

Communication partner training to increase life participation for people with aphasia

Thesis

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Abstract

Background: People with aphasia often are unable to have meaningful conversations or participate in their communities due to language deficits. Research is often focused on typical or familiar communication partners such as friends and family. This study aimed to discover if unfamiliar communication partners in the community can be trained in order to increase life participation by increasing community opportunities.

Aims: The current study aimed to evaluate how effective training potential communication partners is in order to increase life participation for individuals with aphasia.

Procedures: Volunteers were recruited from docent volunteers from the Columbus Museum of Art. They were trained as a group over a 90 min session. The training course educated participants on an overview of aphasia and effective methods to utilize when communicating with a person with aphasia (PwA) in order to provide opportunities for communication. Alternative modes of communication and techniques were taught in the training course. The course aimed to increase the participants' knowledge of 1) the role of a communication partner 2) how aphasia affects a PwA's conversation 3) strategies to utilize when communicating with a PwA, and 4) overview of aphasia. Two measures including the Communication Effectiveness Index and an aphasia quiz were completed before and after the training course in order to examine the knowledge of the participants.

Outcomes and results: There was statistically significant improvement on both the CETI and aphasia quizzes after the training course was complete as compared to the results before the training course.

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Chapter 1 Introduction

Aphasia is an acquired language impairment that is a result of damage to the language areas of the brain (Davis, 2014). Comprehension and formulation of language can be impaired, as well as the ability to read and write. Often other cognitive capacities are left intact. The most common cause of aphasia is a stroke, although other causes such as traumatic brain injuries, tumors or infections are possible as well (Davis, 2014). There are approximately 2 million individuals in the United States with aphasia (Aphasia FAQs, 2017). There are a variety of types and symptoms of aphasia depending on the location and severity of the stroke. A common symptom of aphasia is difficulty in word retrieval that can be described as a word “on the tip of the tongue”. Aphasia may impact a single aspect of language, such as word retrieval or multiple aspects of language such as reading, writing, and language comprehension.

Aphasia significantly affects an individual’s ability to communicate, subsequently affecting his/her everyday life. A PwA’s self-identity is often compromised due to aphasia being a potential barrier in conversations, and restricting the purpose of conversation to essential needs and wants as opposed to discussion about thoughts and dreams, which can lead to decreased social participation (Ross et al., 2006). An individual’s sense of self is affected by aphasia due to a loss of ability to communicate effectively. This lack of effective communication can also lead to a decrease in self-esteem. One treatment for aphasia is communication partner training (CPT), which focuses on training caregivers or other people who communicate with a PwA, to maximize communicative effectiveness and subsequently increase life participation for the PwA.

Although there is a significant number of people with aphasia, there is relatively little public knowledge of this disorder. Results of a survey show limited public awareness and

knowledge of aphasia across all sites. 13.6% of people surveyed have said they heard of aphasia and only 5.4% of those surveyed showed basic knowledge of aphasia (Simmons-Mackie et al., 2002). Public awareness of aphasia can impact adjustment of individuals with aphasia. A lack of public knowledge of a disorder with which one is struggling, can lead to social isolation, loneliness and depression. Individuals with aphasia often have lower confidence when communicating due to communication breakdowns, subsequently leading to decreased attempts at communication. Communication is essential for an individual's identity to engage in social relationships, express personal attitudes and basic wants. Public lack of knowledge of aphasia restricts an individual's ability and opportunity to engage in conversation which can impact the daily life and social participation of individuals with aphasia (Kagan et al., 1993).

The current study aimed to increase life participation for individuals with aphasia by training potential communication partners and educating these individuals about aphasia. Research is often focused on typical communication partners such as friends and family, so this study aimed to discover if unfamiliar communication partners in the community can be trained in order to increase life participation by increasing community opportunities. Employees at an art museum were trained on strategies to communicate with individuals with aphasia in order to promote effective communication exchanges. With more knowledgeable communication partners in the community, a PwA may be able to enjoy more experiences, which has the potential to increase life participation and quality of life.

Chapter 2 Literature Review

LIFE PARTICIPATION APPROACH FOR APHASIA

Participation is defined by the World Health Organization as involvement in life situations (WHO, 2001). An individual's everyday life is altered by aphasia, including challenges in maintaining a satisfying lifestyle, and feelings of isolation. The Life Participation Approach for Aphasia (LPAA) is an indirect treatment, which is a treatment that changes communication partners' behaviors in order to improve a PwA's communication abilities. The LPAA emphasizes inclusion in daily life for a PwA (Davis, 2014). LPAA provides a highly supportive environment in order to increase participation in work, society and relationships for the PwA to in turn improve their quality of life. CPT can lead to meaningful life changes, enhanced life participation and improved quality of life. Increased life participation can also be achieved by altering communities via modifying an environment. An environment may be changed by identifying barriers for life participation, improving access to information about aphasia by educating, and provide methods of communication between a partner and PwA (Davis, 2014). The LPAA focuses on the re-engagement in life by strengthening the daily participation and communication opportunities for individuals with aphasia (Chapey et al., 2000). LPAA emphasizes involvement in a broad range of life activities, initiation, and maintenance of social connections, and promotion of internal well-being (Kagan et al., 2001). An increased communicative ability by a PwA would have a positive effect on their social participation and therefore their quality of life (Cruice et al. 2003).

A study completed by Dalemans and colleagues (2010b) investigated the social participation of people with aphasia and factors related to that social participation. Participants were individuals who were at least three months post-stroke. The study took place in the form of questionnaires in an interview-format at their home (Dalemans et al., 2010b). The Community Integration Questionnaire (CIQ) (Willer et al., 1994) was used to measure social participation. Results indicated a variety of participation in individuals with aphasia, but overall a mean score of 14.2 on the CIQ, indicating a low level of social participation. They found that stroke severity was a main determinant in the level of social participation for a PwA. The majority of participants did not prepare meals by themselves, do everyday housework, plan social arrangements or look at personal finances alone. They typically had someone else complete these activities (Dalesmans et al., 2010b).

Cruice and colleagues (2003) investigated which aspects of language affect an individual's quality of life and sought to determine how overall impairments of communication determine quality of life. The study included 30 individuals who had mild-to-moderate aphasia, and more than half of the individuals in the study had impaired naming. The study investigated the relationship between the individuals' impairments, their functional communication ability and their participation in social network and activities. The study results indicated that individuals with higher functioning and better communication ability had fewer social functioning limitations, higher quality of life and higher self-acceptance (Cruice et al., 2003). These researchers suggested a more broad range intervention for individuals with aphasia that would include training family/friends on how to communicate and addressing barriers to participation in order to improve patient's emotional health.

