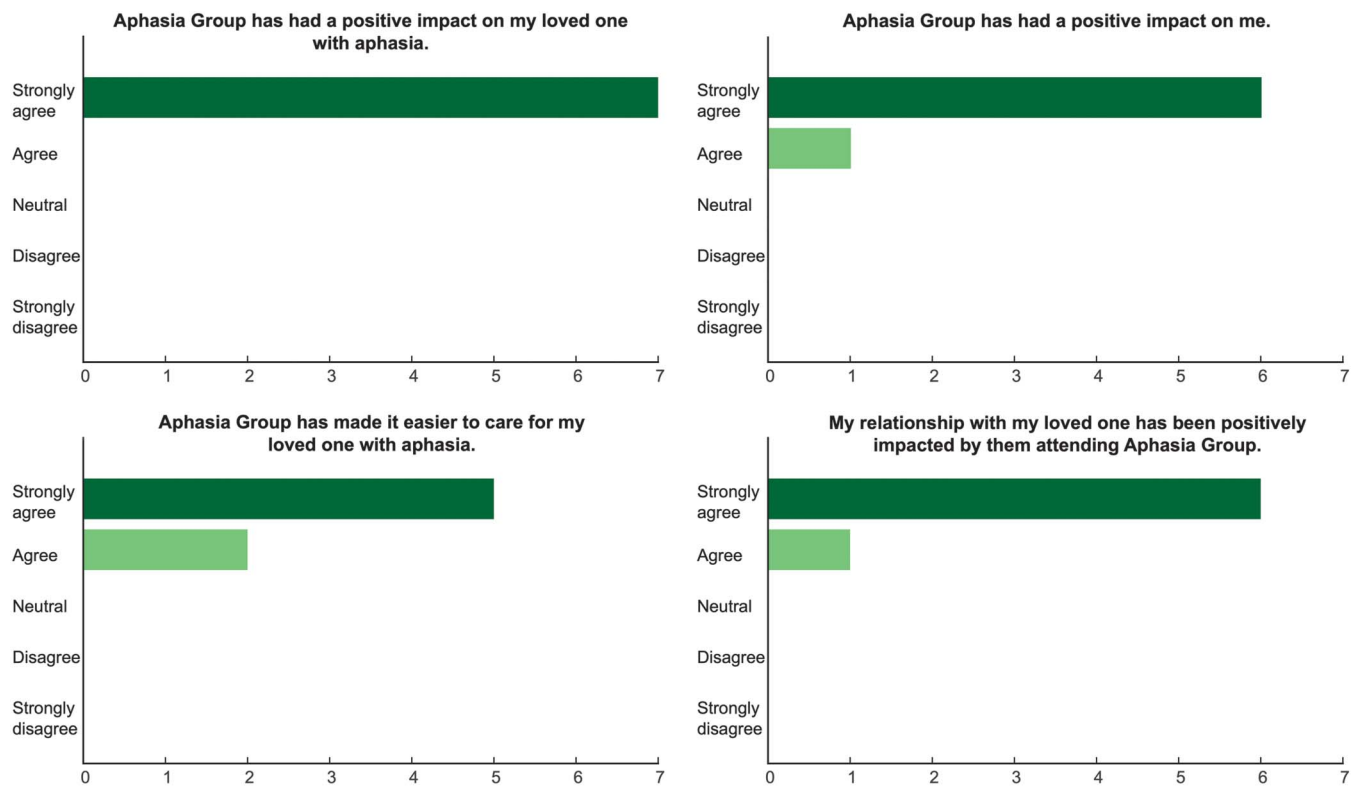
**Figure 2.** Psychosocial well-being before and after joining Aphasia Group of Middle Tennessee (AGoMT).



**Figure 3.** What group members say they get out of Aphasia Group. PIC stands for Partners in Communication, in which group members work one-on-one with a student clinician to target language abilities.

