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How participation in aphasia support groups influences perceptions of aphasia

Sally Jakeway

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How Participation in Aphasia Support Groups Influences Perceptions of Aphasia

by

Sally Jakeway

Thesis

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Thesis Chair:

Sarah Ginsberg, Ed.D., CCC-SLP

Thesis Committee:

Ana Claudia Harten, Ph.D., CCC-SLP

Jayne Yatzak, Ph.Dc., M.A., OTRL

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Abstract

The ability to communicate with others plays a critical role in what defines us as social beings. For a person with aphasia (PWA), the change in communicative status can alter his or her perception of self-identity (Shadden & Agan, 2004). After a stroke, a person enters a world of rehabilitation without promise of recovery, whether physical or psychological. This sudden change can alter a stroke survivor's attitude of him- or herself from that of one without a disability to one with a disability. This change in self-perception is inextricably linked with the new communicative challenges brought on by the aphasia. For some persons with aphasia, and their caregivers, participation in support groups becomes an augmentative part their ongoing recovery. This research project explored how participation in aphasia support groups influenced how a PWA perceived his or her communication disorder. Analysis of the data indicated that participation in an aphasia group effected a change in how they perceived their aphasia and learned to live with it by providing a feeling of acceptance, being a place to learn about their aphasia, and helping participants set personal goals. As clinicians we can recognize and promote the value of aphasia groups.

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Chapter 1: Introduction

The ability to communicate with others plays a critical role in what defines us as social beings. When that skill is removed, damaged, or hindered, our roles in society and self-perceptions can also change (Shadden & Agan, 2004). We use language “to initiate, build and maintain relationships; to carry out transactions; to achieve status; to project our personalities; [and] to assess other people” (Jordan, 1996, p. 1). However, language related disorders caused by neurological damage disrupt how stroke survivors use and understand language. Aphasia, an acquired neurological disorder resulting from damage to areas of the brain that facilitate language, is often a result of stroke. Aphasia can affect language expression, comprehension of the spoken and written word, writing, reading, numerical skills, and the production of speech (Jordan, 1996). For a person with aphasia (PWA), the change in communicative status can alter his or her perception of self-identity (Shadden & Agan, 2004). “The experience of stroke is intensely personal. A stroke survivor’s life is suddenly reduced to the immediate impact of the injury,” writes Alison Bonds Shapiro, a stroke survivor, in her article “A Story to Create: Stroke Survivors’ Broken Narratives.” After a stroke, a person enters a world of rehabilitation without promise of recovery, whether physical or psychological. “A survivors’ world is turned upside down. Patterns of lives are irrevocably altered” (Shapiro, 2011, p. 22). This sudden change can alter a stroke survivor’s attitude of him- or herself from that of one without a disability to one with a disability. This change in self-perception is inextricably linked with the new communicative challenges brought on by the aphasia. For some persons with aphasia, and their caregivers, participation in support groups becomes an augmentative part their ongoing recovery. “Group interventions are often considered to be an important transitional step in moving beyond a strictly language-based focus” (Shadden & Agan, 2004, p. 177). This research project explored

how persons with aphasia, who participate in support groups, perceived their aphasia by investigating their attitudes toward their disability. For this project, I used the terms “support group,” “aphasia group,” or “group setting” to include treatment-based group therapy (groups that have specific, quantifiable goals with start and end dates; may or may not be concurrent with psychosocial-based groups and/or individual speech therapy) and psychosocial-based group settings (ongoing; may or may not be concurrent with treatment based groups and/or individual treatment). “Groups vary according to content, structure, leader credentials, participant makeup, treatment focus, level of interaction, and degree to which participants have a role in directing group activities” (Shadden & Agan, 2004, p. 178). This diversity across group settings was also true for the different groups that the participants in this study attended. Participants had experience with treatment-based groups and/or psychosocial-based groups.

Purpose of the Study

The primary goal of this study was to understand how participation in aphasia support groups influenced how a PWA perceived his/her communication disorder. I explored whether experiences in support groups changed attitudes and behaviors toward their own communication disorders. Previous research has explored the influence of support groups on a PWA's social circles, quality of communication life, and life participation. This research focused on support groups and how they affect attitudes, behaviors, and perceptions of aphasia and included interviews with caregivers and speech therapists.

Research has been conducted on the effects of group participation on social connection for PWAs (Vickers, 2010), the role of group participation in the renegotiation of self-identity (Shadden & Agan, 2004), and the psychosocial influences of group intervention (Ross, Winslow,

Marchant, & Brumfitt, 2006). But does group participation affect a person's attitude toward his or her aphasia? This qualitative research project investigated whether group participation shaped a PWA's perception of his or her aphasia by interviewing PWAs, their caregivers/spouses/family members, and their speech therapists. A PWA's perception of his or her communication disorder was assessed by exploring their personal stories of the trauma of stroke and asking about their perceptions about their aphasia as they embarked on their rehabilitation augmented by participation in aphasia groups. I explored issues surrounding attitudes toward disabilities and whether support groups played a role in shaping those attitudes. All the participants were currently a part of an aphasia group.