A study by Dalesman et al. (2010a) investigated how individuals with aphasia perceive their participation in social life in order to gain insight into what factors influence participation. This study was executed via interview questions related to their social participation, as well as interview of caregivers. All of the individuals described themselves as social before their stroke and reported that their social activities were decreased after their stroke. Social participation was perceived as being involved, not being a burden to someone, knowing what is going on and being respected while participating in a social activity (Dalesman et al., 2010a). The participants of the study reported there were barriers to participation such as motivation, physical condition, communication skills, role of caregiver and environmental factors, such as the degree of quietness and familiarity of a place. Findings indicate that a PwA feels that being active and participating in social life domains is often difficult and that they want their social participation to be more meaningful. Furthermore, an individual can have more opportunity for participation when they live with their caregiver, have access to a quiet environment and interact with individuals who are able to adapt their communication in order to better communicate with the PwA (Dalesman et al., 2010a).

Johansson and colleagues (2011) conducted a study to explore how people with aphasia experience communication difficulties, have conversations, and perceive how others use communication strategies. Individuals enrolled in the study were at least 12 months post-stroke and had a significant other with whom they communicated regularly. The areas studied were conversations with significant others, conversations with other people both known and unknown, problems encountered in conversation, and strategies utilized. They found that overall the individuals had reduced conversation opportunities, often spoke less in conversation, and had

less complex or deep conversations. The authors also discovered that individuals reported they had increased communication difficulties, such as word-finding, and that the significant other often had a lack of understanding of comprehension deficits, resulting in frustration for the PwA. The individuals reported their overall experience of conversation became more frustrating and difficult. “Our conversations are no longer about anything interesting. They are about these things, such as medications and such” (Johansson et al., 2011).

It was reported in this study that communication partners often would become upset, frustrated or even lose patience and interest in conversation when communicating with a PwA. They found that people were often uncertain of how to communicate with a PwA and would avoid conversations altogether. The PwA would often have feelings of anger, despair, sorrow, frustration and resignation when it came to communication. Therefore, educating communication partners about aphasia and strategies to utilize during communication is essential in order to improve the quality of life for a PwA. Strategies utilized in this study were gestures, drawings, and communication aid devices. They found that training of functional communication by using strategies with a communication partner is a means to achieve enhanced communicative ability (Cruice et al., 2003). Other people’s actions, attitudes, knowledge and characteristics can influence conversation with a PwA (Howe et al. 2008). The individuals also reported that when individuals take the time to communicate with them, it is appreciated. “It feels really nice that someone...someone that just wants to speak with you! One feels like a human being. It feels ‘wow!’” (Johansson et al., 2011).

Rehabilitation should focus on improving communication, taking into consideration the social participation concerns for the PwA and their life concerns. By reducing limitations in

functional performance as well as by promoting communication, people with aphasia can experience greater participation. Training volunteers to effectively utilize a variety of modalities and strategies for communicating with a PwA is essential for communication opportunities, subsequently increasing life participation for those individuals. In order for people with aphasia to have better experiences in the community, it is essential for individuals in the community to be educated on the effects of aphasia and how to communicate with a PwA. This can subsequently lead to an increase in life participation.

COMMUNICATION PARTNER TRAINING

Treatment of aphasia conventionally is more focused on direct therapies to improve communication and reduce the language impairment severity. An indirect treatment of aphasia is CPT, whereby individuals who communicate with a PwA are trained on strategies and techniques to facilitate effective communication. The LPAA modifies a PwA's environment to assist with communication. CPT is designed to educate a person with whom a PwA could interact, such as community members or family members, in order to alter the communication setting for the PwA (Simmons-Mackie et al., 2010). Communication is a basic right for individuals and CPT allows individuals with aphasia to practice that right. This treatment plan teaches potential partners effective ways of communicating and interacting. This involves teaching basic conversation techniques to provide participants with the skills to offer conversational support for any PwA in their volunteer role and reveal the competence of those with aphasia (Turner et al., 2006). This training provides strategies and methods such as using a variety of modalities including speech, gestures, drawing, writing and pointing to pictures. This allows for partners to achieve the goal of increased communication for a PwA. (Simmons-

Mackie et al., 2010). This intervention aims to improve the language, communication, participation and overall well-being of the PwA. This can be achieved through educational programs typically involving increasing knowledge of aphasia (Simmons-Mackie et al., 2016). This approach can facilitate and improve overall social interaction for the PwA.

Studies have shown the importance and impact of partner training on language, communication activity, facilitating conversations in aphasia, and participation, to help reduce the handicap associated with communication loss (Lyons 1989, Kagan and Gailey 1993). When there is an increased communication ability for people with aphasia, there will be a positive effect on social participation. The ultimate goal in rehabilitation of aphasia is to improve the quality of life (Warrall and Holland, 2003). Therefore, it is vital to educate individuals about aphasia and how they can communicate with a PwA in order to allow for more communication opportunities, facilitate improved communication, and overall increase the life participation and quality of life for the PwA.

Simmons-Mackie et al. (1999) conducted a study looking at good versus poor speaking partners (Simmons-Mackie et al., 1999). The study included communication interactions that were videotaped between 10 individuals with aphasia and 10 communication partners. ‘Good’ speaking partners included individuals who used acknowledgements such as head nods, “yeah right” or ‘mhm’ to demonstrate understanding of what the PwA was intending to communicate. ‘Good’ communication partners were also able to adapt and utilize strategies during interaction including utilizing pictures or gestures. Those that were rated as ‘poor’ communication partners did not accommodate to a variety of discourse styles in order to facilitate communication and followed a talking only style. ‘Good’ speaking interactions included clarification during

breakdowns, such as providing options for the individual to choose when they had word finding difficulty due to deficits. Overall, the communication partner who was perceived as ‘good’ treated the PwA as a competent and interesting individual, utilized strategies and accommodated communication styles depending on the partner with aphasia. Whereas the ‘poor’ communication partners did not treat the PwA like they were competent individuals, did not accommodate communication styles, and appeared to perceive the PwA as a weak individual. This model of treating individuals with aphasia as competent and trustworthy is called the “structure of caring” and suggested that understanding competence leads to well-being and self-healing for a PwA.

