Development of a Training Session for Caregivers of Persons with Aphasia:

A Pilot Study

THESIS

Presented in Partial Fulfillment of the Requirements for the Degree Master of Arts in the Graduate School of The Ohio State University

By

Shannon Melvin, B.A.

Graduate Program in Speech-Language Pathology

The Ohio State University

2017

Master’s Examination Committee:

Stacy Harnish, Ph.D., CCC-SLP Advisor

Jennifer Brello, M.Ed., CCC-SLP
Abstract

The current study aims to collect pilot data on the effects of a newly developed communication partner training protocol for caregivers of persons with aphasia (PWA), particularly on their knowledge of aphasia and their perceived abilities to facilitate communication with PWA. Two middle-aged adults, one male and one female, participated in a 90-minute training course addressing educational information about aphasia and strategies for supporting communication with PWA. A community member with aphasia also presented his personal story to the participants. Participants completed a short quiz about aphasia knowledge and a short survey about their perceived ability to facilitate communication with PWA; the quiz and survey were taken once by each participant prior to the training course, and once by each participant following the training course. Both participants reported positive changes in their perceived abilities to communicate with PWA between pre- and post-session surveys. One participant had a slightly improved score on the aphasia knowledge quiz between pre- and post-session, while the other had a slightly decreased score. Overall results indicate that the training session protocol may be effective in improving caregivers’ perceptions of their abilities to facilitate communication with PWA.
Acknowledgments

First I want to express my gratitude to my advisors, Stacy Harnish and Jennifer Brello, for all of their assistance throughout this project. I am extremely grateful for all of the suggestions, feedback, and time that was so generously shared. I would also like to thank Robert Gast, for willingly volunteering his time and sharing his personal experiences. Thank you also to Christine Meer for her vital contributions to this project, including her help and feedback in the orchestration of the training program. Finally, I would like to thank Dodd Hall Rehabilitation Center at Wexner Medical Center, for allowing me to utilize facility resources for this project.
Vita

2015…………………………………………B.A. Linguistics, The Ohio State University

2015 to present…………………………...Graduate Student, Department of Speech

and Hearing Science, The Ohio State

University

2016 to present………………………………Graduate Clinician, Department of Speech

and Hearing Science, The Ohio State

University

Expected, 2017………………………………M.A. Speech-Language Pathology, The

Ohio State University

Fields of Study

Major Field: Speech-Language Pathology
# Table of Contents

Abstract ............................................................................................................................ii

Acknowledgments .............................................................................................................iii

Vita .....................................................................................................................................iv

Table of Contents ...............................................................................................................v

List of Tables ......................................................................................................................vi

Chapter 1: Background .....................................................................................................1

Chapter 2: Methods ..........................................................................................................5

Chapter 3: Results ............................................................................................................11

Chapter 4: Discussion .....................................................................................................14

Chapter 5: Conclusion .....................................................................................................20

References .......................................................................................................................21

Appendix A: The Aphasia Quiz ......................................................................................23

Appendix B: Communicative Effectiveness Index (modified) ........................................26
List of Tables

Table 1. *Overview of supported conversation strategies described in training protocol*…9

Table 2. *Participant scores on objective and subjective measurements taken pre- and post-session*………………………………………………………………………………………………………………………11
Chapter 1: Background

Aphasia is a term used to describe language impairment resulting from localized lesions in areas of the cortex responsible for language function. Aphasia is most often caused by cerebrovascular accident (CVA) (“Aphasia FAQs,” n.d.). It may also arise from other circumstances, such as traumatic brain injury. Approximately 80,000 people acquire aphasia each year, and over 1 million people in the US currently have aphasia (“Aphasia,” n.d.). Characteristics of aphasia may include a wide variety of language dysfunctions, such as disordered syntax (i.e. sentence structure), sound substitutions, and word-finding difficulties (“American Speech-Language-Hearing Association,” n.d.). The most rapid language recovery occurs immediately following the stroke, in the acute stages. In one study, 95% of stroke patients reached stationary language function within 6 weeks of admission to acute care (Pedersen, Jørgensen, Nakayama, Raaschou, & Olsen, 1995). Improvement in communication and language has been found to be significantly influenced by the initial severity of aphasia; milder initial aphasia is predictive of better speech and language outcomes (Pederson et al., 1995; Laska, Hellblom, Murray, Kahan, & Von Arbin, 2001; Plowman, Hentz, & Ellis, 2011; Watila & Belarabe, 2015).

