

## University Affiliated Aphasia Groups: Benefits to Persons with Aphasia, Families, and Student Trainees

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### Abstract

Aphasia groups offer a range of social and communicative benefits to persons with aphasia (PWA) and their caregivers. However, little is known about the perceived benefits of aphasia groups for the caregivers of PWA or the benefits of student trainees participating in those groups. A survey design was used to examine the benefits of aphasia groups for PWA, caregivers of PWA and student trainees engaged in a university-affiliated aphasia group. Survey findings for PWA indicated benefits in four general areas: increased ability to communicate needs more effectively, increased social communication, increased community involvement and increased overall quality of life. Caregivers reported feeling more comfortable communicating with their loved ones and having an increased sense of community with other caregivers. Graduate student trainees reported beneficial clinical education experiences that offered opportunities to better understand the type of communication performance to expect from a PWA, the nature of patient limitations from the patient's perspective, and how to assist PWA with their communicative deficits. These findings revealed that university-affiliated aphasia groups offer a diverse range of social and communicative benefits for PWA and their caregivers as well as a unique opportunity for students to better understand the unique communicative difficulties of PWA.

**Keywords:** Aphasia; Aphasia groups; Students; Speech

### Introduction

The incidence of stroke in the United States is 795,000 individuals annually and of that number, it is estimated that 180,000 Americans experience post-stroke aphasia. Aphasia is a condition that results in a range of communication deficits including language comprehension, language expression, reading, writing, attention, memory and other cognitive domains. Persons with aphasia (PWA) often experience a decline in emotional health and psychosocial well-being that is generally associated with their inability to communicate effectively. In addition, the cost of care associated with having aphasia is substantially greater than having a stroke and the absence of aphasia [1-6].

Extensive research on treatment of aphasia has shown that those who receive treatment have positive improvements [7]. Customary aphasia treatment has focused primarily on the improvements in one-to-one (clinician and patient) settings. Less is known about the efficacy of aphasia treatment in group treatment settings (clinician and multiple patients). Davis and Wilcox explain "the term 'group treatment', by itself means no more than simply the treatment of more than one client in one session [8]. Just as individual treatment varies as a function of goals and procedures, group treatment also may vary according to differing goals and respective formats... there are as many objectives for group treatment as there are objectives for treatment in general."

The benefits of aphasia group treatment can extend beyond the treatment of multiple individuals in a group setting. According to Williamson, aphasia treatment groups can: (a) provide opportunities for PWA to communicate with peers in a structured and supportive setting, (b) allow clinicians to teach specific communication strategies,

(c) allow PWA to practice learned strategies that facilitate more natural communication and (d) facilitate successful communication that can be observed by the peers of PWA [9]. Group settings whether emphasizing patient treatment or patient/family support offer a range of social and communicative benefits. Evidence from the literature on strokes, the primary cause of aphasia, indicate that group settings allow peers who are experiencing the same condition to engage in activities that facilitate understanding, empathy and offer relevant support [10]. Similarly, evidence has emerged in the aphasia literature indicating substantial benefits for PWA including but not limited to: (a) increased communicative interaction, (b) more natural communicative interactions resulting from various communicative partners, (c) increased psychosocial functioning due to the supportive environment, (d) improved life participation, (e) opportunities to establish new and positive identities and (f) reduce the disconnection between PWA and society [11].

However, the direct benefits of aphasia groups are not limited to PWA. In addition to the improvements PWA experience in communicative abilities and psychosocial functioning, aphasia groups offer at least two additional and unique opportunities to improve the broader difficulties associated with aphasia. First, aphasia groups that include the caregivers or family members of PWA can offer much needed educational and social support to families who also experience the substantial burden associated with aphasia [12,13]. According to Glista, aphasia groups can provide a social assessment of the educational and counseling needs for families of PWA [12]. Second, unique opportunities also exist for students enrolled in Communication Sciences and Disorders (CSD) programs that offer aphasia groups. Purves, Petersen and Puurveen developed an aphasia mentoring program for students enrolled in a speech-language pathology programs. Students reported that the aphasia mentors

provided a significant contribution to their educational experience by repeated opportunities that improved their perspectives about aphasia. Similarly, Cubirka et al. engaged four undergraduate speech-language pathology students in aphasia groups programs and found that students reported a dramatic learning curve in understanding aphasia resulting from their aphasia group experiences. Therefore, aphasia groups can offer critical opportunities for student trainees to participate with PWA and their families while learning valuable skills related to aphasia management [14,15].

