University of Arkansas, Fayetteville

ScholarWorks@UARK

Rehabilitation, Human Resources and Communication Disorders Undergraduate **Honors Theses**

Rehabilitation, Human Resources and **Communication Disorders**

5-2023

The Relationship between Communicative Confidence and Identity in Everyday Life for People with Aphasia

Karina Escobar

Follow this and additional works at: https://scholarworks.uark.edu/rhrcuht



Part of the Communication Sciences and Disorders Commons

Citation

Escobar, K. (2023). The Relationship between Communicative Confidence and Identity in Everyday Life for People with Aphasia. Rehabilitation, Human Resources and Communication Disorders Undergraduate Honors Theses Retrieved from https://scholarworks.uark.edu/rhrcuht/81

This Thesis is brought to you for free and open access by the Rehabilitation, Human Resources and Communication Disorders at ScholarWorks@UARK. It has been accepted for inclusion in Rehabilitation, Human Resources and Communication Disorders Undergraduate Honors Theses by an authorized administrator of ScholarWorks@UARK. For more information, please contact scholar@uark.edu.

The Relationship between Communicative Confidence and Identity in Everyday Life for People with Aphasia

Karina Escobar

Undergraduate Honors Thesis Proposal

Communication Sciences and Disorders

May 2, 2023

Abstract

Aphasia is primarily a neurological language disorder, which can also affect cognition, attention, and executive functioning skills. In recent years, researcher has taken an interest in understanding quality of life for people with aphasia, specifically communicative confidence, social relationships, and identity. The aim of this study was to determine how communicative confidence and social relationships affect a person's identity, as well as the importance of therapy groups. We designed and used confidence and independence survey scales pre-aphasia, post-aphasia but before attending aphasia therapy groups, and post-aphasia and after having attended aphasia therapy groups. We also asked clarifying questions based on participants' answers received from the survey scales. We found that social relationships are the driving force to building communicative confidence and renegotiating identity for a person with aphasia. We also found that therapy groups were impactful for providing our participants with opportunities to communicate freely.

Keywords: aphasia, communicative confidence, quality of life, identity, social relationships, group therapy

The Relationship between Communicative Confidence and Identity in Everyday Life for People with Aphasia

In the United States, approximately two million people are living with aphasia (Simmons-Mackie & Cherney, 2018). Aphasia is an acquired neurogenic language disorder commonly caused by a stroke. Aphasia negatively affects one's ability to communicate, but it is not a motor, sensory, or intellectual disorder (Hallowell & Chapey, 2008). For the purpose of this study, we adopted this definition to investigate how aphasia affects important aspects of quality of life for people with aphasia (PWA), including communicative confidence, social interactions, role changes, and identity.

Much of the focus of aphasia research has been on the impact of aphasia on linguistic abilities, as well as on cognitive skills, most notably working memory, attention, and other executive functions. In more recent literature, however, there has been a shift to focus on a person's quality of life in a more holistic manner. For example, Chiou and colleagues (2018) studied not only cognition in aphasia but the impact of aphasia on communicative confidence. In addition, Cruice and colleagues (2003) studied social and emotional health and psychological well-being for PWA; the authors found that quality of life is negatively affected by limitations in communication and social interaction, as well as one's perception of their identity. The results of these studies point to the importance of factors that may affect the daily life of a person with aphasia. These factors may include aphasia severity, emotional well-being, communication and activity limitations, comorbid medical conditions, and other social factors that affect one's quality of life (Hilari et al., 2012). In this study, we primarily focused on communication limitations and social factors in relation to a person's identity. This study is, therefore, motivated by a research gap regarding how these factors affect not only a person's quality of life but also their identity.

Literature Review

Communicative Confidence and Social Relationships

Confidence is defined as one's belief in their abilities (Cherney, et al., 2011), and communicative confidence refers to a person's feelings toward engaging in a conversation and their ability to comprehend conversation partners (Babbitt et al., 2011). According to Chiou et al. (2018), communicative confidence has an impact on one's quality of life and self-perception, and the lack of it can cause PWA to limit their participation in familiar and unfamiliar environments. In addition, the importance of communicative confidence not only affects the person with aphasia communicatively but can sometimes lead to frustration and a desire to return to their pre-aphasia lifestyle.