Justification and Significance

While research has looked at social interaction, well-being, and communication in the context of group participation in an aphasia group, this research explored PWAs' attitudes toward their aphasia and whether their perspectives changed with participation in an aphasia support group. I examined their attitudes toward their disability and determined whether their attitudes were changed from participating in a group setting. The results could inform clinicians working with people with aphasia and professionals facilitating group treatments and support groups, and promote additional qualitative investigation in the area of client attitudes toward aphasia and support groups.

Research Question

Research has examined the functional roles of aphasia support groups, as well as the benefits regarding social interaction and the process of reshaping self-identity. This research

augmented what has already been observed by looking at attitudes that people with aphasia have about their communication disorder and whether those attitudes or perceptions were influenced or changed through the participation of an aphasia support group. The purpose of this research was to understand how participation in aphasia support groups influenced how a PWA perceived his/her communication disorder.

Chapter 2: Review of Literature

Research literature has revealed that aphasia group participation has been examined in context of social network participation, feelings of inclusion, and in renegotiating self-identity. The effects of group participation in the context of social networks have been researched. Vickers (2010) examined how participation in an aphasia group affected the social networks of people with aphasia by examining the frequency of social interactions in social networks before and after the onset of aphasia. Vickers also gathered data on communication and social participation as well as the subjects' feelings of isolation and/or support. Interviews with the subjects and questionnaire surveys revealed reduced social networks and interaction with partners after the onset of aphasia for both groups of subjects. However, subjects who participated in a group setting reported more social interaction and reduced feelings of social isolation than the subject group not participating in a group setting. The group who participated in the support group also reported increased feelings of social support. The reduction of social opportunities and the increased feeling of isolation after a stroke are important factors to be addressed by clinicians (Vickers, 2010) and can be remedied, as indicated in her data regarding increased social interaction and feelings of support, through the participation in an aphasia group setting.

In a qualitative focus group study by Legg and Stott (2007), the authors analyzed the functional purposes of the Volunteer Stroke Services (VSS). VSS, part of Chest Head & Stroke Scotland (CHSS), is a support group for stroke survivors, particularly those with communication difficulties secondary to stroke. From the data, eight function themes emerged. The participants reported a feeling of "inclusion" from the VSS group as a result of the social networks that the groups provided (Legg & Stott, 2007, p. 796). "Interpersonal relationships" (Legg & Stott, 2007,

p. 796) were also perceived to be supported through participation in the VSS groups. The networks and interpersonal connectedness provided means of exchanges for “support” (Legg & Stott, 2007, p. 796) on several levels including emotional and informational support. The theme of “personal exploration, growth, and development” (Legg & Stott, 2007, p. 797) emerged as a result of the opportunities the groups provided for self-initiation and engagement in activities. In further exploration of this theme, the authors referred to the personal narratives of the participants to illustrate how participation in activities helped them “develop beliefs about their capabilities,” “[gave] members access to a group of similar others,” and “[provided] members with information on fellow members attitudes, abilities and beliefs” (Legg & Stott, 2007, p. 798). In addition, the theme of “purpose” (Legg & Stott, 2007, p. 796) was identified: “The [Volunteer Stroke Service] group members describe the VSS groups as giving them a purpose in life, routine, structure and a reason to get up in the morning and look forward to the future” (Legg & Stott, 2007, p. 799). “Social identity” (Legg & Stott, 2007, p. 796) was another theme identified as a result of participating in the VSS groups. “Performance and productivity” (Legg & Stott, 2007, p. 796) was a theme that was shaped by the subjects’ descriptions of their participation in meaningful activities that they perceived to be relevant to their needs and interests. The VSS group also provided “opportunities to influence others and be influenced” (Legg & Stott, 2007, p. 796) in a social context. In addition to identifying the purpose that the VSS serves, the authors state two important clinical messages: “People with communication difficulties after stroke have a valuable contribution to make” and “Our research suggests that group dynamics are important and therefore should be harnessed in the clinical setting” (Legg & Scott, 2007, p. 803). Both messages align with the results of Vickers’ work on the effects of group participation on social networks. Legg and Scott outlined important themes of the functional purpose of groups that

provided a conceptual framework for my research of how those themes relate to personal attitudes about aphasia.