This pilot project examined the multiple perceived benefits of university-affiliated aphasia groups. We define university-affiliated aphasia groups as those aphasia groups completed on university campuses, affiliated with Communication Sciences and Disorders (CSD) programs and designed to: (1) offer services to persons with aphasia and (2) offer clinical training opportunities for students enrolled in CSD programs. Therefore, the goal of this project was to examine the perceived benefits of participation in a university-affiliated aphasia group among PWA, caregivers of PWA and students who will subsequently serve PWA.

## Methods

### Description of the aphasia group

The East Carolina University (ECU) aphasia group was established in 2009 by clinical faculty of the ECU Speech-Language and Hearing Clinic. The group was formed to serve and support the continually growing population of PWA in eastern North Carolina as well as their families. The aphasia group is led by a CSD program clinical supervisor with >20 years clinical experience treating adults with neurogenic communication disorders. In addition to the clinical supervisor, graduate student trainees co-lead the group each semester. Student trainees are typically first or second year graduate students enrolled in the Master's program in CSD. Average group attendance is 7-10 PWA per week as well as their caregivers.

A total of 12 PWA and 12 caregivers were involved in the aphasia group. Among those who participated in the survey were ten individuals actively participating in the ECU Speech-Language, and Hearing Clinic's Aphasia Group, eight caregivers of group participants, and five student trainees. Two student trainees were participating in aphasia group at the time of the survey and the additional three student trainees participated in aphasia group during the previous semester. The group meets for two hours per week to address functional communication through activities that target word finding, silent and oral reading skills and functional reading comprehension, as well as functional expressive and receptive language tasks in both a small and large group setting. These activities ranged from word association and sentence completion task to open-ended discussion of current events. Similarly oral reading, reading comprehension and auditory comprehension were addressed via news paper articles and internet news reports. The expected outcome of the group is to give PWA the skills needed to communicate in their preferred way through written language, spoken language or communicative gestures.

### Participants

**Persons with aphasia:** The study sample included participants with post-stroke aphasia who were participants in the East Carolina University (ECU) Speech-Language and Hearing Clinic aphasia group. This project included PWA who was capable of providing information

regarding the benefits of group therapy for treatment of post stroke aphasia. All participants were: 1) age  $\geq$  18 years old, 2) history of aphasia as confirmed by a speech-language evaluation and 3)  $\geq$  1 year participation in the ECU Speech-Language and Hearing Clinic Aphasia Group. See Table 1 for a summary of demographic characteristics of PWA.

Age (mean)	65
Educational level (mean)	14.8
Duration of aphasia (mean years)	6.32
Gender (% male)	60

**Table 1:** Demographic Characteristics of PWA

PWA exhibited generally functional auditory comprehension skills with deficits primarily in expressive language and speech production. PWA exhibited either anomia or Broca's aphasia with expression skills that were mild-moderately impaired.

**Caregivers:** Caregivers were identified as a spouse, family member, or friend who assisted the PWA most often. Primary caregivers included in this study were, on average, 62.6 years of age and 50% were male. Some caregivers were observed quietly in the group whereas others sat in the lobby area. All caregivers reported being a primary caregiver of an aphasia group participant for at least one year.

**Student trainees:** Student trainees participating in this study consisted of five graduate students enrolled in the ECU Department of Communication Sciences and Disorders Speech-Language Pathology Master's program. Each student trainee spent at least 11 weeks co-leading the aphasia group.

### Participant consent

**Recruitment:** All participants (PWA, caregivers & students) were provided a letter explaining the study. The letter provided an explanation of the study requirements and clarified that only subjects meeting certain eligibility criteria would be able to participate in the study. PWA agreeing to participate was seen during their normal time of participation in aphasia group. PWA agreeing to the survey provided verbal consent to participate in the study in the presence of their caregiver. Similarly, caregivers were provided with information about the study and explained the study requirements. Caregivers agreeing to participate were given a copy of the survey to complete independently. Finally, student trainees were sent an email containing the survey as well as information about the study and study requirements. Students agreeing to participate completed the survey independently and returned it to the first author via email. This study was approved by the local university institutional review board (IRB).

### Survey data collection

**Person with aphasia survey:** A short survey was created for the pilot project (See Appendix A). All survey questions were administered verbally. The survey was designed to obtain demographic information including: age, time of stroke, gender, education, and years of participation in aphasia group. To explore the perceptions and benefits of aphasia group participation, ten Likert-style questions were administered. The survey also contained one open-ended question designed to examine the participant's opinions about the benefits of the aphasia group; "How have you benefited from aphasia group?" The

question was asked in an open-ended fashion and all responses were accepted. The participant's facial expressions and gestures were also considered during their responses due to their language and/or motor speech impairments. For example, yes/no gestural responses were considered when verbal responses were not provided. All responses were written verbatim.