Beyond the language impairment itself, aphasia can impact an individual’s ability to communicate with family members, interact in social situations, and participate independently in everyday life. In a qualitative study, persons with aphasia reported
changes in communication as well as changes in interpersonal relationships, loss of autonomy, restricted activities, and stigmatization (Le Dorze & Brassard, 1995). Specific reported changes included loss of friends, anxiety meeting strangers, reduced employment opportunities, and embarrassment about speaking and walking (Le Dorze & Brassard, 1995). These changes in relationships and activity level, as well as stigmatization, are suspected to be due in part to changes in communication abilities. Thus, PWA experiencing such changes may benefit from therapy targeted to improve the quality of their communication interactions.

Aphasia also has profound effects on the family and care partners of PWA. Le Dorze and Brassard (1995) found that relatives and friends of PWA reportedly experienced handicaps and coping behavior (e.g. loss of friends, role changes, avoiding certain topics, and distancing themselves from the PWA) as a result of their relationships with PWA. Consequently, the authors conclude that aphasia treatment should address the needs of family and caregivers, in addition to the needs of PWA. Furthermore, Tatsumi et al. (2016) examined the relationships among self-efficacy (i.e. one’s ability to envision the possibility of success), communication burden, and mental health experienced by care partners of PWA. The authors found that higher self-efficacy is associated with lower communication burden and better mental health in caregivers. Training in communication strategies aimed to support communication with PWA may increase caregiver self-rating of ability to support communication with PWA and consequently decrease caregiver communication burden.
Increased caregiver training in communication support strategies could also lead to improved outcomes for the PWA, as caregivers’ behaviors have been found to positively impact participation of PWA (Dalemans, de Witt, Wade, & van den Heuvel, 2010). Effective caregivers focus on creating circumstances that engage the PWA with others, and providing other communication partners with communication strategies and tips to aid the PWA conversations with others. In contrast, caregivers who have a negative impact on the participation of PWA may be seen as “overprotecting,” and thus prevent the PWA from having adequate opportunity to engage themselves with their environments (Dalemans, de Witt, Wade, & van den Heuvel, 2010). Thus, care partners of PWA play a significant role in outcomes for the persons for whom they are caring. As a result, the inclusion of care partners in the treatment process, especially in the training of communication support strategies, is essential in order to maximize outcomes for PWA.

Moreover, the benefits of training care partners of PWA in supported conversation strategies have been examined in numerous studies (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Simmons-Mackie, Raymer, & Cherney, 2016). In two systematic reviews of communication training studies, communication trainings were found to have positive impacts on a variety of outcome measures (e.g. knowledge of aphasia, quality of life, participation) related to both the care partners and PWA (Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016). Despite research support for the training of caregivers of PWA in the absence of the PWA (Hagge 2014; McGilton et al. 2011; Saldert, Johansson, & Wilkinson, 2015; Kagan, Black, Duchan,
Simmons-Mackie, & Square, 2001), this practice remains unbillable; Current Procedural Terminology (CPT) codes do not exist for services rendered to care partners, and therefore, these services cannot be billed (“American Speech-Language-Hearing Association,” n.d.). Though the billing of services provided in the absence of the primary patient may seem unusual, there are clear benefits to performing such services, particularly for caregivers of persons in the acute, post-stroke stage who have recently been diagnosed with aphasia. PWA in the acute stage have a variety of medical needs in addition to speech and language needs, and may provide more of a distraction than contribution to therapy focused on the education of care partners. Additionally, care partners may feel more comfortable asking open questions about stroke and aphasia when the PWA is not present in the room, and would then be able to gain greater knowledge about potentially sensitive but important topics.