The effects of aphasia on social network participation and the feelings of inclusion also affect how a PWA renegotiates his or her perceptions of self-identity. In a study by Shadden and Agan (2004), the authors examined how identity is shaped and negotiated through social interactions and how aphasia affects how one is able to participate in those social actions. The communicative limitations brought on by the aphasia limits one's ability to negotiate self-identity through social exchange "because identity is by its very nature social and embedded in interaction" (Shadden & Agan, 2004, p. 180). The authors state, "The powerful link between aphasia and social interaction is clearly established. Unfortunately, most societies value independence, measure identity in terms of contributions, and rejects illness and impairment. By definition, the individual with aphasia no longer fits in that social milieu, at least not immediately poststroke" (Shadden & Agan, 2004, p. 174). The authors examined how group interventions can help a PWA negotiate self-identity in a social context after individual language therapy. Moving from individual speech and language to a group setting shifts the focus of language of a particular language activity to one with social focus, thus promoting the need to renegotiate self-identity in a social context. The authors observed how subjects navigated the social interactions to establish their self-identities in a group setting and stated that a group setting is "the one place where that experience [of stroke] becomes something positive, and where the aphasia that is disrupting one's life also gains one membership in this new community" (Shadden & Agan, 2004, p. 180). My research sought to look at how the disruption of aphasia is changed through the participation in aphasia groups.

Goldfarb and Pietro (2004) studied individual as well as group interventions for two populations: a subject group with aphasia and a subject group with dementia. The authors refer to research by Wertz, Collins, Weiss, Kurtzke, Friden, and Brookshire (1981) that indicated that both individual and group intervention resulted in gains, but individual therapy resulting in greater improvement. However, aphasia groups, both treatment-based and non-treatment-based, can provide emotional support and opportunities to re-engage in social networks. Interaction with other participants in a group setting can remove the sense of learned helplessness (Goldfarb & Pietro, 2004) and promote psychosocial well-being. My research sought to further explore how and why the themes of emotional support and social reengagement affected attitudes about the PWAs' communication abilities. In addition, I sought to inquire if the benefits of emotional support and social re-engagement was being generalized outside of the group setting.

Hersh (2009) asked, "How do people with aphasia view their discharge from therapy?" This research applied grounded theory to analyze interviews with 21 people with aphasia, as well as 16 family members. Three themes emerged from their narratives: biographies, recovery, and feelings about therapy (Hersh, 2009, p. 331). Hersh noticed that their narratives about their discharge included biographical information. Subjects used metaphors of their pre-stroke lives or other personal qualities to illustrate the effects of their therapy and discharge (Hersh, 2009, p. 335). By placing the experience of therapy and discharge in a larger context (their biographies), the subjects were able to offer a more complete picture of their experiences. The participants' notions of recovery also colored their attitudes about their discharge experience. Their attitudes about their own recoveries affected how they participated in their own discharge, regardless of the source of recovery information (Hersh, 2009, p. 337). The interviewees' feelings about therapy were important in shaping their feelings about their discharge experience. In addition to

discussing the therapy experience, participants discussed elements that affect their feelings toward therapy, such as transportation, the setting, the schedule, and frequency of meetings (Hersh, 2009, p. 338-339). Hersh also found that the subjects felt “uncertainty and confusion surrounding discharge” (Hersh, 2009, p. 331). These unsettling feelings resulting from discharge from therapy can affect how a PWA sees his or her self identity: if the communication disorder is not fully remediated, then that person’s sense of self-identity is one of fracture and brokenness. In addition, clients found that they have to break away from a valued relationship with the therapist. Hersh stated, “A key source of anxiety at discharge for people generally post-stroke relates to perceptions of ongoing need to assistance and the degree to which they feel that are able to adjust to chronic disability independently” (Hersh, 2009, p. 332). The theme of biographies was illustrated in the subjects’ narratives of their discharge, which included their personal biographies. Weaving their personal biographies into their experience of therapy and discharge from therapy indicated their need to fully express the importance of the experience. The second theme, “notions of recovery” (Hersh, 2009, p. 336), was expressed by the subjects whether they felt uncertain about future progress or hopeful that a full recovery would occur. “In context of such individual responses to recovery, it is not surprising that discharge decisions will hold varying significance for people with aphasia. ... These stories show that people with aphasia get their information about potential recovery from many sources, not just their speech pathologist” (Hersh, 2009, p. 337). Hersh also pointed out that a lack of communication was expressed in many of the discharge narratives (Hersh, 2009, p. 343). Some clients did not know what they could ask for, whether it was additional individual therapy or other options. Hersh concluded with a proposal for a discharge experience where the client feels confident of the exchange and is able to interact and be part of the process (Hersh, 2009, p. 348).

In light of Hersh's study of the narratives of discharge, providing options such as aphasia support groups could help ease the feelings of uncertainty by providing opportunities to work on one's sense of self-identity within a social context, extending the client/clinician relationship (or other related professional role) via a group setting, encouraging decision-making contributions, and encouraging the exchange of information with others. Hersh's study explored the need for a client-centered discharge experience and opened up the discussion of how offering information on group opportunities may alleviate some of the uncertainty clients may feel. This study was influential in forming the implications of the data and what we as SLPs can do.