**Caregiver survey:** Primary caregivers completed a survey designed to examine the benefits and perceptions of aphasia group (See Appendix B). The survey was also designed to obtain demographic information including: age, employment, and relationship to the PWA. To explore the caregivers' perceived benefits of their participation in the group, eight Likert-style questions were administered. The survey also contained three open-ended questions designed to elicit additional benefits not addressed in the initial Likert questions.

**Student trainee survey:** Student trainees independently completed a survey (Appendix C). Students were asked to record demographic information about the following: educational level; current place of employment; and if they currently worked with PWA. The student trainee surveys included four open-ended questions to explore their perceived benefits during participation in the groups.

**Data analysis:** Descriptive analyses of demographic data were completed for PWA, caregivers and student trainees. Similarly, summary descriptive analyses were completed to analyze the Likert-style questions. A qualitative analysis of open-ended survey responses was conducted through multiple close readings of the survey responses by two of the authors (KN, CE). Each author generated an independent list of thematic responses to categorize the data. These responses were then expanded by the two authors (KN, CE). The authors then met in a consensus conference to discuss the responses, resolve questions, and refine key responses. Close agreement was present among investigators and survey facilitators regarding the responses.

## Results

### Persons with aphasia

Data from the Likert-questions indicated that all of the PWA agreed: (a) they always/almost always feel more comfortable communicating since joining aphasia group, (b) they always/almost always enjoyed attending aphasia group, (c) they always/almost always feel as though their quality of life has improved as a result of participation in aphasia group, (d) they are always/almost always happier since joining the group, (e) they are always/almost always more comfortable communicating with peers in the aphasia group and (f) they are always/almost always comfortable when communicating with student trainees and aphasia group instructors. In addition, 88% of PWA reported always/almost always communicating their needs more effectively since joining aphasia group, 75% use information learned in aphasia group when communicating outside of the group and 75% always/almost always communicate more for social purposes since joining the group. In contrast, only 38% reported always/almost always feeling more involved in their community since joining aphasia group. The primary findings of the open-ended question were somewhat limited due to the communicative limitations of the PWA. However, all PWA reported that the aphasia group was beneficial to their communicative abilities and need for support.

### Primary caregivers

Data from the Likert questions indicated that 88% of primary caregivers reported they always/almost always felt more comfortable communicating with their loved one since they joined aphasia group, 57% reported that aphasia group always/almost always provided them with more time to be socially independent, 88% always/almost always felt a sense of community with other caregivers of aphasia group participants and 60% reported always/almost always feeling more involved in their community since their loved one joined the group. Additionally, 67% agreed that their quality of life was always/almost always improved since their loved one joined aphasia group, 72% agreed that they are always/almost always happier since their loved one joined the group, 88% reported that they always/almost always feel comfortable communicating with student trainees and aphasia group instructors, and 88% agreed that they would always/almost always recommend aphasia group to other caregivers of PWA. In summary, 100% of primary caregivers reported believing that aphasia group is beneficial for their loved one.

A review of open-ended questions revealed that the general perception of the primary caregiver group was that the aphasia group provided benefits including: (a) increased social interaction for themselves and their loved one, (b) greater joy observing their loved one in a comfortable communicative environment and (c) downtime to run errands or communicate with other caregivers. The caregiver group also reported that communication with their loved one had improved as a result of aphasia group participation. More specifically, their loved ones (PWA) exhibited increased verbal skills and interest in communicating. They also reported a better understanding of their loved one's ability to communicate, allowing for a reduced communication barrier with the PWA. In addition, primary caregivers reported an increase in PWA's independence and regaining of previous responsibilities.

### Student trainees

A review of qualitative data revealed that the general perception of the group was that it increased the student's understanding of aphasia, aphasia deficit profiles and aphasia recovery patterns. In regards to clinical education, all student trainees indicated that they gained a better understanding of communication versus speech and language. They all also reported a better understanding of how to assist adults with communicative deficits. In summary, 100% of student trainees reported that aphasia group was beneficial to their clinical education experience.

## Discussion

The purpose of this pilot project was to examine the perceived benefits of participation in a university-affiliated aphasia group among PWA, caregivers of PWA and student trainees. For PWA, the findings parallel previous reports that note increased communication interaction and effectiveness, increased psychosocial functioning, improved life participation and more positive identities [11]. These findings are important during this period of substantial health reform when clinicians are required to make decisions emphasizing increased productivity in the context of less reimbursement [9].