For example, the study by Cherney and colleagues (2011) suggests that a person with aphasia may not have the confidence to communicate when needed, which may lead to a decline in their quality of life. The results of other studies also suggest that communicative confidence could affect the way PWA communicate with others. In Fotiadou's (2014) study, for example, the authors collected anecdotes from PWA who had created blogs about their experience. These authors found recurring instances where PWA felt as if they could not communicate quickly enough, or communication had become too hard, and avoidance became easier than trying to communicate. Importantly, in this study, PWA had difficulties participating in family activities, felt they needed to depend on others more, participated less in community events, and expressed a shift in familial roles.

Furthermore, Johansson and colleagues (2011) examined how PWA communicate with others, as well as their perceptions of themselves and their communication partners. The authors found that communication breakdowns occurred when PWA had word-finding difficulties, and when slow conversation speed led to boredom from communication partners. Despite these communication barriers, PWA felt more satisfied participating in conversations

when the conversation partner adapted to their communication strategies. In this respect, these authors found that when PWA had a communication partner that was understanding of their circumstances, they had much better conversations. According to the authors, the only pitfall is that PWA may not always be able to explain to others that they may need more time to communicate. The authors conclude that, although training family members, friends, and relatives of PWA on communication strategies is feasible, it is not so for strangers and community members, which potentially limits a person's participation and social circle.

Overall, these instances contribute to a lack of confidence, because PWA cannot express themselves without becoming discouraged. For some PWA, the disorder can be crippling and cause a lack of desire to talk to others based on their own communicative confidence. This, in turn, means PWA may have limited communication opportunities throughout the day, affecting their emotional and mental health and support. Given that having emotional support and a sense of self is crucial for recovery if a person with aphasia does not have these resources, they may recover at a slower rate or remain stagnant in their progress (Ross & Wertz, 2003). Overall, the social implications of having aphasia are long-lasting and can cause discouragement felt by PWA, which, in turn, may affect their recovery.

The Person with Aphasia, the Caregiver, and the Role Changes

Aphasia may affect all aspects of a person's life, including familial and community dynamics. Emselie (2000, as cited by Gillespie et al., 2010), suggests that role changes experienced by caregivers and family members as well as PWA may come in many forms, including a shift in financial burden and household responsibilities. For example, in a study done by Fox and colleagues (2004), caregivers and PWA were invited to attend a two-day camp, where caregivers and PWA joined their respective groups and had open discussions. Difficulties for caregivers arose in the form of simply no longer having the same roles as they once had and missing contributions that the person with aphasia could do prior to the stroke.

In another study by Shafer et al. (2019), a caregiver expressed having financial struggles while attempting to hide them from her husband with aphasia. The financial struggle may also come in the form of splitting the caregiver's time between working to maintain their source of income and simultaneously caring for the person with aphasia. These role changes do not only affect the caregiver but also reduce the independence of the person with aphasia, as they may require assistance from others.

In Shafer and colleagues (2019) study, it is evident that blurred boundaries, such as being overbearing, giving little independence to the person with aphasia, or sacrificing personal activities to care for PWA, can negatively impact the relationship between the caregiver and the person with aphasia. While the person with aphasia craves independence, the caregiver may struggle to determine the extent to which they should assist. This can result in the person with aphasia feeling unable to perform previous duties and losing their sense of independence. For instance, in the study conducted by Fotiadou et al. (2014), a mother with aphasia tells a story of being unable to read her daughter a bedtime story, make important decisions for herself, or help raise her children. These changes in familial dynamics can be devastating and disorienting for some stroke survivors with aphasia, particularly for those with more severe forms of aphasia.

Our roles in our daily lives hold a significant meaning to our identity and help shape our sense of self. For a person with aphasia, the stroke may lead to complete alterations in their lives that were not present before. Coping with these changes in a healthy and constructive way is challenging when a vital aspect of one's identity has been stripped away. Hence, this is a crucial research area to explore.

Identity

Overall, communicative confidence, social relationships, role changes between the person with aphasia and the caregiver, and independence are all part of integral components

that contribute to a person's identity. Shadden (2005) describes this notion as "identity theft" for PWA, highlighting how their identity can be significantly impacted by a stroke. In her core sociocultural constructs, Shadden (2005) suggests that identity is a fluid concept that can be influenced by various factors, including language and communication, as well as the initial treatments received for aphasia. This emphasizes the importance of developing strong social relationships and confidence for PWA, as these notions are crucial in shaping their new identity and recovery after the stroke. Overall, it seems that communicative confidence is where the breakdown occurs because PWA may feel embarrassed and rather hide what they portray as a weakness. Therefore, having a support group consisting of family, friends, or other PWA in similar situations is vital.