In the literature, the bulk of trainings for care partners of PWA have been conducted for caregivers of persons with chronic aphasia; there is insufficient information on the effects of care partner training for persons with acute aphasia (Simmons-Mackie et al. 2010; Simmons-Mackie et al. 2016). The conduction of training sessions during the acute stage could be significant, due to the rate of recovery experienced in patients during this time; as improvements in language function are greatest in the time immediately following stroke (Pederson et al. 1995), communication training delivered in the acute stage would be best aligned with the typical progression of language recovery.
In consideration of the potential benefits of early training for care partners in supported communication strategies for PWA, as well as the advantages of conducting such trainings in the absence of PWA, the current study aims to examine the effects of a care partner training session in communication support strategies that is conducted for caregivers of persons with acute aphasia and in the absence of all PWA for whom they are caring. This will be achieved through the examination of knowledge acquisition on aphasia, causes, statistics, and symptoms, as well as the identification of strategies to support communication for PWA.

Research Questions

1. What are the effects of the training session on participants’ objective knowledge of aphasia (causes, statistics, and symptoms)?

2. What are the effects of the training session on participants’ perceptions of their abilities to support communication with PWA?
Chapter 2: Methods

Development of Protocol

The protocol was developed to address basic educational information about aphasia, including causes, symptoms, and statistics; to provide insight into the perspective of those suffering from aphasia; and to introduce and describe strategies to support communication with PWA within a 90 minute training session. It was designed specifically for care partners of PWA with little to no previous knowledge of or experience with aphasia.

Educational information was drawn from public resources, including the National Aphasia Association (NAA), the National Institute on Deafness and Other Communication Disorders (NIDCD), and the American Speech-Language Hearing Association (ASHA). Videos from Aphasia Access (“Aphasia Access Educational Videos,” 2016) were incorporated to illustrate effective communication facilitation strategies performed with PWA. The communication strategies described within the training session were adapted primarily from the Aphasia Institute Supported Conversation for Adults with Aphasia (SCA™) communication method. Finally, at the end of the session, a community member with aphasia presented his personal story and shared the perspective of PWA and the impact that aphasia has on those individuals’ lives.
Participant Information

Participant 1

Participant 1 is a 46-year-old female with a Master’s degree who is employed in health care administration. Given her background and education, she likely has knowledge and experience with strokes and aphasia that is atypical of an average person. She participated in the training session in order to gain more knowledge and to better communicate with her father-in-law, who recently suffered a stroke and received speech-language therapy services in the inpatient rehabilitation setting in order to address his newly acquired aphasia. Participant 1 reports that she spends approximately ten hours per week with her father-in-law, and that he requires total assistance as a result of his recent stroke. The PWA for whom she attended the training session is currently living in a skilled nursing facility due to the impairments he acquired from his recent stroke.

Participant 2

Participant 2 is a 53-year-old male with a Master’s degree who is employed as a radiologic technologist. Given his education and background, he may have greater knowledge related to healthcare, strokes and aphasia than is typical. He participated in the training session to better communication with his father, who is the same PWA as mentioned above in relation to Participant 1. Participant 2 reports that his father requires moderate assistance as a result of his recent stroke.
Procedures

The training session was conducted in the Ohio State University Wexner Medical Center at Dodd Hall Rehabilitation Hospital. It was led by a graduate student from the Department of Speech and Hearing Sciences at Ohio State University, as well as a licensed and certified Speech-Language Pathologist employed in the medical center. A guest speaker, a community member with aphasia, presented his personal experiences as the final part of the training session.

Prior to the start of the presentation, participants were asked to complete two surveys. One survey, “The Aphasia Quiz,” contained ten objective questions about aphasia. The other survey was a modified version of the Communicative Effectiveness Index (CETI) (Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A., and Zoghaib, C., 1989), used to assess participants’ subjective ratings of their own abilities to facilitate communication with PWA. Both “The Aphasia Quiz” and the modified CETI can be found in the appendices of this paper.