Kagan et al. (2001) conducted a study to evaluate the efficacy of the approach, “Social Conversation for Adults with Aphasia” (SCA) in order to improve communication between those with aphasia and their communication partners. They trained volunteers as partners in order to determine the influence of the training on the comprehension for a PwA. They used a single-blind randomized controlled design for 80 participants (40 dyads-20 for experimental group and 20 for the control group) who were recruited through the Aphasia Centre. All the individuals with aphasia had moderate-to-severe aphasia, the ability to have a conversation through some form of modality, were at least one-year post stroke, and competent in English. The structure of the study included pre-training of the experimental group volunteers and consisted of semi-structured interviews in a conversational format. Pre-training consisted of educating how to talk naturally, avoid being patronizing, ensuring the acknowledgement of the competence of the PwA and teaching techniques such as writing key words, using drawings and gestures to communicate. Data collected included watching the videotapes of the conversation between the

PwA and the communication partner and rating the conversation in terms of skill in acknowledging competence, and level of participation in interaction.

Overall, the researchers discovered that communication partners and people with aphasia in the experimental group scored higher on the second interview after being trained than the first interview. Interestingly, it was found that in the control group many participants did worse in the second interview than the first. This corresponds with a natural environment, such as a health care environment, where often health care providers have a negative first encounter that then negatively effects the encounters that follow (Kagan et al., 2001). This study provides support for the importance of providing SCA to individuals who interact with a PwA including family members, individuals they may encounter in the community and individuals in the medical community. Training is essential for communication partners in order to overcome a barrier of effective communication for individuals with aphasia.

Rayner and Marshall (2003) evaluated whether training changed volunteers' knowledge about aphasia and their interactions with a PwA. Six volunteers who were not caregivers for a PwA were targeted for this study because unlike caregivers, it is a choice for volunteers to talk to individuals rather than a necessity. The study aimed to improve the volunteers' knowledge of aphasia and provide an opportunity to utilize skills learned in order to increase communication and participation for individuals with aphasia. Participants were recruited from volunteers from an aphasia group and the PwA all were 1-year post stroke and had moderate-to-severe aphasia. Training focused on knowledge and understanding of aphasia, impairments associated with aphasia, importance of conversation, and how conversation can impact those with aphasia (Rayner and Marshall, 2003). Questionnaires were provided before and after training in order to

evaluate the communication partners' knowledge about aphasia and communication strategies. Conversations were videotaped before and after training. The videos were evaluated by speech-language pathologists and rated on the Kagan scale that included rating the volunteer's ability to acknowledge competence through natural conversation as well as through sensitivity, volunteer's ability to ensure the PwA understands, ability to ensure the PwA can express themselves and ensure the volunteer correctly received information through verification (Rayner and Marshall, 2003). The volunteers who participated in study had been involved in an aphasia club so this study shows that training can even improve the practice of experienced individuals who have established patterns of communication (Rayner and Marshall, 2003). One weakness of the study found a slight decline in maintenance of skills from a mean sum rating of 17.5 to 14.8 which could show a potential in eliminating the effects of training overtime (Rayner and Marshall, 2003). Further research is needed to follow the effects of training over time with a potential refresher course. Overall, there were significant improvements in both the participation of the PwA and improvement in the questionnaires after the communication partners were trained in how to communicate with people with aphasia (Rayner and Marshall, 2003).

Hickey, Bourgeois and Olswang (2004) examined the effects of training college students to communicate with nursing home residents who had aphasia. The individuals with aphasia had a primary diagnosis of a single left hemisphere CVA resulting in right hemiparesis, apraxia of speech and Broca's aphasia. The communication training included general education, identification of communication modality being implemented in video, self-evaluation of use of communication, conversational practice with feedback and conversational practice without feedback (Hickey et al., 2004). Data were collected as the communication partner moved through

baseline, training, and post-training phases. After the training was completed, the students participated in 10-minute conversations with the residents. The individuals communicated with one another through speaking, drawings, gesturing to convey a meaning, pointing to visual stimuli and writing (Hickey et al., 2004). Fifteen unfamiliar judges measured the comfort level of each participant, amount of information conveyed by the participants, effectiveness of the partner's behaviors, turn taking and topic maintenance (Hickey et al., 2004). They found that communication partners were using speech-only communication and after training they participated in multi-modality communication. It was discovered that individuals had increased comfort, more effective communication, increased turn taking and topic maintenance (Hickey et al., 2004).

A study was conducted examining communication between 10 triads of a patient, caregiver and communication partner (Lyon et al., 1997). The individuals with aphasia were one year post-onset, able to communicate basic content in any modality, and a demonstrated a normal range of cognitive abilities (Lyon et al., 1997). Before the protocol was established the individual's abilities to interact were evaluated prior to formal instruction (Lyon et al., 1997). The first phase of treatment consisted of 2 sessions during which a clinician taught and demonstrated communication strategies. The communication partner was instructed to select a situation and practice these strategies, which led to communicating effectively with the PwA over the rest of the month. A clinician observed these interactions and provided feedback. At the end of the first phase the interactions were evaluated. The second phase of treatment was a review of the first phase and then the remainder of the time was spent completing a variety of activities such as a favorite activity like going to the movie theater, gardening, or volunteering. It

was found that after the study was complete individuals with aphasia often continued the activities by volunteering at a variety of organizations and making new friends through the activities (Lyon et al., 1997). Questionnaires related to participants' comfort, confidence, purpose in life, contentment and active participation in life were administered before and after the treatment. There were significant improvements after the treatment. Overall, this study provides evidence that training communication partners can increase confidence, self-worth and active life-participation for the individual affected by their aphasia.

Turner et al (2006) completed a systematic review to examine the key themes and participants' roles in conversational partner training in aphasia. The purpose of the review was to determine who benefits from CPT by focusing on characteristics of participants and if outcomes of studies were effective depending on measures used and format of training. The authors examined studies that focused on (1) supported conversation for adults with aphasia where conversation partners were trained to provide more communication opportunities for people with aphasia and (2) conversation coaching where conversational skills are reviewed and altered to use strategies throughout conversation. The training involved teaching conversational skills to provide the individuals with the skills to offer conversational support for a PwA.