However, despite the PWA in the sample reporting increased comfort in communicating with their peers and communicating their needs since joining the group, that comfort did not consistently translate into greater community involvement. Far less than half (40%)

reported improved community involvement despite 75% reporting use of information learned in the group to communicate outside of the group and for social purposes. Similarly, the majority reported being happier and having improved quality of life. These findings may indicate that even though substantial benefits are received from group participation, benefits may be limited to communication with families/caregivers and a narrow range of other communicative settings. These findings reflect the complex nature of aphasia and the difficulties clinicians and PWA experience while attempting to achieve optimal communicative outcomes.

Similar to PWA, caregivers of PWA also reported a range of communicative and psychosocial benefits since joining the aphasia group. Aphasia groups offer opportunities for caregivers to better understand the nature of aphasia and support for the burden and difficulties associated with caregivers of individuals with the condition [12]. The sample of caregivers of PWA reported similar outcomes including: feeling a source of community, improved quality of life, increased happiness and greater comfort communicating with their loved one. In addition, aphasia group offers the caregiver an additional opportunity for interactions with the group and independent interactions during the downtime when they did not participate. They also noted a better understanding of their loved one's difficulty with communication as their communication barriers decreased. Group participation among caregivers serves to reduce their isolation as few formal therapy projects that involve caregivers exists due to reimbursement issues [13]. Many caregivers experience multiple layers of isolation due the communication burden of aphasia. For example, reductions in the communicative ability of the PWA subsequently limits the quality of their interactions with their loved ones. These reductions also limit community involvement as a result their inability to participate in premorbid activities because the communication difficulty. Beyond educational opportunities, aphasia group participation offers substantial peer support with other caregivers to address the difficulties of caring for individuals who frequently have physical disabilities along with aphasia-related communication impairments.

Finally, student trainees reported a range of educational benefits when participating in aphasia groups. Most notably, students reported a better understanding of aphasia. They noted an improved understanding of the various types of aphasia and common issues associated with limited communicative ability. All students were either concurrently enrolled in an aphasia course or had completed the course. The aphasia group served as an additional review and direct observation of aphasia types learned in the course. Therefore, the students were able to compare/contrast the group participants to aphasia profiles learned in class. Understanding these concepts are critical to student trainees who desire to manage individuals with aphasia and other neurologically based disorders of communication when they advance to future clinical positions. Students note that opportunities to engage in an aphasia group allow them an opportunity to spend substantial time with PWA to better understand the difficulties they experience and aphasia from their perspective. The findings reported here support those reported by Purves et al. who found that students participating in groups "get to know the person" because they were able to hear the experiences of PWA and understand the uniqueness of their perspectives [14]. The aphasia groups also offered opportunities to socialize with the PWA and gain more valuable experience than traditional training settings. Finally, students note that group participation "made the classroom learning real" and

the experiences deepened their understanding of aphasia and in particular the nature of aphasia recovery.

Additionally, the aphasia group offered required training needs for student clinicians with aphasia. In compliance with Standards for the Certificate of Clinical Competence in Speech-Language Pathology, aphasia groups offer "supervised clinical experience sufficient in depth and breadth to achieve the specified knowledge and skills outcomes" [16]. Coinciding with the needs of those enrolled in the aphasia group, Standard IV-C is specifically addressed as student clinicians experience communication strengths and weaknesses of clients who have been diagnosed with difficulties in "receptive and expressive language, cognitive aspects of communication, and social aspects of communication". In addition, numerous other standards are addressed during aphasia groups. One might argue that aphasia groups similar to the one discussed here go beyond the standard and enrich student clinicians with experiences that are unique to the university setting.

Further, aphasia groups, akin to the one discussed here, adhere to the roles and responsibilities for speech-language pathologists as established by American Speech Language Hearing Association (ASHA) [17]. These include "developing treatment plans, providing treatment, documenting progress, and determining appropriate dismissal criteria; counseling persons with aphasia and their families regarding communication-related issues and providing education aimed at preventing further complications relating to aphasia; and consulting and collaborating with other professionals, family members, caregivers, and others to facilitate program development and to provide supervision, evaluation, and/or expert testimony, as appropriate" [17].

The findings reported here are interesting, yet they emerge from a small sample of PWA, caregivers and students. In addition, some survey questions may have only elicited a narrow response while offering limited opportunity for variability. Regardless of these limitations, the findings reported here do highlight the substantial benefits of aphasia group participation including communicative and psychosocial benefits for PWA and their caregivers as well as educational benefits for student trainees. The findings reported by PWA and caregivers also highlight the difficulties of aphasia in that even in the context of improvements following group participation, PWA can continue to experience difficulties in community setting and caregivers are likely to continue to experience substantial burden.

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