The session began with introductions of the presenters and participants. Participants were provided with educational information about aphasia. They were then asked to discuss their personal experiences with aphasia. Following initial discussion, the topic of supported communication was introduced. An overview of the supported communication strategies and content, in the order in which it was presented, is provided below in Table 1. Participants were introduced to the concept of supported communication itself, their role as care partners in supporting conversation, and specific techniques to use in order to fill that role. Videos from Aphasia Access were presented
alongside descriptions of supported communication strategies. The videos addressed how to adjust one’s talking, use body language and gestures, and use writing and images to facilitate a variety of communications. The discussion of strategies concluded with recommendations for execution of the strategies themselves, as well as suggested materials that would be beneficial in aiding communication. Binders containing materials for communication supplementation were provided to participants.
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description Provided in Presentation Text</th>
</tr>
</thead>
</table>
| Show understanding                     | • Verbally acknowledge that PWA understands better than is able to show  
• Acknowledge communication partners’ roles in communication breakdowns  
• Remember that aphasia is not a cognitive impairment, but an impairment of language                                                                                           |
| Make speech more easily understandable | • Aphasia Access video “Adjusting Your Talking”  
• Use short, simple sentences  
• Use clear intonation  
• Use visuals – gestures, pictures, written key words  
• Eliminate audible and visual distractions  
• Be mindful of PWA’s body language and facial expression  
• Aphasia Access video “Using Body Language and Gestures”                                                                                                                                 |
| Help the PWA to express his/her thoughts | • Ask yes/no questions  
• Ask one question at a time  
• Ask fixed choice questions  
• Ask for gestures, pictures, and/or written key words when possible  
• Give time for the PWA to respond  
• Aphasia Access video “Using Writing and Graphics”                                                                                                                             |
| Confirm communication by summarizing    | • Use gestures and key words to summarize  
• Repeat/rephrase message  
• Expand on what you think PWA is trying to say  
• Recap long conversations                                                                                                                                                     |
| How to use strategies                   | • Be patient and natural  
• Repair communication when there is a breakdown  
• Watch the PWA and respond accordingly                                                                                                                                                                                                 |
| Useful materials                        | • Paper and pencil for writing key words/drawing pictures  
• Pictures for illustration  
• Paper “frame” to highlight key information in text  
• Flashcards of key words to indicate/change topic                                                                                                                                 |

Table 1. Overview of supported conversation strategies described in training protocol.
The session concluded with a presentation by a community member with aphasia. The community member shared his personal story, beginning with his stroke in 2013. He described challenges to progress and his personal approach to managing his new communication difficulties. He described changes in others’ perceptions of him as a result of his aphasia, and the profound impact these changes have had on him. His talk ended with questions and answers regarding his experiences.

Following the community member’s presentation, two surveys were again administered to the participants to assess changes in their objective knowledge and subjective perceptions following the information provided in the day’s training session. Participants again completed “The Aphasia Quiz” and the modified CETI for this purpose. The results of those surveys completed pre- and post-training session are described below.
Chapter 3: Results

Results of “The Aphasia Quiz” (objective measure) and the modified CETI (subjective measure) are shown below in Table 2.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Aphasia Quiz, Time 1</th>
<th>Aphasia Quiz, Time 2</th>
<th>CETI, Time 1</th>
<th>CETI, Time 2</th>
<th>CETI Score Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>10/10 (100%)</td>
<td>9/10 (90%)</td>
<td>10.5</td>
<td>60.0</td>
<td>49.5</td>
</tr>
<tr>
<td>Participant 2</td>
<td>9/10 (90%)</td>
<td>10/10 (100%)</td>
<td>12.0</td>
<td>26.8</td>
<td>14.8</td>
</tr>
</tbody>
</table>

Table 2. Participant scores on objective and subjective surveys administered pre- and post-session.