Support Groups

Group therapy or support groups can be beneficial for PWA, especially in helping them reclaim aspects of their identity they felt they had lost. According to Shadden et al. (2004), since society values independence, a person with aphasia may no longer be seen as fitting into the larger society, which is why PWA need to renegotiate their identity. Not only do PWA now have to navigate a new diagnosis, but they also have to learn how to identify themselves through other aspects of life that may not tie into communication. For instance, Lauer and Corsten (2018) demonstrated that support groups can enhance the quality of life for PWA by fostering a sense of empowerment and providing them with a platform to express themselves, figuratively and literally. Through support groups, PWA can communicate at their own pace and connect with individuals facing similar challenges. As Shadden et al. (2004) noted, although communication plays a vital role in shaping one's identity, broader social interactions also contribute significantly to the process. Therefore, if PWA lack communicative confidence and do not rely on social relationships to participate in daily activities, it may negatively affect their self-perception and have adverse implications

on their physical and mental well-being. This highlights the importance of attending group therapy or support groups as treatment options to help PWA regain a sense of empowerment in their lives.

As the results of previous studies have shown, communicative confidence and social relationships have an impact on quality of life, which, in turn, may affect a person's identity. Specifically, the support system that surrounds a person with aphasia can increase communicative confidence, improving their quality of life. This support system may include support groups and specific group therapy programs, both of which provide safe spaces for PWA to express themselves and offer opportunities to foster social relationships. As a result, PWA could regain their communicative confidence, which paves the way for renegotiating one's identity.

The Current Study

It is crucial to understand how a person's identity and quality of life are affected by a sudden shift in their life (a stroke). As indicated by previous studies, one's perception of self and quality of life may be associated with their communicative confidence and social relationships. Therefore, it is important to understand the implications of decreased communicative confidence and social relationships after aphasia. In addition, although PWA may find it challenging to connect with their everyday communication partners, group therapy could provide a way to strengthen their communication skills. In these respects, the specific aims of this study are to determine whether (a) communicative confidence and social relationships have an impact on identity and quality of life; and (b) whether group sessions increase communicative confidence in PWA.

Methods

The target population was PWA who had participated in a group therapy as a part of a reading club in Northwest Arkansas. During the group therapy sessions, potential participants

were provided with icebreakers and then had the opportunity to engage in one-on-one therapy sessions. The group met twice a month to read, debate, and discuss the theme of the week's reading. Participants for the study were recruited from this reading club consisting of PWA. The inclusionary criteria were (a) being older than 18 years old, (b) having aphasia due to a brain injury with a post-onset of at least 3 months, and (c) having attended the group therapy for at least three sessions.

Participants

Two PWA met the inclusionary criteria and participated in our study. Both participants had attended the group therapy for many years. Participant One was a 50-year-old, white male who had obtained a high school degree. He had one stroke in 2018, which left him with partial mobility in the right side of his body. Participant Two was a 56-year-old, white male who had attended trade school. He suffered a stroke in 2019, which took most mobility away from the right side of his body.

Recruitment

Recruitment for the study was conducted during aphasia group therapy sessions, where the researcher explained the study and distributed flyers with relevant information. Interested participants were required to fill out consent and intake forms, with the researcher available to assist them, if needed. The study lasted four months, between January and April, and the researcher observed each group session during this period to track attendance. There were two interview sessions done, once at the beginning of the group sessions and once at the end of the sessions. The first interview began with the survey and then survey questions were asked based off their answers. The first interviews included three surveys on their life before aphasia and then after aphasia but before attending the group sessions. The second interviews were done at the end of the four-month period to give PWA time to reflect on the sessions. By giving them time to participate in the group sessions, they could evaluate how the group

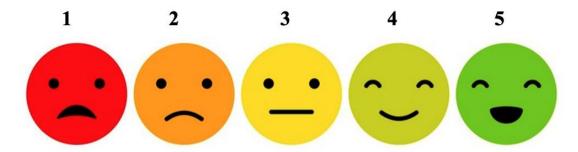
sessions had helped them when answering the survey. Once a participant had attended three sessions, they were approached to do their second interview. Data collection was done through recordings of each interview, which were then transcribed and de-identified. The scale survey data was collected using Qualtrics (Qualtrics, Provo, UT). Once participants consented to the study, they were interviewed within two weeks at the place of their choosing. This was done to ensure participants' comfort when answering questions. This study was reviewed and approved by the Institute Review Board (IRB) of the University of Arkansas.