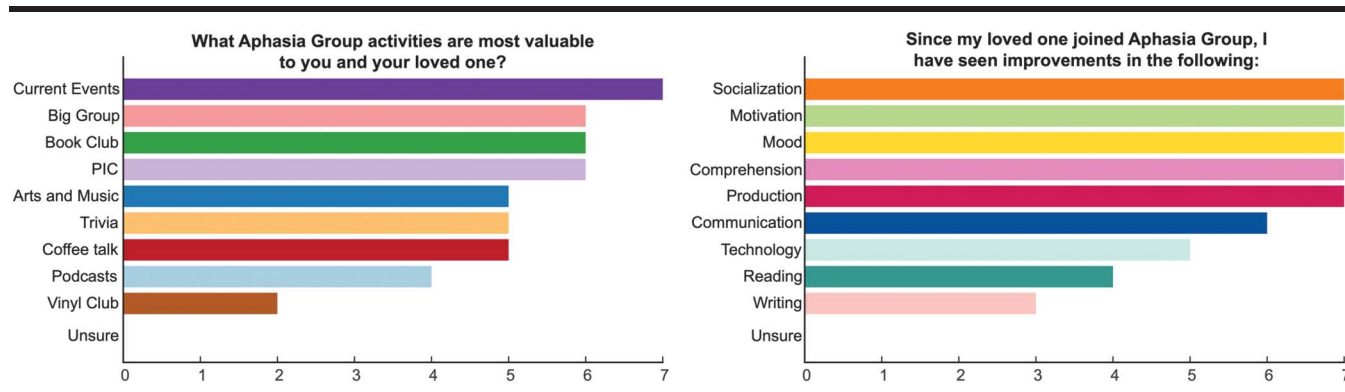


**Figure 4.** Loved ones' experiences of Aphasia Group.





**Figure 5.** What loved ones see group members getting out of Aphasias Group. PIC stands for Partners in Communication, in which group members work one-on-one with a student clinician to target language abilities.



best way to communicate with [my loved one] and trying different methods.”

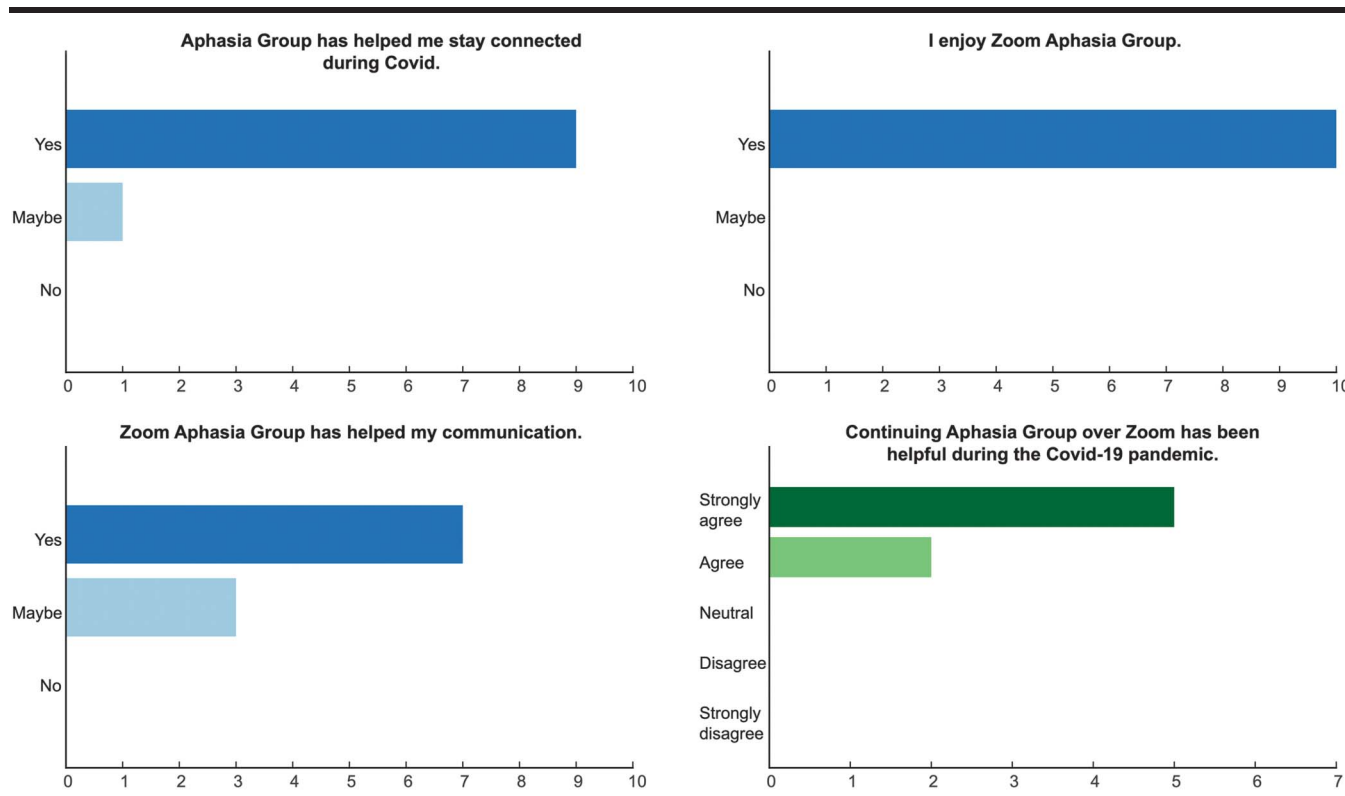
“Aphasias Group positively impacted my life by giving me respite, and it improved my loved one’s life therefore improving mine.”