They found that in studies that involved a volunteer as a conversational partner, there were positive outcomes as volunteers became more knowledgeable in identifying the competence of the person with aphasia (i.e. Kagan et al., 2001), utilizing multi-modality communication (Hickey et al., 2004), and an increase in overall knowledge of aphasia and how to utilize a variety of strategies for communication (Raynor and Marshall, 2003). There was an increase in positive social validation, comfort and effectiveness of volunteer communication

(Hickey et al., 2004). When a PwA participated in conversation with a volunteer, there was an increase in number of conversational interactions, a person's comfort using communication strategies, and psychosocial well-being (Lyon et al., 1997). The studies found an overall positive change in interactions and communication when compared to the control groups. A weakness to the studies was that the long-term effects for CPT ranged from 1 month following intervention (Simmons et al., 1987) to 9 weeks following intervention (Raynor and Marshall, 2003) which does not evaluate long-term effects for people with aphasia. In addition, studies failed to establish a baseline (Booth and Swabey, 1999).

Well-educated and highly motivated communication partner volunteers attained better success in communicating with a PwA across studies. Therefore, characteristics of volunteers interacting with a PwA warrants further investigation. Moreover, volunteers' attitudes that fostered respect and genuine interest in communicating with a PwA facilitated better outcomes across studies. This warrants future research in areas of personality, attitudes and perceptions. Lastly, communication style can affect the outcomes of conversation. If a PwA has poor communication abilities, but a skilled partner, then conversation can be successful. Whereas, a PwA with excellent communication skills but a poorly skilled conversational partner may experience poor conversation. This shows the importance of including participants' characteristics when reporting the outcomes of studies. Findings of this systematic review indicate that research needs to include more information regarding the communication partner volunteers when reporting the impact of the study to take into consideration particular variables that are influential to the impact of CPT (Turner et al., 2006).

According to a systematic review by Simmons-Mackie et al (2010), CPT appears to be an effective method of improving and maintaining partner skill in supporting communication for people with aphasia. Thirty-one studies were examined, with half involving training both the PwA and conversation partner, with less than half solely training conversation partners. They found that overall the training of communication partners is an effective method of improving partner skill in supporting communication for people with aphasia. This study shows that a variety of communication partners can profit from CPT, including volunteers, and that communication can be effective across a variety of severities of aphasias.

An updated systematic review was conducted by Simmons-Mackie et al. (2016) on language, communication, quality of life and participation. Of the 56 articles reviewed, nine of the studies trained communication partners alone. Typically unfamiliar partners, such as volunteers, were taught generic strategies and educated about aphasia in groups. They found that compared to their previous systematic review (Simmons-Mackie et al., 2010) there was an increase from 10% of the studies included volunteers for communication training to 24% focused on volunteers or health care providers (Simmons-Mackie, 2016). This shows a growing interest in improving communication for patients and community members. Through their study the authors continue to recommend training that focuses on communication skills for enhancing the function of communication for individuals with aphasia (Simmons-Mackie et al., 2016).

Overall, the literature supports CPT as a recommended method for improving partner communication skills to facilitate communication with aphasia. Speech-language pathologists need to take into consideration the importance of quality of life when providing therapy services for patients. Quality of life is perceived as “an individual’s perception in their position in life in

the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of their environment" (WHOQOL group, 1995). Quality of life is vastly affected by aphasia due to emotional depression, severity of aphasia, communication disability and aspects of support or social network (Hilari et al., 2015). Participation, meaningful relationships, support, communication positivity, independence and autonomy are all factors that influence quality of life (Hilari et al., 2015) that should be considered during rehabilitation of aphasia. Rehabilitation needs to not only focus on aspects of communication but also emotional well-being and increasing social participation. CPT can help facilitate increased life participation and increased quality of life in order to create more meaningful and pleasant interactions for a PwA. Overall, CPT is essential to improve for both life participation and quality of life for people with aphasia.

Chapter 3 Methods

STUDY DESIGN

The study aimed to evaluate the effectiveness of the communication partner training program for communication partners of a PwA delivered at the Columbus Museum of Art to eleven volunteers. The study used a pre/post design. This study followed the same Social Conversation for Adults with Aphasia design as Kagan (1998) and Kagan et al. (2001). SCA focuses on providing people with aphasia opportunities for conversation. SCA provides conversation partners with methods and materials for achieving this goal (Kagan 1998), which was completed in this study. To evaluate the efficiency of the training course the Communication Effectiveness Index (CETI) (Lomas et al., 1989) was administered to each volunteer before and after the presentation (see Appendix A). This index was adapted by groups of individuals with aphasia and their caregivers who generated a variety of communication situations that occur in everyday life. This index can assess how comfortable an individual is with communicating with a PwA in a variety of situations. A quiz (see Appendix B) adapted from the National Aphasia Association (Aphasia Quiz, 2017) was given before and after the presentation as well. The quiz tested the volunteers' knowledge about aphasia and communication strategies.

HYPOTHESIS

It was hypothesized that the training course would result in volunteers demonstrating increased knowledge about strategies to use in conversation, as measured by the CETI and increased knowledge pertaining to aphasia, as measured by the pre/post quiz.

PARTICIPANTS

See Table 1 for a summary of the participants' characteristics. Nine adults participated with one individual who was 36 years old and the rest of the individuals between the ages of 64-74 years old. Two additional individuals attended the training course, but opted not to participate in the study. Two participants were male (22%) and seven participants were female (78%). Participants were recruited from docent volunteers at the Columbus Museum of Art. This opportunity was available to any volunteer at the museum who was interested in attending the presentation of supporting communication for a PwA. Prior to participation in this study, written informed consent was obtained from participants. All of the participants had at least a college education; one individual had an Associate's degree, one individual had a Bachelor's degree, six had a Master's degree, and one individual had their Doctor of Medicine.

Table 2 shows the participants' previous exposure to aphasia and experience communicating with a PwA. None of the individuals were caregivers to a PwA. Two of the individuals had experience interacting with a PwA. One individual (Participant 2) had a friend with aphasia and also had interactions as a docent with people with aphasia. Another individual (Participant 7) is a hospice volunteer and is a companion to a PwA. Neither of these individuals had a PwA dependent on them for assistance.