Procedure

Initial interviews included three survey scales (see Appendix A, B, and C). These scales were adopted from the Communication Confidence Rating Scale for Aphasia (CCRSA; Cherney et al., 2011) and modified to meet the aims of our study. The CCRSA scale has a range of 0-100 with no visual aid and includes themes of intelligibility and understanding of media. For the purpose of our study, the CCRSA was modified to include visual aids (Figure 1). We also modified the scale by including themes of environmental distractions and multitasking to learn about possible struggles experienced by PWA when conversing with others. Another separate scale was created to target independence (see Appendix C), as many studies reported negative feelings associated with it. The modified survey scales asked about (a) confidence before acquiring aphasia, (b) confidence post-onset but prior to attendance in aphasia therapy sessions, and (c) independence post-onset but prior to attendance in aphasia therapy sessions. The questions included in the scales ranged from six to seven. Each scale consisted of a question with a one to five Likert scale. Participants were asked to point at the number to rate their communicative confidence and independence.

Figure 1

Confidence Survey Scale



Before your stroke, how confident were you in your ability to socialize?

Note: This is the format of the questions in the communication and independence survey scales.

Participants were then asked clarifying questions based on their answers to the surveys (See Appendix F and G). Participants were given full discretion over what they shared and given no time limit. We also conducted two post-assessment surveys (see Appendix D and E). that included the same questions as the confidence and independence scales with the difference of using present tense questions. Clarifying questions were once again asked based on participants' responses to the survey questions. Participants were compensated for their participation upon completion of the study.

Results

For each participant, we first present the results of the survey questions. We then report the results of the follow-up questions for each participant.

Survey Questions

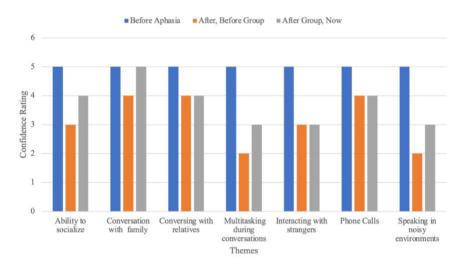
Participant One: Figure 2 shows communicative confidence rated by Participant One; the participant rated his confidence before acquiring aphasia at a five in all seven categories.

After aphasia but before attending the group therapy, his ratings lowered, with his confidence

in multitasking during conversations and speaking in noisy environments receiving the lowest ratings. After attending the group therapy, all his seven scores increased or remained consistent; the participant still had relatively low scores when multitasking during conversations, interacting with strangers, and speaking in noisy environments; the participant's highest score was associated with his confidence in conversing with family.

Figure 2

Participant 1: Confidence

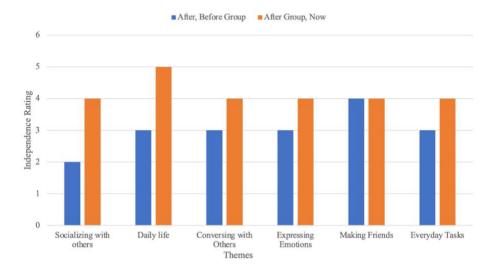


Note: These are the results from the confidence scale done by Participant Two.

Figure 3 illustrates independence rated by Participant One; the participant showed an increase in independence after attending the group therapy. The largest increases were in his independence in daily life after attending the group sessions. All other scores post-attendance increased as well, with the exception of his rating for making friends, which remained the same.

Figure 3

Participants 1: Independence

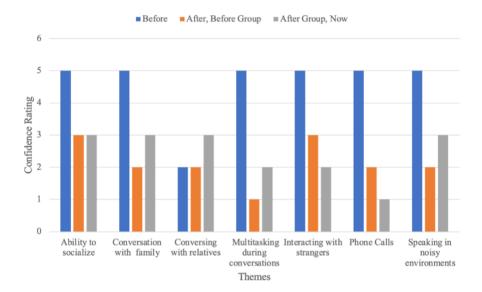


Note: These are the results from the independence scale done by Participant One.