the Aphasias Group of Middle Tennessee (AGoMT), with the aim of demonstrating its benefits and feasibility for implementation at other locations. Our survey results indicate that AGoMT is highly valuable to its group members and their loved ones, and provide useful information on which activities are valued the most. This information may be useful for burgeoning groups, perhaps particularly those with more modest resources, in determining which activities are likely to be the most impactful for prospective group members. Similarly, should a member of an institution or community wish to propose a new aphasias

**Discussion**

The purpose of this clinical focus article was to describe the philosophy, implementation, and outcomes of

**Figure 6.** Group members’ (blue) and loved ones’ (green) experiences of group during the COVID-19 pandemic.



group, the findings herein can serve as evidence that any up-front investment of time and resources will be worthwhile. Finally, even in communities where an aphasia group already exists, the detailed description of activities and the benefits of group described here may serve to inform individuals with aphasia or their loved ones who are considering joining an aphasia group, or even inspire them to check out a local group that they may not have considered otherwise. Our survey findings align with other literature showing social and communicative benefits from community aphasia groups (Attard et al., 2015; Shadden & Agan, 2004), benefits to loved ones of group members (Elman, 2007), and benefits to group members themselves (Lanyon et al., 2018).

It is important to note the distinction between aphasia groups and support groups; while support groups similarly offer community and social support (Christensen et al., 2019; Hartford et al., 2019), they do not necessarily target the improvement of functional communication as a shared goal. However, support groups may also be valuable to individuals with aphasia; in fact, there are instances of individuals with aphasia specifically *preferring* groups that provide general stroke support rather than specifically focusing on aphasia, due to the fact that their “aphasia does not exist in a vacuum” (Shadden & Agan, 2004). It may therefore be appropriate for clinicians to consider both support and aphasia group models in terms of what is most likely to meet their clients’ goals. Other models to consider include peer-led groups, which empower individuals with aphasia to take ownership over their own communities (see the work of Tregoe & Brown, 2013, for example); the “Executive Group” described here may serve as an example of incorporating such a goal into a predominantly clinician-led group structure.

The aphasia-friendly version of this clinical focus article and accompanying aphasia-friendly materials (consent form, survey questions from Zoom; see Supplemental Materials S1–S3) are meant to serve as an accessible, educational resource for individuals living with aphasia themselves and their loved ones. Surprisingly, most academic research about aphasia is inaccessible to those who may benefit from it the most—these papers sit behind expensive paywalls and institutional logins/affiliations that many clinicians cannot access. Moreover, the language used in these academic papers is often cumbersome and designed to be most understandable for those with a specific scientific/clinical background. The inaccessibility of these research materials, and the language therein, presents barriers to individuals with aphasia, their loved ones, and community leaders who are interested in learning about the design, benefits, and implementation strategies for community aphasia groups.