Objective Measures: The Aphasia Quiz

“The Aphasia Quiz” was selected as an objective measure because it is short, straightforward, and addresses multiple aspects of aphasia, including causes, symptoms, and statistics. Participant 1 showed a decrease in aphasia knowledge between the pre- and post-testing periods. While she had a perfect score on her first completion of the survey (10/10), she missed one question on her second completion of the quiz (9/10). This could be due to a variety of reasons, which are discussed in more detail in the limitations section below in the discussion. In contrast, participant 2 showed a slight improvement in his scores between pre- and post-test times. Participant 2 incorrectly answer question four on the quiz in his first trial (scoring 9/10), while he correctly answered all questions in his
second completion of the quiz (scoring 10/10). Possible reasons for the improvement in his score are discussed below in the discussion as well.

Subjective Measures: CETI (modified version)

A modified version of the CETI was selected as a subjective measure because it addresses a variety of areas of communication (including both expression and comprehension) which the training session was intended to address and improve upon. Additionally, the CETI was used in the current study because it was developed as a tool to measure changes over time (Lomas et al., 1989); this tool appears particularly appropriate for use, therefore, in the current study which also seeks to assess changes over time. The instructions to the CETI were modified in the particular version used in the current study in order to better address the role of the care partner in the communication interaction with PWA.

The CETI is scored based upon a 10-cm visual analogue scale; the ratings provided on the survey are indicated by drawing a mark across a 10-cm line to indicate, on a spectrum from “not at all able” to “as able as before stroke,” how able participants feel in assisting PWA in communicating in 16 different communicative contexts. Participant markings for each survey item are converted into numbers based upon measurement of millimeters between the beginning of the line and the participant’s marking. Therefore, the lowest possible rating for each item is 0, and the highest possible rating for each item is 100. Following the protocol set forth by Lomas et al. (1989), the measurements for each survey item were added together and divided by 16, the total number of questions on the survey, in order to calculate the average overall score for the
survey. This process was completed for both pre- and post-training surveys completed by each participant in the study.

On the pre-training survey, participant 1 scored an average of 10.5/100 on the CETI. Participant 2 scored similarly, with an overall score of 12.0/100 on his pre-training completion of the survey. These pre-training scores suggest that both participants felt fairly unconfident in their abilities to provide support in communication with PWA prior to participating in the training session.

On the post-training survey, participant 1 scored 60.0/100, demonstrating a large increase in confidence in supporting communication with PWA (a gain of 49.5 points). Participant 2 also demonstrated an increase in score, with an average measurement of 26.8 at the second testing period. The difference between his two scores was smaller than that for participant 1, at 14.8; however, both participants showed increases of over 10 points, or 10%, in their scores between pre-and post-training administrations.
Chapter 4: Discussion

The purpose of this study was to examine the effects of a newly developed training protocol addressing supported communication strategies on care partners’ objective knowledge of aphasia and self-assessments of their abilities to facilitate communication with persons with aphasia. Given the small number of participants in this pilot study, generalizations made about the effectiveness of the training session are limited. However, based on the data collected, the training protocol appears effective in improving care partners’ perceptions of their abilities to support communication with persons with aphasia. This finding is consistent with those described in previous studies examining the impact of other caregiver trainings (Hagge 2014; McGilton et al. 2011; Saldert, Johansson, & Wilkinson, 2015; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016).

Overall results of this study indicate that a 90-minute training session covering aphasia education and supported communication strategies may be effective in improving caregivers’ perceptions of their abilities to facilitate communication between PWA and themselves and/or others. Subjective measures taken in the study via the modified CETI improved for both participants between pre- and post-session administration. Participant 1 demonstrated a 49.5 point improvement, while participant demonstrated a 14.8 point gain. Together, these gains for both participants indicate that the protocol contributed to
increasing participants’ confidence in aiding PWA in communicating in a variety of contexts. These improved scores appear to be the result of the content presented in the protocol developed for the current study, as no other known variables were introduced between pre- and post-test that could be responsible for altering the participants’ subjective impressions.