Participant Two: Figure 4 displays the communicative confidence ratings for Participant Two. Before aphasia, he rated his confidence at five in all themes except when conversing with relatives. Following aphasia but before attending group therapy, the participant's scores decreased, with his confidence in multitasking during conversations and making phone calls being the lowest. After attending group therapy, most of his confidence scores increased, with the largest increase seen in his confidence to communicate with family and relatives and speaking in noisy environments. The participant rated his confidence in making phone calls lower after attending the group sessions.

Figure 4

Participant 2: Confidence



Note: These are the results from the confidence scale done by Participant Two.

In Figure 5, the ratings of independence by Participant Two are presented. Postaphasia but prior to attending group sessions, the participant rated his independence at five for all six questions. However, after attending the group therapy, the participant's scores from independence in daily life and when socializing with others decreased. The participant rated his independence in expressing his emotions and making friends with the highest scores after attending the group sessions.

After, Before Group After Group, Now 6 5 Independence Rating 1 0 Socializing with Daily life Conversing with Expressing Making Friends Everyday Tasks others Others Emotions Themes

Figure 5

Participant 2: Independence

Note: These are the results from the independence scale done by Participant Two.

Post-survey Questions

Participant One: The participant was asked if attending the group sessions had helped him. He said, "[i]t's mostly me to other people, other people, me...Mm no, I look, and they, OH good, not alone." In saying this, the participant was referring to the fact that being with other PWA in the group not only helped him but helped others as well. The participant was then asked if he liked it when people tried to guess what he was saying and if he had trouble finding words. He responded, "[g]ray area, usually shh hold on, come on, I get it." He was then asked if the longer pauses within his sentences affected his ability to make friends. He said, "[u]sually, mm, I have broken brain they know it's okay." When asked if aphasia has changed his identity, the participant said, "I'm right here, me and down here are still," while pointing to his head then heart. He then continued, "but sometimes not. I'm mostly me, still, sometimes angry but that's only to be expected." The participant was then asked what he had struggled with the most after having aphasia. He responded "[s]peaking, and this thing, this side more but speaking it is yeah. I use to be an actor, and I can't do that now." By "this

thing, and this side," he was referring to the lack of mobility on the right side of his body, which still affected him. The participant was then asked if he knew other PWA outside of the group, and he said that one friend of his has a stutter and that it was different, but they are able to identify together. In his second interview, the participant stated that he was confident speaking to his family, which for him meant close friends. His largest struggle was communicating in noisy environments. He stated, "[t]hat use to okay, but now bad, I can filter out, but it is hard sometimes." The participant also stated that he was very independent in doing everyday tasks; however, at times when he could not do something, he would simply ask for help.

Participant Two: The participant was asked if attending the group sessions had helped him. He said, "[y]eah! It is here, at home uuugh." The participant was then asked if he was bored at home and whether the group sessions offered him the most interaction. He responded that he received very little interaction outside of the group meetings. He expressed that, although he enjoyed conversing with others, being able to get willing conversation partners was a barrier for him. He also stated that he loved interacting with people who understood aphasia, and that he was very glad to be able to get out of the house for the interview. In addition, he was asked if his caregiver tried guessing what he said, to which he expressed his agreement and frustration to the question. He stated that he rarely went out, and his partner often tried to finish his sentences by guessing what he was trying to say without letting him have enough time to process his thoughts. The largest differences came in the form of his independence in daily life and being able to speak over the phone. He was able to form short sentences at times, but it was too difficult for him to try and hold a conversation over the phone. The participant was then asked if he felt aphasia had completely changed his life, and he responded in affirmative with a thumb down, emphasizing that aphasia had made his life take a turn for the worst. When asked what had changed the most, the participant said,

"[d]riving! My life, eeeeer." His response was then clarified, as he meant that his life had come to a complete stop and driving was a passion that he could no longer enjoy due to his mobility limitations. The participant had nothing more to add in the second interview.

Discussion

The specific aims of the study were to determine whether (a) communicative confidence and social relationships have an impact on identity and quality of life; and (b) whether group sessions increase communicative confidence in PWA.

Overall, Participant One's largest struggle was with noisy environments. This was his primary difficulty, as the community around him had played a large part in his recovery. During the interview, the participant reinforced the fact that word-finding can bring difficulties when having conversation partners who do not know about aphasia, which is in line with previous studies (e.g., Johansson et al., 2011). This emphasizes that having a support group whether that be friends or other PWA that understand their communication challenges, allows for more effective communication. Overall, during the interview, we observed the following common themes as determiners of the participant's recovery: helping others by being able to relate to them, word-finding difficulties, a disconnect from his identity, and having a good community.