Table 1. Participant demographic information

Participants	Age	Gender	Education	Occupation
1	74	M	Master's	Programing development and Management
2	74	F	Master's	Mental Health Therapist
3	67	F	Master's	Teacher
4	64	F	Associate's	Interpreter for the Deaf
5	67	F	Master's	Writer/ Hospice Chaplain/ Yoga Instructor
6	36	F	Master's	Manager of Volunteers
7	68	F	Doctorate Of Medicine	Professor
8	73	F	Bachelor's	Teacher
9	70	M	Master's	Retired

Table 2. Participant exposure to aphasia

Participant	Relationship to PwA	Same home as this individual?	Hours spent with this individual a week	How dependent is this person upon you for assistance	Additional information
1	N/A	N/A	N/A	N/A	N/A
2	Docent/Friend	No	1	Minimal	N/A
3	N/A	N/A	N/A	N/A	N/A
4	N/A	N/A	N/A	N/A	N/A
5	N/A	N/A	N/A	N/A	N/A
6	N/A	N/A	N/A	N/A	N/A
7	Hospice Worker	No	2	Minimal	Interactions take place in nursing home
8	N/A	N/A	N/A	N/A	N/A
9	N/A	N/A	N/A	N/A	N/A

Chapter 4 Procedure

The course consisted of a 90-minute session in a small group format. The course aimed to teach the role of a communication partner, how aphasia affects a PwA's conversation, strategies to utilize when communicating with a PwA, and increase the volunteers' knowledge of aphasia. The training course was conducted by a Speech-Language Pathology graduate student from The Ohio State University. The presenter invited the volunteers to participate throughout the course with questions and an open discussion of opportunities at the museum when participants could utilize strategies taught.

This study followed Kagan's structure by providing potential conversation partners in order to provide opportunities for a PwA to have genuine adult conversation and interaction (Kagan, 1998). This current study used the same basis of the module including supported conversation and basic information about aphasia. The aim of the training course followed Kagan's aim including ensuring comprehension, ensuring that the PwA can respond and verifying the response of the PwA.

Participants completed a CETI (Appendix A) that included 16 items to rate, in order to determine how effective the participant perceived themselves in communicating with someone with aphasia. The participants were able to rate items from 'not at all able' to help someone with aphasia complete a task to 'as able as before stroke'.

The participants then completed a pre-quiz (Appendix B). This quiz included determining true statements about aphasia, with five true statements and five foils. The participants then had

to determine appropriate communication techniques to utilize with a PwA in order to support conversation, understand their message and assist an individual with expressing their thoughts. There were 13 accurate techniques and 21 foils.

The training course educated the participants on an overview of aphasia, what causes aphasia, the prevalence of aphasia, and communication deficits individuals experience who have aphasia. The participants were then trained on effective methods to utilize when communicating with a PwA in order to provide opportunities for communication, assist the individual with comprehending the communication partners' message, and assist the PwA with expressing their thoughts. Volunteers were familiarized with ways to support a PwA in order to support communication in the environment at the museum. The conversation opportunities could include discussing a piece of art, asking questions about knowledge of art, giving directions to an area in the museum, etc.

Alternative modes of communication and techniques were taught including using gestures, writing down key words, and utilizing pictures and drawings in order to communicate. Video clips from Aphasia Access (Whiteside, n.d) were used, including 'Adjust your talking', 'Using gesture and body language', and 'Using writing and graphics' (Communication Tools: Communication Access and SCA 2015). These videos provided participants with examples of how to effectively communicate with a PwA.

A community advocate who has aphasia attended the training course in order to share his experience with having a stroke. This individual was able to show the participants that a PwA can have significant improvements even after six months and that anyone, any age, can be affected by aphasia. He described his long road to recovery after having a stroke that even

continues on years later. The community advocate was able to share his own preferred methods he has found to be effective for communication, as well as difficulties he encounters in his everyday life.

After the training course was completed, participants were given the same CETI and post-quiz in order to measure the participants' knowledge of aphasia and communication methods after completing the training course. These measures were completed in view of the researcher, to ensure independence during completion.

A resource was left with the art museum staff that is similar to Kagan's Pictographic Communication Resource Manual. This binder includes alphabet boards, basic communication boards (yes/no, etc.), and maps as an alternative way of communication for a PwA. This resource can be utilized when docent volunteers encounter a PwA visiting the museum, in order to support conversation with this individual.

Chapter 5 Results

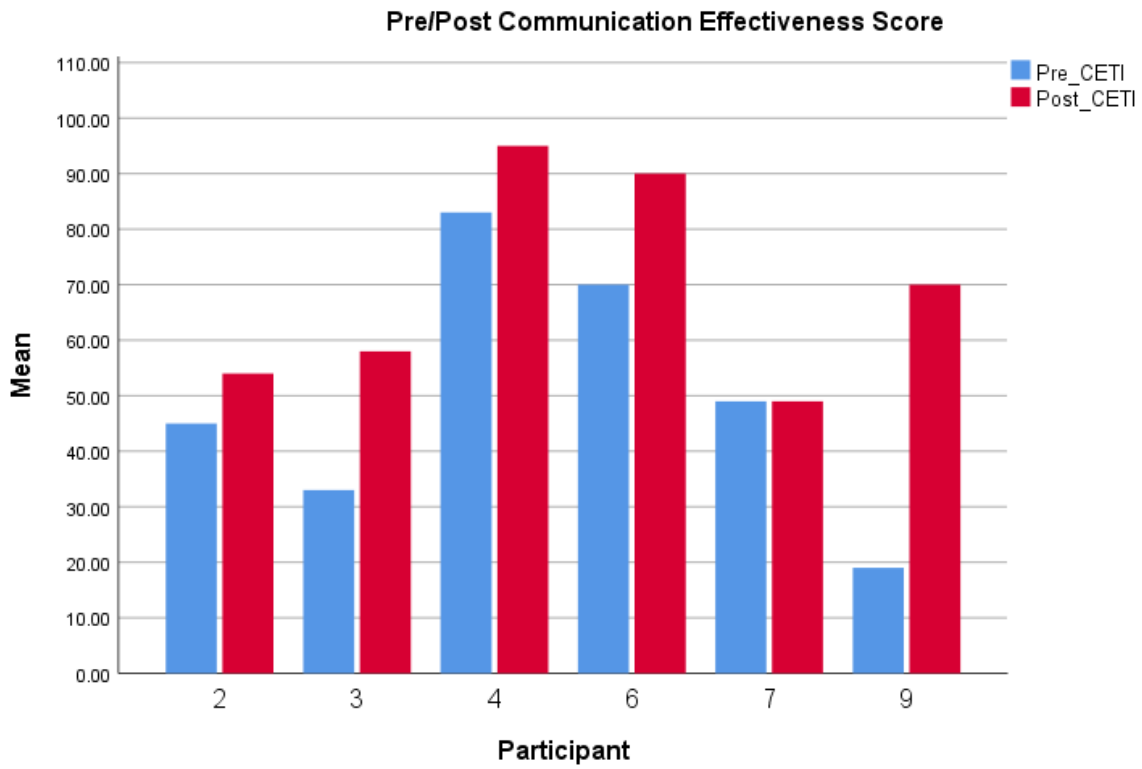
The CETI was scored based on the method used in the study conducted by Lomas et al. (1989). The participants' self-rating for each situation was converted into a score by using a 10-cm scale marked with millimeter divisions and the value was scored between 1 and 100. The total CETI score was calculated by dividing the sum of the individual situation ratings by the total number of situations. A "high score" indicated the individual was comfortable communicating with a PwA in many situations and a "low score" indicated the individual was not comfortable communicating with a PwA in the listed situations.