To help process the reality of a stroke, Shapiro (2011) wrote that "efforts to reconstruct broken narratives will occur almost immediately as individuals strive to create coherence" (p. 19). This notion of rewriting the narrative of self becomes a tool that is used to help a stroke survivor cope with the reality that his or her life has been irrevocably changed. While Shadden and Agen's (2004) research on redefining self-identity emerged from observation of a support group, Shapiro writes from her own experience with stroke and recovery. According to Shapiro, redefining the self started as soon as a person started reconstructing his or her understanding of his or her roles in their personal narratives.

Personal narratives and attitudes and behaviors toward disability were explored by McCarthy, Donofrio-Horwitz, and Smucker (2010). This research examined perceptions of disability after reading a personal narrative of a person who uses alternative and augmentative communication (ACC). Included in their qualitative findings was the theme that reading the personal narrative made some participants feel that they would try to "avoid underestimating individuals with disabilities" (McCarthy, Donofrio-Horwitz, & Smucker, 2010, p. 68). Together with Shapiro's account, the idea of reshaping personal identity, whether through self-narratives,

interaction in a support group, or through documented narratives, brings to light attitudes of disability from both those without disabilities and those with disabilities.

Chapter 3: Methods

Study Design

A phenomenological approach was used to collect and analyze data and identify thematic relationships based on the commonalities revealed through the coding of the data. Utilizing descriptive studies of human experience, this qualitative approach to research is traced back to the work of philosophers Edmund Husserl and Alfred Schutz (Cohen, Manion, & Morrison, 2000). Considered the founder of the phenomenological approach, Husserl sought to “look beyond the details of everyday life to the essences underlying them” (Cohen et al., 2000, p. 24). This approach was meant to question assumptions and look at human experience as knowledge. Schutz expanded the phenomenological approach to examine social behavior (Cohen et al., 2000, p. 24). “Of central concern to him was the problem of understanding the meaning structure of the world of everyday life One can only impute meaning to [experiences] retrospectively, by the process of turning back on oneself and looking at what has been going on” (Cohen et al., 2000, p. 24).

I conducted this qualitative research to give voice to the unique perspectives of the participants and analyze a PWA’s attitudes about his/her communication in the context of aphasia group participation. “The phenomenological attitude is reflective. It selectively turns from the existence of objects to the processes and meanings through which they are subjectively given” (Wertz et al., p. 126). According to Bogden and Biklen (2003), a qualitative researcher is “concerned with understanding behavior from the subject’s own frame of reference” (p. 2). I explored the “how” and “why” and examine how participants “make sense” of their individual experiences (Bogden & Bicklen, 2003, p. 7). “Phenomenology is neither a doctrine nor a contrived method but a diverse, living movement that is still changing. Phenomenological

research utilizes the full sensitivity, knowledge, and powers of comprehension of the researcher and is consequently quite personal" (Wertz, Charmaz, McMullen, Josselson, Anderson, & McSpadden, 2011, p. 130). In an effort to reflect the personal nature of the narratives and give voice to the participants, quotes were included verbatim, reflecting sentence structure, word finding, and grammatical errors and inconsistencies that are common with aphasia.

Three perspectives were explored in order to gain a multidimensional and fuller understanding of how group participation influences attitudes about aphasia. The perspectives came from the person with aphasia, his caregiver/spouse/family member, and his Speech-Language Pathologist (SLP). Interviews with the PWA provided an opportunity for him to express his experience with aphasia groups and whether participation affected those perceptions. Interviews with the caregivers explored their own experiences as well as what they observed in the person with aphasia. Interviews with the SLPs looked into the person's attitudes toward aphasia from a clinician's perspective. Together, the multiple perspectives both enriched and disambiguated the data. Triangulation of data through the use of multiple data sources allowed for a cohesive interpretation of the data (Mason, 2002). "Triangulation using multiple sources of data means comparing and cross-checking data collected through observation at different times, of in different places, or interview data collected from people with different perspectives or from follow-up interviews" (Merriam, 2009, p. 216).

Participation Criteria and Study Population

Participants included PWAs, their caregivers, and their speech therapists. PWAs were recruited from two local aphasia groups, regardless of the type of group design. Information about the study was disseminated by group facilitators to approximately 20 people with some

overlap if participants attended both groups. In addition, I made a personal visit to a group, with the permission of the group facilitator, to accommodate a variety of communication modality preferences, explain the project, and answer questions. It was important for me to be able to speak one-on-one with possible participants as reading comprehension can be affected by aphasia and written information about the project may not have been read or fully understood.

My contact information was made available to the group, so individuals could contact me in private to express interest or ask questions. Some participants openly expressed interest in the study during my visit. In this case arrangements were made to contact the group member outside of the group setting to discuss the project. Information about the participation criteria and scope of involvement in my study was shared with individuals who expressed interest in participating. Verbal explanation of the research goals and procedures was provided in person to them. When necessary, Supported Conversation Techniques (SCTs) were used to augment the verbal explanation of the procedures to the volunteer and confirm their decisions. One volunteer chose to have a caregiver present during the explanation of the project and procedures. The documentation stated that participation was voluntary and that the participants may withdraw at any time without negative consequences. Participation was open to males and females with aphasia secondary to stroke, who participated in aphasia groups, who were ages 18-99, and from all socioeconomic and cultural backgrounds. Participation was open to all levels of physical and language abilities, though they needed to be healthy enough to participate in the interview process.