In comparisons, Participant Two struggled mostly with daily interactions as his communication abilities were more severe, and the fact that he had little to no contact with others outside of the therapy group. This points to the reason he enjoyed attending the group since he had previously expressed his enjoyment in conversing with others. Since his caregiver often tried guessing what the participant was trying to say, he was not able to truly enjoy their conversations. This was one of his largest complaints against his caregiver as his aphasia was more severe with longer wait times between his speech units. Much of his autonomy and independence had lowered after having aphasia due to the lack of mobility

from his stroke and being unable to communicate effectively. This is on par with Shafer and colleagues' (2019) study showing that PWA often wish for autonomy since they now struggle with independence. In Johansson and colleagues' study (2011), they also found that PWA enjoyed conversations with people who understood aphasia or adapted to their communication strategies.

Based on the results we received from the confidence and independence rating scales, we can see that there are distinct differences between both participants. The first participant struggled the most with multitasking during conversations, interacting with strangers, and speaking in noisy environments. Although his confidence in himself had not been completely restored, we could see that where there were decreases in his answers from before having aphasia that either remained consistent or increased after having joined the aphasia therapy groups. As Figure 3 shows, all aspects of independence for Participant One increased, which may indicate an increase in quality of life.

As the results show, Participant Two had a vastly different experience with aphasia than Participant One, as his severity differed. Overall, Participant Two showed increases within his aspects of life pre- and post-aphasia therapy group meetings, which allowed us to see the importance of the group sessions for PWA. He reiterated the fact that the group meetings were his main interactions, and they only occurred every two weeks. Therefore, while Participant Two seemed to enjoy interacting with others, his inability to do so at regular intervals could be some of the reasoning behind the results in Figure 4. Figure 5 has interesting results because although Participant Two has shown to struggle more with confidence, he demonstrated that at the onset of his aphasia, his independence was particularly high. This could be because he could have had more support at the onset of his aphasia through therapy and family support and that could have dwindled down. In addition, there were limitations with insurance as his therapy sessions could have ended before he was

ready to take on aphasia on his own. The results then decreased greatly when having to socialize with others and do tasks in his daily life. His lack of independence in his daily life seemed to weigh him down and create a lot of frustration for him. The participant had shown more struggles in being able to create a new identity and social footing after acquiring aphasia.

The results of the rating scales and post-survey questions point to the importance of communicative confidence as an important aspect of quality of life for PWA. Importantly, what truly creates this confidence seems to be the support group around a person with aphasia. Both participants had very different support groups and communities, and we can see that a participant's communicative confidence comes from their ability to interact with others consistently. While Participant One had been unable to take on his passion for acting again, he had found different outlets and created his own identity through the relationships he had fostered with friends. This created a difference between the two participants, as Participant Two struggled to create a new identity due to the lack of social relationships. Although attending the aphasia group was helpful for Participant Two, he was still missing the interactivity he needed in his daily life. The aphasia group helped him build his communicative confidence, but the barriers still arose when meeting others in the community. Although Participant Two's communicative confidence was not at its peak, it could potentially rise from having more consistent conversation partners. Based on these results, group sessions prove to be more beneficial when a person with aphasia has less of a community that can provide support. For Participant One who had already formed a new identity, he found solace in the therapy group by being a familiar face rather than personally feeling as if he needed to make social relationships. He received self-gratification by being able to help others and was also fulfilled by meeting other PWA. This was not the case for Participant Two, as the therapy group was his main source of interaction and identity

renegotiation. These results suggest that, for PWA who have not created social groups to foster communication, aphasia therapy groups are key to their success in reaching new milestones. This is specifically what we saw with Participant Two's response; he expressed his appreciation for the aphasia group, as well as for the researcher for getting them out of the house. As Participant Two mentioned, the ability to express himself was very important to him, but he was often not given the chance to do so. When the community was more accepting of his communication strategies, he was able to have enjoyable conversations, which strengthened his communicative confidence.