To our knowledge, this is the first time an aphasia-friendly companion piece is presented alongside a more

formal academic article. Specifically, this companion version uses simplified language, pictorial aids, and high-contrast formatting to make the content about the AGoMT easy to understand for individuals living with aphasia. We believe such aphasia-friendly materials are an important step forward in making science accessible to those who could benefit from it the most. We strongly encourage aphasia researchers at large (i.e., other subfields of aphasia research including recovery, language outcomes, etc.) to do the same.

## Limitations

One potential issue with a survey of this sort is that those who chose to participate were self-selected, meaning the results may show a bias toward positive assessments from those group members that are most enthusiastic about the group. The fact that the individuals conducting the survey were familiar to the group members may have induced a positive bias, as well. However, the high mean rate of retention across all group members, including those who did not participate in the survey (mean length of group membership: 2.5 years), as well as the continuously large group size across all 17 years (mean group size per semester: approximately 20 members), suggests that the group is likely viewed positively even by those who were not surveyed.

Similarly, our sample size was relatively small ( $N = 10$  group members and  $N = 7$  loved ones). Given that the vast majority of aphasia groups have group sizes between two and 10 individuals (Pettigrove et al., 2021), this sample size is likely sufficiently representative; however, future work could attempt to survey more members and confirm these results.

Additionally, these surveys required self-report and reflection upon aspects of group that were no longer occurring at the time of survey during the COVID-19 pandemic. For example, no group member reported PIC as their favorite activity, despite the clinicians’ impressions that these activities were enjoyed during in-person meetings, as well as this activity’s perceived importance by loved ones. It is possible that this seeming lack of preference for PIC may simply reflect the fact that it was not a part of the virtual programming. However, the extent to which this particular activity truly is or is not preferred by group members is an open question that warrants further investigation when in-person group resumes.

Finally, Vanderbilt University Medical Center is a large and well-funded nonprofit enterprise with significant resources available. We acknowledge that not all prospective community aphasia group locations have these same resources, including access to technology, dedicated students, and funding for group needs. However, AGoMT is for the most part funded by nominal contributions from group members and consists largely of free activities based

around socialization, conversation, and community. Therefore, we are hopeful that the aphasia group design aspects described herein can be modified according to the resources available at a given institution or community center.

## Conclusions

The AGoMT is a success story in aphasia group implementation—group members and their loved ones alike indicated highly positive assessments of its format and value. We are hopeful that this clinical focus article can serve as a clear model for clinicians and other community leaders hoping to start their own aphasia groups, and that the accompanying aphasia-friendly materials will empower individuals with aphasia to learn about and understand the benefits of community groups firsthand.

## Data Availability Statement

The data sets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

## Acknowledgments

This research was supported in part by the National Institute on Deafness and Other Communication Disorders (F32 DC020096 awarded to Deborah Levy; F31 DC020112 awarded to Anna Kasdan; R01 DC013270 awarded to Stephen Wilson), a National Science Foundation GRFP Award awarded to Anna Kasdan, and the Curb Center for Art, Enterprise, and Public Policy. We gratefully acknowledge Pi Beta Phi Rehabilitation Institute at Vanderbilt University Medical Center; the Curb Center for Art, Enterprise, and Public Policy; all student clinicians; dear friends and colleagues Zack DeWall and Carley Haggerty; and finally, all group members and their loved ones over the last 17 years who have made the Aphasia Group of Middle Tennessee what it is today.