Once the PWA participant group was defined, letters of consent were reviewed with each caregiver and speech therapist. Each caregiver and speech therapist was aware that the PWA had granted permission via a signed letter of consent to contact that person. The scope of

participation and the voluntary nature of participation were discussed with each caregiver and speech therapist, and each was given the opportunity to ask questions. Letters of consent were signed prior to interviewing.

The volunteer participants consisted of four people with aphasia (PWA), secondary to stroke, all males, from a variety of cultural and socioeconomic backgrounds, and healthy enough to participate in the research. The range of time post-stroke was one-and-a-half to fourteen years. The age of onset range was mid-thirties to late-seventies. Each PWA was involved with at least one aphasia group. Often, participants attended more than one group and were familiar to each other through the groups. Participants who had physical limitations as a result of their stroke were able to participate in the research without any negative consequences. Each PWA was able to answer for himself and complete the interview without complications regardless of their particular set of symptoms and abilities as a result of their aphasia. No additional accommodations such as augmentative and alternative communication devices (AAC) were necessary. Though the study was open to all levels of aphasia and physical ability, those who expressed interest in participating shared some common qualities: they were all male, lived independently, could speak without the need of an AAC, used SCT strategies, and were ambulatory. These commonalities may suggest that the interview process may appeal to PWAs within a certain level of language and physical abilities, as well as within a certain level of self-confidence in their abilities. However, despite sharing these characteristics, their narratives remain their unique experience and contribute to our understanding of whether aphasia support groups influence attitudes of aphasia.

In addition, the participants included three people who were caregivers of the PWAs. A caregiver was asked to participate only if consent by the PWA was granted. It was important to

get the perspective of the caregiver to expand up on the PWAs' narratives and offer another perspective on the PWAs' experience with aphasia groups. Like the PWAs, each caregiver was given a pseudonym to protect his or her identity. I included their relationship to the PWA (mother, son, wife) to give context to their comments about the PWA. One PWA did not give consent to contact a caregiver. It was observed that he said he did not have a caregiver, and consent was not granted when I asked if there was a family member or close friend whom I could speak with regarding this research. It is unknown why he preferred not to include a caregiver/family member/friend. Despite not having a caregiver's perspective for this particular participant, his story remained an important account of trauma and rehabilitation and a reflection on an individual's desire to be independent after a stroke.

A total of four speech therapists, both male and female, from a variety of cultural and socioeconomic backgrounds, and healthy enough to participate in the research were interviewed. Each PWA granted permission to contact his speech therapist from either individual therapy or group therapy, and two of the volunteers specified the same speech therapist. The SLPs came from a variety of therapy settings and had varying levels of involvement with aphasia groups. One of the four SLP interviews was a facilitator of an aphasia group who volunteered to be interviewed for this project to offer her perspectives on facilitating groups. Speech therapists who worked directly with a volunteer PWA were contacted only after consent was signed by the PWA. Additional consent was given by the SLPs prior to starting the interview.

Data Gathering

Descriptive data were collected to substantiate the analysis. These data were gathered from personal interviews and included interview transcripts, audio recordings, video recordings,

and field notes of the behaviors of the volunteers I observed. Semi-structured interviews included both open-ended and close-ended questions as well as probing questions for further clarification. Supported Conversation Techniques (SCTs) were used to assist with communication exchange with the subjects with aphasia. SCTs used included speaking slowly and directly to the subject, using simple sentences, printing key words, asking yes/no questions, and providing pen and paper for the subject. The locations for the interviews varied depending on the volunteer's request and where he or she felt most comfortable in order to provide a naturalist environment. The majority of the volunteers were interviewed in their homes. Two of the four PWAs were interviewed in their homes. One was interviewed in a public location of his choice, with the caregiver present, and another PWA participant was interviewed in a meeting room of his choice. The caregivers also could choose where to be interviewed. Of the three volunteer caregivers, two were interviewed in their homes; one was interviewed alongside the previously mentioned PWA in a public space of their choice. The speech therapists were interviewed in either their place of work or a public location, and one was conducted over the phone.

Key Interview Questions

The main research question which sought to understand if participation in aphasia groups affected the PWA's perception of his or her aphasia was addressed by semi-structured interviews. "Qualitative interviewers are interactive and pay close attention to the language and concepts used by those they interviewed" (Schiavetti, Metz, & Orlikoff, 2011, p. 94). A semi-structured format provided the flexibility to ask follow-up questions and pursue unexpected topics as they emerged. Interview questions included:

- Tell me about your stroke and experience with aphasia group.