The participants' self-rating scores for each situation on the CETI was calculated to determine an overall mean score for each participant for the 16 situations listed in the CETI. The mean scores for each participant is indicated in Table 3 for both the pre-CETI and post-CETI. Table 4 is a visual representation of how comfortable each participant is communicating with a PwA via a bar graph before the training course and after the training course.

Table 3. Means scores for CETI

Participant	Pre Communication effectiveness index	Post Communication effectiveness index
1	-	-
2	45	54
3	33	58
4	83	95
5	-	-
6	70	90
7	49	49
8	-	-
9	19	70

Table 4. Pre/post CETI score



Participant 1, Participant 5 and Participant 8 opted to not complete the CETI, so their scores were not included. Participant 2's score improved by 9%, Participant 3's score improved by 25%, Participant 4's score improved by 12%, Participant 6's score improved by 20%, Participant 7's score stayed the same, and Participant 9's score showed the most improvement by 51%. Participant 7 indicated that her answers were the same as before. This shows that all of the participants' scores, besides Participant 7, improved from before the training course and after the training course on the CETI. After completing the training course, the majority of the participants felt more comfortable in situations when communicating with a PwA.

Table 5 presents the lowest scores, highest scores, mean and standard deviation for the CETI completed by volunteer participants. This table shows that the lowest score for the pre-CETI was a 19.0 and the highest was a 49.8. The lowest score for the post-CETI was a 49.0 and the highest score for the post-CITI was a 95. This table shows that the mean score of the CETI for the six participants who completed the CETI before the training course was a 49.8.

Table 5. Descriptive Statistics-pre/post CETI

	N	Minimum	Maximum	Mean	Std. Deviation
Pre_CETI	6	19.00	49.80	49.8333	23.51524
Post_CETI	6	49.00	95.00	69.3333	19.30458
Valid N (listwise)	6				

As described by Lomas et al. (1989) a “low score” indicates that an individual is not comfortable communicating with a PwA in a number of situations as shown in Appendix A (i.e. having a one-to-one conversation indicating that he/she understands what is being said, describing or discussing something in depth, etc.). Once the training course was completed, the participants completed the CETI again in order to determine if the information presented in the training course effectively trains individuals how to be effective communication partners to a PwA. The mean score of the six participants who completed the CETI, after the training, was a 69.8. A higher score, as opposed to the CETI completed before the training course, indicates that an individual is more comfortable communicating with a PwA in many situations (Lomas et al., 1989). This improvement shows that the participants of this study felt more comfortable communicating with a PwA in many situations after the training course was completed. There was an overall improvement of 20% before and after the training course. This indicates that the training course was effective in teaching the participants strategies to utilize when communicating with a PwA and the role of a communication partner.

The effects of the training course were analyzed using descriptive statistics and a paired sample t-test, shown in Table 6, in order to determine if the difference of the CETI scores from before the training course to after the training course were statistically significant and to determine the effect size. Results showed that the training effect was statistically significant for improvement on the CETI from before the training to after the training at $p < .05$ [$t(5) = 2.696$, $p = .043$].

In addition to statistical significance, the results show a large effect size. Cohen’s (1988) convention was used in order to determine the magnitude of differences between two groups.

According to Cohen, a correlation coefficient of .2 is considered a small or weak association, a correlation coefficient of .5 is thought to be a moderate correlation and a correlation of .8 or larger is thought to represent a large or strong correlation. The effect size was determined by calculating the mean difference between the measures and then dividing the standard deviation. In the case of determining the difference between the pre and post CETI, the effect size was found to be 1.1, which is considered a large effect size.

Table 6. Paired Samples Test-CETI

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	Pre_CETI - Post_CETI	19.50000	17.71722	7.23303	.90691	38.09309	2.696	5	.043

Table 7 shows the improvement of each participant from their results of the quiz before the training course and after the training course was completed. Table 8 summarizes the results of the participants' percentage correct for both the pre-quiz and post-quiz. Table 9 shows a visual representation of each participants' improvement via a bar graph. Two of the participants (Participant 3 and Participant 8) did not complete choosing true statements for both the pre-quiz and post-quiz. These individuals opted to only complete the second part of the quiz that required the participant to circle effective methods to use when communicating with a PwA. This affected their overall scores and did not allow for more significant improvement.