## References

- Aphasia Access.** (2022). *Training videos*. <https://www.aphasiaaccess.org/videos/>
- Aphasia Institute.** (2022). *Free resources*. <https://www.aphasia.ca/health-care-providers/resources-and-tools/free-resources/>
- Attard, M. C., Lanyon, L., Togher, L., & Rose, M. L.** (2015). Consumer perspectives on community aphasia groups: A narrative literature review in the context of psychological well-being. *Aphasiology, 29*(8), 983–1019. <https://doi.org/10.1080/02687038.2015.1016888>
- Breitenstein, C., Grewe, T., Flöel, A., Ziegler, W., Springer, L., Martus, P., Huber, W., Willmes, K., Ringelstein, E. B., Haeusler, K. G., Abel, S., Gлиндemann, R., Domahs, F., Regenbrecht, F., Schlenck, K. J., Thomas, M., Obrig, H., de Langen, E., Rocker, R., . . . Bamborschke, S.** (2017). Intensive speech and language therapy in patients with chronic aphasia after stroke: A randomised, open-label, blinded-endpoint, controlled trial in a health-care setting. *The Lancet, 389*(10078), 1528–1538. [https://doi.org/10.1016/S0140-6736\(17\)30067-3](https://doi.org/10.1016/S0140-6736(17)30067-3)
- Caute, A., Cruice, M., Devane, N., Patel, A., Roper, A., Talbot, R., Wilson, S., & Marshall, J.** (2021). Delivering group support for people with aphasia in a virtual world: Experiences of service providers. *Disability and Rehabilitation, 1–19*. <https://doi.org/10.1080/09638288.2021.2011436>
- Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons-Mackie, N.** (2000). Life-participation approach to aphasia: A statement of values for the future. *The ASHA Leader, 5*(3). <https://doi.org/10.1044/leader.ftr.05032000.4>
- Christensen, E. R., Golden, S. L., & Gesell, S. B.** (2019). Perceived benefits of peer support groups for stroke survivors and caregivers in rural North Carolina. *North Carolina Medical Journal, 80*(3), 143–148. <https://doi.org/10.18043/ncm.80.3.143>
- Dalemans, R. J. P., De Witte, L. P., Beurskens, A. J. H. M., Van Den Heuvel, W. J. A., & Wade, D. T.** (2010). An investigation into the social participation of stroke survivors with aphasia. *Disability and Rehabilitation, 32*(20), 1678–1685. <https://doi.org/10.3109/09638281003649938>
- Dalemans, R. J. P., Wade, D. T., van den Heuvel, W. J. A., & de Witte, L. P.** (2009). Facilitating the participation of people with aphasia in research: A description of strategies. *Clinical Rehabilitation, 23*(10), 948–959. <https://doi.org/10.1177/0269215509337197>
- Ellis, C., Simpson, A. N., Bonilha, H., Mauldin, P. D., & Simpson, K. N.** (2012). The one-year attributable cost of post-stroke aphasia. *Stroke, 43*(5), 1429–1431. <https://doi.org/10.1161/STROKEAHA.111.647339>
- Elman, R. J.** (2007). The importance of aphasia group treatment for rebuilding community and health. *Topics in Language Disorders, 27*(4), 300–308. <https://doi.org/10.1097/01.TLD.0000299884.31864.99>
- Elman, R. J.** (2016). Aphasia centers and the Life Participation Approach to Aphasia. *Topics in Language Disorders, 36*(2), 154–167. <https://doi.org/10.1097/TLD.0000000000000087>
- Elman, R. J., & Bernstein-Ellis, E.** (1999). The efficacy of group communication treatment in adults with chronic aphasia. *Journal of Speech, Language, and Hearing Research, 42*(2), 411–419. <https://doi.org/10.1044/jslhr.4202.411>
- Elman, R., & Bernstein-Ellis, E.** (2006). Aphasia book clubs: Making the connection. *Stroke Connection, 32–33*.
- Finch, E., Fleming, J., Brown, K., Lethlean, J., Cameron, A., & McPhail, S. M.** (2013). The confidence of speech-language pathology students regarding communicating with people with aphasia. *BMC Medical Education, 13*, Article 92. <https://doi.org/10.1186/1472-6920-13-92>
- Fridriksson, J., & Hillis, A. E.** (2021). Current approaches to the treatment of post-stroke aphasia. *Journal of Stroke, 23*(2), 183–201. <https://doi.org/10.5853/jos.2020.05015>
- Galletta, E. E., & Barrett, A. M.** (2014). Impairment and functional interventions for aphasia: Having it all. *Current Physical Medicine and Rehabilitation Reports, 2*(2), 114–120. <https://doi.org/10.1007/s40141-014-0050-5>
- Hartford, W., Lear, S., & Nimmon, L.** (2019). Stroke survivors' experiences of team support along their recovery continuum. *BMC Health Services Research, 19*(1), 723. <https://doi.org/10.1186/s12913-019-4533-z>