- What were your attitudes about “disabilities” prior to your stroke?
- Have they changed?
- How did you feel about your communication immediately post stroke?
- Did you have any expectations or assumptions about a group setting?
- How do you feel about your aphasia now?
- How does it feel to have aphasia?

The open-ended questions along with follow-up questions allowed the PWA to contribute his own opinions and allowed the interview to follow a natural progression. “Both the interviewer and interviewee are given the opportunity to clarify possible misconceptions or to pursue topics in more detail. By encouraging such diversions, unanticipated topics and responses can be explored. Semistructured interviews are . . . well suited for answering qualitative research questions” (Schiavetti et al., p. 94-95).

Similar questions focusing on the behaviors of the PWAs were asked during the caregiver and speech therapist interviews, while allowing for the interviewee’s own experiences to be shared. Questions included:

- Tell me about [the PWA’s] stroke.
- Tell me about how [the PWA] felt about having aphasia before participating in an aphasia group.
- Do you think participation in a group helped? If so, how?
- Did you see any changes in attitudes or behaviors?

Not all interviews with the caregivers and SLPs followed a predictable path. Influencing factors included the relationship of the caregiver to the PWA, the length of time an SLP worked with a PWA, and whether the SLP worked with the PWA on an individual basis or a group setting.

Safety and Confidentiality of Human Subjects

All subjects were informed of the research procedures and the voluntary nature of participation, and were assigned a pseudonym. No identifying information of the volunteers, aphasia groups, or institutions was used in this written report. Because participants in aphasia groups are not limited to participating in one group, overlap across group settings was seen.

Because some PWAs used gestures and printed key words when they speak, separate permission for participants with aphasia was sought for video-recording to capture facial expressions, printed communications, and other physical gestures. Capturing gestures and printed communications helped confirm participants' responses and communicative intent and provided record for when SCTs were used during the interview. In addition to confirming communicative intent, analysis of the videos helped form a holistic and humanistic perspective of the participants' narratives. All but one PWA was video-recorded. For the one volunteer who was not video-recorded, field notes captured gestures that were used, though the volunteer did not need to use printed key words. Transcriptions were completed by a transcriptionist and all volunteers were assigned a pseudonym. All audio/videotapes were destroyed at the completion of research.

In addition, strategies outlined by Bogden and Biklen (2003) were used to ensure an ethical approach to fieldwork and working with human subjects. Among their guidelines, Bogden and Biklen advise to "honor your informants' privacy" (Bogden and Biklen, 2003, p. 44). In doing so, the participants were fully aware that participation was voluntary. They were also informed of the purpose of this research and how their interviews would be used. Participants could choose if they wished to be video-recorded and were informed that video

would be used for the sole purpose of observing gestural responses and confirming communicative intent of their spoken responses. Bogden & Biklen also suggest that “the subjects’ identities should be protected so that the information you collect does not embarrass or in other ways harm them” (Bogden & Biklen, 2002, p. 45). To protect identities, all participants were given pseudonyms and ages were expressed in decades. No institutions were mentioned by name, and all efforts were made to portray the participants with sensitivity in an open and truthful manner, as well.

All protocols were followed for approval to work with human subjects, and permission was granted by Eastern Michigan University’s Human Subjects Review Committee. In addition, the required training courses in research ethics through the Collaborative Institutional Training Initiative (CITI) were completed.

Limitations of the Study

While this research examined themes within the data, the qualitative findings will not be representative of all people with aphasia who participate in aphasia groups, nor will they be representative of all aphasia groups. “The Phenomenological approach is at once broad and narrow. Its breadth stems from its applicability to research problems that require understanding and description of the essentials of lived experience. It also has strict limitations.

Phenomenological [approach] is not an appropriate method for investigating physical (environmental, biological, evolutionary) phenomena and processes; for constructing abstract theories and models; for testing causal hypotheses; for estimating empirical magnitude, frequency, and prevalence; or for assessing quantitative relationships among variables” (Wertz et al., p. 134). Attitudes and perceptions of a person’s communication disorder and personal

experiences with aphasia groups were highly individualized, though shared qualities were explored and analyzed.

The participants in this study were all males, able to successfully communicate for themselves, ambulatory, and able to participate without any additional accommodations such as alternative speech technology. Their stories and perspectives are potentially different from others who may be living with more challenging forms, or levels of severity, of aphasia and other resulting conditions from stroke. In addition, participants who actively seek out information on aphasia groups and who volunteer to be interviewed will, with great probability, have very different attitudes than those who do not seek out group opportunities or wish to be interviewed. This research involved volunteers who were currently participating in a group setting, wanted to contribute to research, and wanted to share their personal stories about the trauma of stroke and their unique experiences with aphasia groups.