Table 7. Mean scores for pre/post quiz

Participant	Pre-quiz Score	Post-quiz Score
1	10	17
2	15	16
3	13	13
4	13	14
5	16	16
6	11	15
7	13	16
8	9	13
9	11	14

Table 8. Mean percentage for pre/post quiz

Participant	Pre-quiz Score (%)	Post-quiz Score (%)
1	55	94
2	83	88
3	72	72
4	72	77
5	88	88
6	61	83
7	72	88
8	50	72
9	61	90

Table 9. Pre/post quiz scores

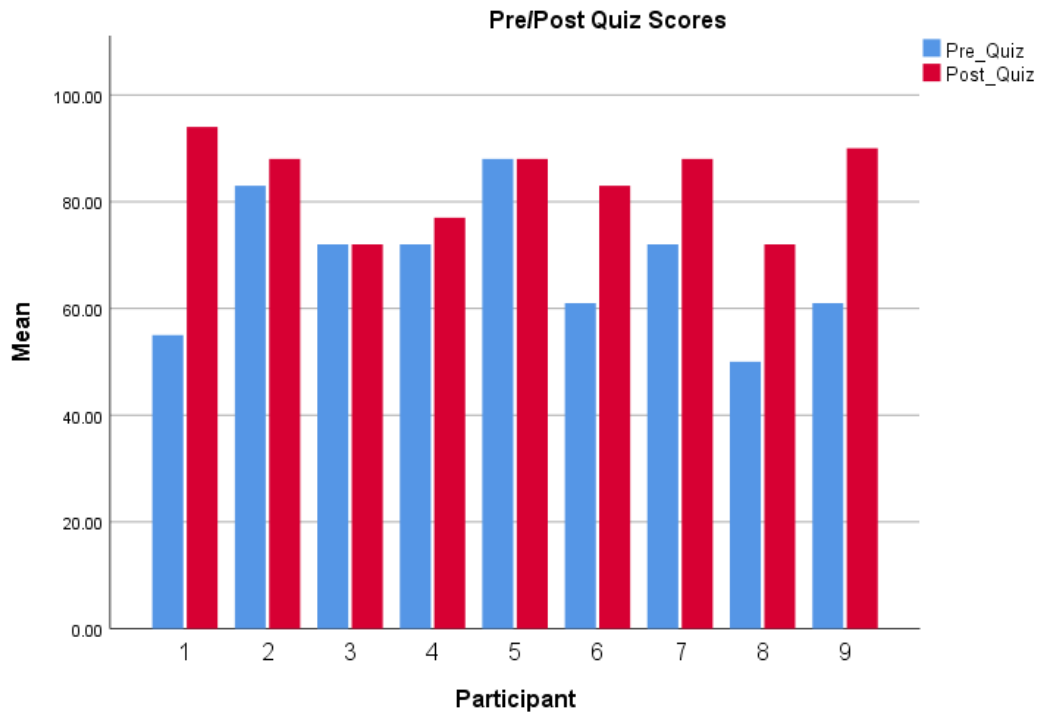


Table 10 displays the lowest percentage for the pre-quiz was 50.0% and the highest percentage was 88%. The lowest score for the post-quiz was 72% and the highest score was 94%. Table 10 also shows the mean percentage of the nine participants before the training course and after the training course, which was 68% before the training course and 83.5% after the training course.

Table 10. Descriptive Statistics-pre/post quiz

	N	Minimum	Maximum	Mean	Std. Deviation
Pre_Quiz	9	50.00	88.00	68.2222	12.56760
Post_Quiz	9	72.00	94.00	83.5556	8.06398
Valid N (listwise)	9				

Before training, the mean score of the pre-quiz was 12.3/18. After the training course it rose to 14.8/18, which was an improvement of 2.5 points. This shows that the course was effective in teaching an overview of aphasia, how to support conversation, how to assist a PwA to understand a communication partner's message and how to assist a PwA in expressing their thoughts.

The results of the pre/post quiz were analyzed using descriptive statistics and a paired sample t-test as well. A t-test was used to determine whether the mean difference between the scores was statistically significant. Table 11 displays the analysis of the improvement between the two quizzes. This analysis was used in order to discover if the difference of the pre/post quiz scores from before the training course to after the training course were statistically significant and to determine the effect size. The effect of training was statistically significant for improvement on the pre/post quiz as well from before the training to after the training [t(8)=3.337, p=.010, p<.05].

In addition to statistical significance, the results show a large effect size. Cohen's (1988) convention was used in order to determine the magnitude of differences between two groups. In the case of determining the difference between pre/post quiz the effect size was found

to also be 1.1. The effect size for this study corresponds to Cohen’s benchmark of a large effect size $r=0.5$.

Table 11. Paired Samples Test-pre/post quiz

		Paired Differences				t	df	Sig. (2-tailed)	
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower				Upper
Pair 1	Pre_Quiz- Post_Quiz	15.33333	13.78405	4.59468	4.73798	25.92869	3.337	8	.010

Chapter 6 Discussion

This study evaluated the effects of a training course that trained volunteers to be effective communication partners to increase life participation for people with aphasia. The results showed an overall improvement on the CETI that measured how comfortable the participant was communicating with a PwA in a number of different social situations, with an increase of 20%. The results also showed an improvement on the quiz that measured the participants' knowledge of aphasia and effective methods to utilize when communicating with a PwA, with an increase of 2.5 points.

In designing the study, all participants were expected to do better on both the CETI and quiz the second time because of exposure to the training course. These results support the researcher's hypothesis that a training course can increase volunteers' knowledge pertaining to aphasia and demonstrate increased knowledge about strategies to use in conversation, in order to effectively communicate with a PwA. A training course can successfully teach the role of a communication partner, how aphasia affects a PwA's conversation, strategies to utilize when communicating with a PwA, and increase the volunteers' knowledge of aphasia, as proven by the results of this study.

This study contributes to the literature by providing further research on training volunteers in the community. The majority of the research focuses on training caregivers to communicate.

This study replicates the findings of Kagan et al. (2001) that training individuals to be effective communication partners can improve the knowledge and ability to use techniques to communicate with individuals with aphasia. This study was similar to Kagan et al.'s by using participants that willingly volunteered and were highly educated. Kagan et al. (2001) found that communication partners and PwA in the experimental group scored higher on the second interview after being trained than the first interview. This was discovered to be true in this study as well with higher scores for both the CETI and quizzes.

STRENGTHS/WEAKNESSES

The results of the CETI before and after the training course show strong evidence that the training course was effective in teaching the participants how to be effective communication partners. There was a significant improvement of 20% on the CETI ratings from the mean score of the participants' scores before the training course and after the training course. One weakness of the study was that three participants opted to not complete the CETI before or after the course. This contributed to less data collected in order to determine how comfortable participants felt in a variety of communication situations with a PwA.

Two participants incorrectly followed directions when completing the pre-quiz and post-quiz. Two of the participants did not complete choosing true statements for both the pre-quiz and post-quiz and opted to only complete the second part of the quiz that required the participant to circle effective methods to use when communicating with a PwA. This affected the overall mean score for the quiz results and affect how that data shows improvement of the participants. The quiz results also only showed a 2.5 point improvement and 15.3% improvement from the mean

of the pre-quiz to the mean of the post-quiz. Despite a number of the participants not completely filling out the quiz, the improvement from the pre-quiz to the post-quiz are statistically significant and offer strong evidence of improvement after the training course.