- Jacobs, M., Briley, P. M., Wright, H. H., & Ellis, C.** (2021). Marginal assessment of the cost and benefits of aphasia treatment: Evidence from community-based telerehabilitation treatment for aphasia. *Journal of Telemedicine and Telecare*, 1357633X2098277. <https://doi.org/10.1177/1357633X20982773>
- Lanyon, L., Worrall, L., & Rose, M.** (2018). What really matters to people with aphasia when it comes to group work? A qualitative investigation of factors impacting participation and integration. *International Journal of Language & Communication Disorders*, 53(3), 526–541. <https://doi.org/10.1111/1460-6984.12366>
- National Aphasia Association.** (2016). *National Aphasia Awareness Survey: 2016 Results and findings*. <https://www.aphasia.org/wp-content/uploads/2016/11/NAASurveyResults-2016Report.pdf>
- Neate, T., Kladochou, V., Wilson, S., & Shams, S.** (2021). “Just not together”: The experience of videoconferencing for people with aphasia during the COVID-19 pandemic [Paper presentation]. ACM CHI Conference on Human Factors in Computing Systems, New Orleans, USA. <https://doi.org/10.1145/3491102.3502017>
- Parr, S.** (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, 21(1), 98–123. <https://doi.org/10.1080/02687030600798337>
- Pettigrove, K., Lanyon, L. E., Attard, M. C., Vuong, G., & Rose, M. L.** (2021). Characteristics and impacts of community aphasia group facilitation: A systematic scoping review. *Disability and Rehabilitation*, 1–15. <https://doi.org/10.1080/09638288.2021.1971307>
- Rose, M. I., & Attard, M. C.** (2015). Practices and challenges in community aphasia groups in Australia: Results of a national survey. *International Journal of Speech-Language Pathology*, 17(3), 241–251. <https://doi.org/10.3109/17549507.2015.1010582>
- Rotherham, A., Howe, T., & Tillard, G.** (2015). “We just thought that this was Christmas”: Perceived benefits of participating in aphasia, stroke, and other groups. *Aphasiology*, 29(8), 965–982. <https://doi.org/10.1080/02687038.2015.1016887>
- Shadden, B. B.** (2005). Aphasia as identity theft: Theory and practice. *Aphasiology*, 19(3–5), 211–223. <https://doi.org/10.1080/02687930444000697>
- Shadden, B. B., & Agan, J. P.** (2004). Renegotiation of identity. *Topics in Language Disorders*, 24(3), 174–186. <https://doi.org/10.1097/00011363-200407000-00005>
- Simmons-Mackie, N.** (2018). *Aphasia in North America: A comprehensive report on incidence, causes and impact*. Aphasia Access.
- Spaccavento, S., Craca, A., Del Prete, M., Falcone, R., Colucci, A., Di Palma, A., & Loverre, A.** (2013). Quality of life measurement and outcome in aphasia. *Neuropsychiatric Disease and Treatment*, 10, 27–37. <https://doi.org/10.2147/NDT.S52357>
- Tregea, S., & Brown, K.** (2013). What makes a successful peer-led aphasia support group? *Aphasiology*, 27(5), 581–598. <https://doi.org/10.1080/02687038.2013.796506>
- Walker, J. P., Price, K., & Watson, J.** (2018). Promoting social connections in a synchronous telepractice, aphasia communication group. *Perspectives of the ASHA Special Interest Groups*, 3(18), 32–42. <https://doi.org/10.1044/persp3.SIG18.32>