Although the experience of stroke is unique to the individual, much can be learned from the individual's narrative of their experience with stroke and rehabilitation. Shadden and Hagstrom examined how narratives are used in The Life Participation Approach to Aphasia (LPAA), which focuses on "communication support regardless of language or physical status, and facilitation of reengagement in life for all living with aphasia" (Shadden & Hagstrom, 2007, p. 324). The LPAA uses self-narratives as a way for the PWAs to make sense of their experience and reframe their self-identities (Shadden & Hagstrom, 2007). In addition, "One's personal narrative does not exist in isolation, but instead intersects with, incorporated, and responds to the words, ideas, actions interpretations, and timelines of others" (Shadden & Hagstrom, 2007, p. 326). Merriam explained that "what is being investigated are people's constructions of reality—how they understand the world. . . . There will be multiple constructions of how people have

experienced a particular phenomenon, how they have made meaning in their lives, or how they come to understand certain processes” (Merriam, 2009, p. 214). Therefore, self-narratives are a way to process and understand the how and why of that person’s experience. Within the framework of an interview, the PWAs interviewed for this study shared narratives of their experiences with aphasia and participation in aphasia groups. In the process, they revealed how and why participation in an aphasia group influenced their perceptions of aphasia through reengagement in life participation.

Chapter 4: Findings

The PWA participants were Travis, Mike, Will, and Martin; each talked about his experiences of stroke and group participation.

The Participants

PWA	Caregiver	SLP
Travis late 50s, 4 ½ yrs post-stroke	[none]	Mary
Mike late 50s, 3 yrs post-stroke	Josh, son	Mary
Will early 80s, 1 ½ yrs post-stroke	Beth, spouse	Susan
Martin late 40s, 14 yrs post-stroke	Laura, mother	Dan

Travis, who is four and a half years post-stroke, is outspoken and frank about his experience of stroke recovery. He spoke about the people and factors that supported his recovery as well as the obstacles he faced. He is a regular and active participant in a language-based aphasia group. Although consent was not given to interview a caregiver for Travis, I interviewed Mary, a speech therapist who has worked with Travis in a group setting for several years.

Mike is three years post-stroke and is an avid aphasia advocate. He carries an aphasia card with communication tips in his wallet and has an aphasia sign identifying his communication needs on the visor of his car. He doesn't hesitate to tell others what he needs to be a successful communicator. He participates in two aphasia groups: one that is language-based, which Mary facilitates, and another that is facilitated by a music therapist. Josh, his son, was interviewed to obtain a caregiver's perspective and to contribute his perceptions of his father's experience of stroke and group participation. Mary has worked with Mike in the same group setting with Travis and offered her perspective as his speech therapist.

Will, who is one and a half years post-stroke, was interviewed with his wife, Beth. She is by his side, accompanying him to aphasia groups, playing bridge with their long-time friends, and encouraging him to stay positive. Together they attend the aphasia group that Mike attends. Will, at the time of the interview, was planning on starting a language-based aphasia group. Susan, his speech therapists who worked with him in individual treatment during his rehabilitation at a hospital, was interviewed for her perspective of his attitudes about his aphasia.

The youngest of the PWAs interviewed was Martin, who is fourteen years post-stroke. Martin is in his late 40s and lives independently. He strongly associates his identity with who he was pre-stroke and has struggled with health setbacks since his stroke that have resulted in the loss of earlier communication gains he had made during his early treatment. He participates in aphasia groups in the local area as well as occasionally attends aphasia conferences. Laura, his mother, was interviewed to gather a caregiver's perspective on Martin's attitudes about his aphasia. Dan, a speech therapist who facilitated an aphasia group that Martin had been involved with, offered his perspective on Martin's story.

Analysis of the interviews of the PWAs, caregivers, and SLPs revealed that participation in group settings helped effect change in their attitudes toward their communication disorder. These changes in their attitudes emerged as participants talked about moving on with life and learning to live with their aphasia. Three major themes emerged from the narratives. The participants who expressed feelings of moving on with their lives and learning to live with their aphasia talked about the importance of feeling accepted in the group setting. The PWAs also talked about how the aphasia groups were a place to continue to learn about aphasia and become self-advocates. In addition, these feelings of acceptance and self-advocacy that they experienced from group participation helped them to recognize their potential and set future goals. Feelings

of acceptance, continued learning and self-advocacy, and setting goals all pointed to how participation in an aphasia group affected change in the participants' perceptions of their aphasia, helping them to learn to live with their aphasia.

Feeling Accepted: "There's Other Guys . . . the Way I Am"

Participating in an aphasia group provides a feeling of acceptance that is often lost after a stroke. Frequently one of the consequences of stroke is social isolation as friends fall away and social opportunities become limited. Shadden and Agan (2004) observed that aphasia groups are: literally the one place where that experience becomes something positive, and where the aphasia that is disrupting one's life also gains one membership in this new community. In fact, newcomers routinely comment on their surprise at the fact that (a) others shared feelings and concerns; (b) others had an entirely different constellation of deficits; and (c) telling one's story evoked empathy but not surprise. (p. 180)

The acceptance that the participants experienced in an aphasia group helped to create a sense of self-acceptance that was foundational in helping the PWAs learn to live with their aphasia. Acceptance was echoed throughout the interviews as volunteers described times of both acceptance and its counterpart, rejection.