Conclusion

Overall, we can see that communicative confidence and identity are intertwined, and that the factor that seems to have the largest implication is social relationships. While this result was predicted, due to the large differences in quality of life between the two participants, we were able to observe the effects that a lack of social relationships can have on each participant. Further research should be done to identify how the value of social relationships is ranked compared to other aspects of life, and/or if identity and communicative confidence are the most valued. There was also a difference between participants with aphasia who have an active social life and those who do not, which is in line with previous studies (Foutiadou et al., 2014; Lauer & Corsten, 2018). Being present in the community or feeling as though one has a footing in the outside world truly helps PWA find their new identity. In addition, aphasia therapy group meetings do have a significant impact on a person with aphasia, especially if they are constantly in isolated environments. There are clear differences in how PWA view themselves, as we observed in our study; however, it would also be beneficial to include the caregiver's perspective and how it differs from that of the participants with aphasia.

The results of our study may provide a better understanding of how identity is impacted not only by communicative confidence but also by social relationships. The relationships that PWA have with their caregiver, therapy groups, and the community impact their quality of life and identity. Social relationships are the foundation for PWA to find their new identity and have that communicative confidence to interact with others.

Limitations and Future Studies

The focus group in our study was very small, with only two participants. For future studies, it would be beneficial to recruit broader pool of participants rather than restricting it to a specific region or therapy group. This would help to learn more about a wider variety of social lives, aphasia severities, and how different aphasia therapy groups help PWA. In addition, future studies should consider modifying the wording for each scale to be more distinct and clearer for the PWA. At times, the wording seemed to create confusion and required the individuals with aphasia to switch back and forth between different time periods of their life. This limitation could also be addressed by having visuals to demonstrate the different time periods before and after aphasia to decrease confusion. While the wording was repeated each time to clarify the question, the participants may have encountered linguistic difficulties that influenced their responses. It is, therefore, important for future studies to continue research on how the quality of life for a PWA can be improved not only through therapy groups but within the broader community.

References

- Babbitt, E. M., Heinemann, A. W., Semik, P., & Cherney, L. R. (2011). Psychometric properties of the communication confidence rating scale for aphasia (CCRSA): Phase 2. *Aphasiology*, 25(6-7), 727-735. https://doi.org/10.1080/02687038.2010.537347
- Cherney, L. R., Babbitt, E. M., Semik, P., & Heinemann, A. W. (2011). Psychometric properties of the communication Confidence Rating Scale for Aphasia (CCRSA): phase 1. *Topics in stroke rehabilitation*, 18(4), 352-360. https://doi.org/10.1080/02687038.2010.537347
- Chiou, H. S., & Yu, V. Y. (2018). Measuring life participation, communicative confidence, language, and cognition in people with aphasia. *Perspectives of the ASHA Special Interest Groups*, *3*(2), 4-12. https://doi.org/10.1044/persp3.SIG2.4
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being.

 Aphasiology, 17(4), 333-353. https://doi.org/10.1080/02687030244000707
- Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships?. *Aphasiology*, 28(11), 1281-1300. https://doi.org/10.1080/02687038.2014.928664
- Fox, L., Poulsen, S., Clark Bawden, K., & Packard, D. (2004). Critical elements and outcomes of a residential family-based intervention for aphasia caregivers.

 Aphasiology, 18(12), 1177-1199. https://doi.org/10.1080/02687030444000525

- Gillespie, A., Murphy, J., & Place, M. (2010). Divergences of perspective between people with aphasia and their family caregivers. *Aphasiology*, 24(12), 1559-1575. https://doi.org/10.1080/02687038.2010.500810
- Hallowell, B., & Chapey, R. (2008). Introduction to language intervention strategies in adult aphasia. In R. Chapey (Ed.), *Language intervention strategies in aphasia and related neurogenic communication disorders* (5 ed., pp. 3-19). Baltimore, PA: Lippincott Williams & Wilkins.
- Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of physical medicine and rehabilitation*, 93(1), S86-S95.
 https://doi.org/10.1016/j.apmr.2011.05.028
- Johansson, M. B., Carlsson, M., & Sonnander, K. (2012). Communication difficulties and the use of communication strategies: from the perspective of individuals with aphasia.