Insufficient evidence was collected to determine whether caregiver objective knowledge of aphasia improved through the educational training provided in the protocol developed for this study. While participant 2 had a small improvement in scores from pre- to post-test (by a single test item), participant 1 had a small decrease in scores (also by a single test item). Furthermore, both participants scored very high on their first attempt at the quiz (participant 1 scored 100%; participant 2 scored 90%). Based on these scores, both participants appeared to have a basic understanding of aphasia prior to participation in the current study; this prior knowledge may either result from their previous knowledge gained in their careers in the medical field, or perhaps from standard of care education provided by the speech-language pathologist while their loved one was recently admitted in the hospital. Given their high scores on the initial completion of “The Aphasia Quiz,” it is unknown what objective knowledge was gained by the participants through their participation in the study.

Implications

Results indicate that this protocol may be effective in increasing caregivers’ confidence in their abilities to communicate with PWA. The modified CETI was sensitive to changes in caregivers’ perceptions of their abilities to support communication
with PWA. It allows for quantifiable measure of caregivers’ confidence in individual communication situations and as an overall measure of confidence. While participants themselves do not provide numerical ratings on the CETI, their reports are converted to numerical scores, which allows for concrete measurement of a fairly subjective concept. For these reasons, the modified version of the CETI appears to be an appropriate and sensitive measure of caregivers’ confidence. As a result, it is recommended that future examinations of this protocol continue to utilize the modified version of the CETI to measure changes in caregivers’ confidence.

It is additionally recommended that, because the present protocol was effective in changing participants’ perceived communication skills, future researchers continue to address the same communication strategies as those in the protocol in the present study. Similarly, incorporating videos of the communication strategies in use (such as those used in the current protocol) and a guest speaker with aphasia may further contribute to increases in participants’ confidence. To better determine which aspects of the training were most effective in improving participants’ confidence, it is recommended that future researchers provide participants with a survey to collect feedback immediately following the training protocol.

Limitations

While not an exhaustive list of potential limitations, the following section describes the two factors which are thought to have had the most significant impact on the results of the current study. Those factors are the sample size and the objective measure tool (“The Aphasia Quiz”).
Because the current study piloted a new training protocol on only two participants, it is not possible to make confident generalizations about the extent of the effectiveness of this protocol. However, it is important to note that several more prospective participants were invited to the training session held for this study, and there could be common reasons these individuals chose not to participate. It is possible that some of these prospective participants are still experiencing coping feelings, and as a result, are overwhelmed with the newness of their situation and are not emotionally ready for education and training at this time. It is also possible that the prospective participants chose not to participate because the training session was held on a Saturday, when patients at the hospital may be permitted to make plans to leave for the day. Distance and travel may be two additional factors; many patients are not from the immediate area, and as a result, it may be inconvenient for family members and caregivers to be present with their loved ones at the hospital at times.

A second limitation of the study is the use of “The Aphasia Quiz” as an objective measure of participants’ knowledge of aphasia. First, the “true/false” response format of the quiz does not allow for participants to specify their knowledge in cases where the test item is marked “false.” This format does not allow participants, for these “false” items, to clarify what they do believe to be true. Further, the closed set of answer choices allows for guessing and therefore false correct responses in cases where the participant is uncertain of the correct answer. As a result, participants may appear more knowledgeable based on their scores on the quiz than they truly are. This was observed in the scores of the participants on their first attempt at “The Aphasia Quiz.” While both participants
indicated a lack of knowledge and confidence via the CETI, they both scored at or near ceiling on the quiz. This indicates that the quiz is too simple to be used as an accurate measure of participants' knowledge, and that the score comparison of pre- and post-session trials was not sufficient to precisely reflect the changes in knowledge that participants experienced as a result of the session. Finally, this quiz is not focused on the relationship of aphasia to communication, which was the primary focus of the training protocol. As a result, “The Aphasia Quiz” may not have been the most appropriate measure to use to assess the effectiveness of the particular training protocol used in this study.