A limitation of this study is there was no control group or control measure for both the CETI and quiz. All the participants in this study went through the training course with no control group to compare changes in results. Future studies on CPT should include a control group who is not offered the training course, in order to determine the results of the CETI and quiz are reliable.

The sample size and similarity of the volunteers is both a limitation and strength to this study. This study only included nine participants, all of the participants had a college degree with 88% of the participants having a Master's degree or higher and majority of the participants were older adults (64-74). This similarity of the volunteers limits the reliability of the training. On the other hand, a strength of the study was that the majority of the participants were older adults and retired, so they had time to attend and partake in the training course. Another strength of this study was all of the participants were highly educated and highly motivated to participate in the training course. The small sample size also allowed the training course to have an open discussion for questions and to brainstorm potential conversation opportunities.

Lastly, this study did not allow the researchers to observe the participants communicating with a PwA. Participants' scores can improve on the CETI and quizzes, but may not show changes when these strategies are put into practice. Often information learned may not generalize and correspond in real-life situations talking with people with aphasia who may visit the

museum. This observation of communication can determine if life participation does indeed increase after CPT.

RECOMMENDATIONS

The limitations of this study should be addressed in similar research studies in the future in order to obtain more support of the researcher's hypothesis that a training course can result in increased knowledge about strategies to use in conversation with a PwA. Future studies should ensure participants completely fill out both the quizzes and CETI in order to attain as much data as possible. A control group who does not receive training should be utilized in order to ensure the training course is effective and that the experimental group's scores do indeed increase due to the training course. A more diverse group with more individuals should be included for the experimental group in similar studies in the future including a wide variety of ages, ethnicities, and levels of education. Volunteers with a variety of demographic characteristics should be included in a future study in order to determine the generalizability of the results. If a larger group participated, factors could be identified that make individuals more responsive or less responsive to the training course.

Lastly, further research would be needed in order to observe how community members who complete CPT interact with a PwA in the community setting. This is needed in order to determine if there is an increase in communication opportunities and if strategies are effectively used in conversation. Volunteers might be able to increase scores in theory on paper, but research is needed to examine the generalizability to real-life situations interacting with a group

of people with aphasia with varying levels of severity. These recommendations are needed in order to ensure the validity of training courses for communication.

Chapter 7 Conclusion

In conclusion, evidence from the literature shows that training participants as communication partners for a PwA using a training course can improve the communication of the participants. Improving communication skills for communication partners through a training course can be achieved by giving an overview of aphasia, teaching their role as a communication partner, and teaching strategies to utilize when communicating with a PwA. Providing these training courses to individuals a PwA might interact with in the community can lead to increased opportunities for conversation, which could result in increased life participation for a PwA. Further research is required before it is known how changes on the measures actually translate into clinical performance and generalizes to the community. In order for people with aphasia to have better experiences in the community, it is essential for individuals in the community to be educated on the effects of aphasia and how to communicate with a PwA.

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Appendix A CETI

Communicative Effectiveness Index

(Lomas et al., 1989)

This instructions for this questionnaire have been modified for the current study.

DATE:

PARTICIPANT #:

NAME OF CAREGIVER (RELATION):

Draw a line to show how effective you are helping someone with aphasia do each of the following tasks:

1. Getting somebody's attention:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

2. Getting involved in group conversations that are about him/her:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

3. Giving yes and no answers appropriately:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

4. Communicating his/her emotions:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

5. Indicating that he/she understands what is being said to him/her:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

6. Having coffee-time visits and conversations with friends and neighbors (around the bedside or at home):

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

7. Having a one-to-one conversation with you:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

8. Saying the name of someone whose face is in front of him/her:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

9. Communicating physical problems such as aches and pains:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

10. Having a spontaneous conversation (i.e., starting the conversation and/or changing the subject):

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

11. Responding to or communicating anything (including using yes or no) without words:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

12. Starting a conversation with people who are not close family:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

13. Understanding writing:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

14. Being part of a conversation when it is fast and there are a number of people involved:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

15. Participating in a conversation with strangers:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

16. Describing or discussing something in depth:

NOT AT _____ AS ABLE AS
ALL ABLE BEFORE STROKE

Appendix B Aphasia Quiz

Part 1: Circle all TRUE statements:

1. Most people are familiar with aphasia.
2. Aphasia means a person has difficulty retrieving words for speech and usually has some problems reading, writing, and understanding spoken language.
3. The cause of aphasia is usually due to a heart attack.
4. If people have aphasia they will always have a significant memory loss as well.
5. Aphasia is more prevalent than Parkinson's Disease or Muscular Dystrophy.
6. A person with aphasia may have no noticeable physical impairment.
7. All individuals with aphasia have very similar symptoms of the same approximate severity.
8. Although most people with aphasia are older than 50 years of age, it is not unusual for younger people to acquire this disability.
9. Some individuals with aphasia return to work, however, most are forced to retire or change jobs and work in a modified capacity.
10. Recovery from aphasia is usually complete within six months of treatment.

Part 2: Circle all appropriate communication techniques to use with people who have aphasia:

To help <i>support</i>	To help the person	To help the person <i>express</i>
<p><i>conversation</i> you should:</p> <ol style="list-style-type: none">1. Provide opportunities for conversation.2. Speak for the person.3. Use the best/preferred method of communication for that person.4. Eliminate distractions and background noise.5. To reward communication attempts, always say "I understand" even when you do not.6. Recap long conversations	<p><i>understand your message</i></p> <p>you should:</p> <ol style="list-style-type: none">1. Talk to them like they are a child.2. Use short and simple sentences.3. Speak louder if they do not understand you.4. Use clear intonation.5. Use gestures.6. Write down key words and topics.7. Pause between thoughts.8. Add as much detail as you can if they do not understand you the first time.	<p><i>their thoughts:</i></p> <ol style="list-style-type: none">1. Ask as many questions as you can.2. Ask yes or no questions to confirm message.3. Provide multiple choices.4. Correct mispronounced words.5. Finish their sentences if they are having trouble.6. Request the use of pointing, gestures, and written key words.7. Give the person time to respond.