 *International journal of language & communication disorders, 47(2), 144-155.

 https://doi.org/10.1111/j.1460-6984.2011.00089.x
- Lauer, N., & Corsten, S. (2018). Quality of life in leaders and members of peer-led aphasia support groups—preliminary results of a systematic approach. *Aphasiology*, 32(sup1), 119-121. https://doi.org/10.1080/02687038.2018.1485839
- Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, *17*(4), 355-364. https://doi.org/10.1080/02687030244000716
- Shadden, B. (2005). Aphasia as identity theft: Theory and practice. *Aphasiology*, 19(3-5), 211-223. https://doi.org/10.1080/02687930444000697

- Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in language disorders*, 24(3), 174-186.
- Shafer, J. S., Shafer, P. R., & Haley, K. L. (2019). Caregivers navigating rehabilitative care for people with aphasia after stroke: a multi-lens perspective. *International Journal of Language & Communication Disorders*, 54(4), 634–644.

 https://doi.org/10.1111/1460-6984.12467
- Simmons-Mackie, N., & Cherney, L. R. (2018). Aphasia in North America: Highlights of a white paper. *Archives of Physical Medicine and Rehabilitation*, 99(10), e117. https://doi.org/10.1016/j.apmr.2018.07.417

Appendix A

Pre-Assessment: Confidence Before Acquiring Aphasia

Before your stroke, how confident were you in your ability to socialize?
Before your stroke, how confident were you in conversation with your family?
Before your stroke, how confident were you when talking to relatives?
Before your stroke, how confident were you in multitasking during conversations?
Before your stroke, how confident were you in interacting with people you did not know?
Before your stroke, how confident were you in talking over the phone?
Before your stroke, how confident were you in speaking in noisy environments?

Appendix B

Pre-Assessment: Confidence after Acquiring Aphasia but Before Group Attendance

After your stroke, how confident were you in your ability to socialize?
After your stroke, how confident were you in conversation with your family?
After your stroke, how confident were you when talking to relatives?
After your stroke, how confident were you in multitasking during conversations?
After your stroke, how confident were you in interacting with people you did not
know?
After your stroke, how confident were you in talking over the phone?
After your stroke, how confident were you in speaking in noisy environments?

Appendix C

Pre-Assessment: Independence after Acquiring Aphasia, but Before Attending Group

After your stroke, how independent were you when socializing with others?
After your stroke, how independent were you in your daily life?
After your stroke, how independent were you in conversing with others?
After your stroke, how independent were you at expressing your emotions?
After your stroke, how independent were you at making friends?
After your stroke, how independent were you doing everyday tasks?

Appendix D

Post-Assessment: Confidence after Acquiring Aphasia, and After Group Attendance

How confident are you now in your ability to socialize?
How confident are you now in conversation with your family?
How confident are you now when talking to relatives?
How confident are you now in multitasking during conversations?
How confident are you now in interacting with people you do not know?
How confident are you now in talking over the phone?
How confident are you now in speaking in noisy environments?

Appendix E

Post-Assessment: Independence after Acquiring Aphasia and After Group Attendance

How independent are you now when socializing with others?
How independent are you now in your daily life?
How independent are you now in conversing with others?
How independent are you now at expressing your emotions?
How independent are you now at making friends?
How independent are you now doing everyday tasks?

Appendix F

Participant One Post-Survey Questions

If it was anger, were you able to express your emotions better?
When did you start going to the aphasia therapy group?
How has the aphasia group helped you regain confidence?
What skills have you gained if any from the aphasia group?
Do you feel like you help other people?
So you feel like it helps since you're all in a group and they see ou, and feel like they're not alone?
Do you like when people try telling what word you're saying, or is it a gray area?
Do the longer periods between your words make it harder to make friends?
Do you feel like your experience has changed your identity?
What have you struggled with the most after having aphasia?
Do you feel like you have a good community of friends?
Do you know anyone outside the group who has aphasia?
Do you feel like you had a good community after you got aphasia?
So, do you think talking with friends helped you speak more?
Why is your rating for speaking in noisy environments lower?

Appendix G

Participant Two Post-Survey Questions

Do you have a caregiver?
Do you feel like having aphasia has completely changed your life?
Has aphasia changed your life in a good or bad way?
Why do you come to the aphasia meetings?
Do you feel like the aphasia group meetings have helped you?
Do you feel like you're bored at home?
Is this interview the most interaction you have?
What aspect of your life has changed the most?
Is that [driving] what you miss the most?
Your life came to a complete stop?
Have you always had a caregiver with you?
Who do you interact with on a daily basis?
You're not afraid to have conversations with people?
Do you feel like you've improved by coming to aphasia meetings?
You don't feel like noisy environments affects you?
So, you don't have a lot of people you can talk to?