Suggestions for Future Research

It is recommended, first, that further research incorporate a larger number of participants, so that stronger generalizations may be made about the effectiveness of the training protocol. Additionally, a larger number of participants would have provided greater insight into the impact of the training course on caregivers’ objective knowledge of aphasia. In order to ensure that a larger number of participants are available, future researchers may want to consider recruiting participants from several hospitals, rather than only one. Additionally, future researchers may reach out to their prospective participants regarding a convenient day and time for them to attend a training session, in order to maximize attendance of interested individuals.

Further, an alternate objective outcome measure should be utilized. Researchers may want to select an objective measure that has multiple choice or free response answers, rather than true/false. This will allow participants to indicate more specific
thoughts on each test item and to better clarify their knowledge. The outcome measure selected should also better reflect the objective knowledge covered in the training protocol; while much of the information included in “The Aphasia Quiz” was stated or implied, some of the test items were more loosely reflected in the training protocol than others. Additionally, researchers may wish to select an objective measure with more specific test items in order to more precisely capture changes in participants’ knowledge resulting from education provided in the training protocol. For example, asking participants “Is aphasia an intellectual impairment?” would assess whether the participants had learned from the training that aphasia is an impairment of language, and that an impairment in language does not equate with an impairment in intelligence.

It is additionally recommended that future research assess the carryover of the training protocol into the lives of the participants beyond the day of the training session. In order to do so, researchers may re-administer objective and subjective assessments at a delayed time (e.g., three months following the training) in order to assess the lasting effects of the training session on participants’ knowledge and perceived communication skills.
Chapter 5: Conclusions

The current study aimed to pilot a new training protocol designed to provide educational information and communication strategies to caregivers of persons with aphasia. Results gathered in this preliminary study indicate that the current protocol may be effective in increasing caregivers’ confidence in their abilities to facilitate communication with PWA. Participant scores on a modified version of the CETI improved over 10% between pre- and post-session administrations. As a result, this protocol may be a useful tool for providing training to caregivers of PWA in a clinical setting. Because both participants were at or near ceiling in their initial scores on “The Aphasia Quiz,” the extent to which the current protocol impacts caregivers’ knowledge of aphasia is unclear. In future work, it is recommended that researchers utilize an alternate objective measure in order to better ascertain the degree to which the protocol improves caregivers’ knowledge of aphasia. Altogether, findings from the present study indicate that providing education and communication strategies in this training protocol may have positive impacts on caregivers’ confidence in their communications with persons with aphasia.
References


Appendix A: The Aphasia Quiz
Responses are given as TRUE or FALSE. Please circle your answer.

1. Most people are familiar with aphasia.
   True/False

2. Aphasia means a person has difficulty retrieving words for speech and usually has some problems reading, writing, and understanding spoken language.
   True/False

3. The cause of aphasia is usually due to a heart attack.
   True/False

4. If people have aphasia they will always have a significant memory loss as well.
   True/False

5. Aphasia is more prevalent than Parkinson’s Disease or Muscular Dystrophy.
   True/False

6. A person with aphasia may have no noticeable physical impairment.
   True/False

7. All individuals with aphasia have very similar symptoms of the same approximate severity.
   True/False

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.

True/False

10. Recovery from aphasia is usually complete within six months of treatment.

True/False
Appendix B: The Communicative Effectiveness Index (CETI), modified
Appendix B: Communicative Effectiveness Index (CETI) (Lomas et al., 1989), modified

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 ALL ABLE

   AS ABLE AS BEFORE STROKE

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

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

3. Giving yes and no answers appropriately:

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

4. Communicating his/her emotions:

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

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

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

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

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

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

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

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

   NOT AT ALL ABLE

   AS ABLE AS BEFORE STROKE

9. Communicating physical problems such as aches and pains:
10. Having a spontaneous conversation (i.e., starting the conversation and/or changing the subject):

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

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

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

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

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

13. Understanding writing:

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

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

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

15. Participating in a conversation with strangers:

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE

16. Describing or discussing something in depth:

NOT AT
ALL ABLE

AS ABLE AS BEFORE STROKE