Travis is in his late 50s and is four and a half years post-stroke. He has been involved in language-based group therapy and other aphasia groups that provide support and social outlets. During the interview, Travis talked passionately about his recovery and the role that group participation has played in shaping how he has learned to live with his aphasia saying, "This is the happiest I've ever been in my life. It's weird. I got these problems." Getting to this point of accepting his problems and being happy has not been an easy journey. He recalls his experience

immediately after his stroke as a time of not knowing what was going on around him, followed by increasing awareness of the activity around him but not being able to speak. He describes his confusion and inability to communicate during his stroke:

After I think about it, later long time, you know what, when I had my stroke, I didn't drink, but I felt drunk, heavy drunk, you know, really heavy drunk. So then they call the ambulance and I really didn't know what was going on, but was trying to tell my daughter . . . all I could say was nine, nine, nine. After years of and years to think about it, what I was trying to tell her, I'm fine, but I couldn't get it out.

As he became more aware of how the stroke affected him, he knew that he would have to work hard at improving his communication skills. "I knew I had a disorder. I had a stroke and aphasia. I had a disorder. I knew that . . . I knew that I got to work on it." The ability to accept that rehabilitation was going to be hard work served him well in that he expressed pride in his progress. "I work hard to pat myself on the back." He also expresses acceptance of his current communication ability, saying, "I always talk to myself which is OK. I don't mind that. People think I'm crazy." But this strong sense of self-acceptance does not exist without challenges.

People think you had a stroke, you're stupid because you can't talk right. They think that means your mind's not working right. My mind work fine. Problem is, what I want to say, I trouble saying it. My mind is doing right. I just have trouble saying it.

The benefits of feeling accepted and self-acceptance can be intensified after experiences of rejection after a stroke. For Travis, being accepted into a group helped to repair earlier feelings of rejection he experienced in the hospital.

That [social worker], again right to my face, you know, said, 'You're never going to be able to work again.' And that took the soul right out of me. You know. I said you don't

know me. You know, took the soul right out of me. Oh I can't do nothing no more? That's what you're telling me? I couldn't say it. My mind is still there, you know. I know what you're telling me. . . . They shouldn't do what they're doing. You shouldn't judge people when you don't even know these people. You got to give them a chance. . . . Why be telling everybody you can't do nothing, like I'm stupid—I can't do nothing. I said that's wrong for them people, you know. It's really wrong. And I think that should be changed right away. . . . You can't tell nobody—you can't take their soul away—'You can't do nothing no more. You're just stupid. Just sit in your wheelchair and be happy.'

Well, that's the wrong thing to say.

Although the social worker's intentions are unknown, it is clear from account that this exchange was devastating for Travis. This news was, for Travis, commensurate with rejecting his future potential to be an independent and productive individual. Mary, Travis's speech therapist addresses how group participation can alleviate "that awful feeling that they're the only ones [who are] suffering this, they're the only ones that this has happened to" by being a place where a PWA can see that "there's somebody else like me out there." She continues, "I think it instills hope because people are at such different levels. That someone who is maybe lower in terms of physical skills can see someone who's better and listen to them talk about what they do to try to get better." In a more current example, Travis was told that "nobody wants to work with you because if something happens," by his coworkers who feared working with him because they thought that his communication abilities placed them at risk. In another example of experiencing a feeling of rejection, Travis shares the following description of the reaction he gets from people:

Sometimes when I go to a [store] or there places looking for something, and I couldn't say it right and the guy looked at me like, "What's your problem? What are you?"

Dumb?” I can see the look. People that had stroke see the look. I said, “I’m fine. I’m going to do it myself. I don’t need you.” But I can see the look.

Despite experiencing “the look” and the inaccurate assumptions by others that he cannot be relied on, group settings are places that offer feelings of inclusion for the PWAs regardless of their abilities. Travis has also formed friendships that have bolstered his ambition to work on his communication. Travis describes his friendship with June, another PWA whom he met in one of the groups.

I looked at June and said, ‘I want to be as good as you.’ She walked good and her arm was working pretty good. She wasn’t talking real good, you know. I said, ‘I’ll get better as you’ The talking I have. She doing good, too. Don’t get me wrong. She talk just as good as me right now. That made me a little bit better.

June represented a measure of progress that Travis wanted to reach. Travis adds: “We became good friends. . . . We talk on the phone. Both of us couldn’t talk too good but we got it through. We helped ourselves by talking on the phone.” When an individual feels secure about his or her place within a group, he or she is more likely to feel a sense of responsibility to welcome a newcomer. Since they have an established role, they are able to ease a newcomer’s apprehensions about being accepted if they are acknowledged and accepted. According to Travis, aphasia groups are a place of acceptance. He explains, “All these people have different kinds of strokes. . . . All these people are fighters. They have not given up. I am too I gotta do it. I gotta get as good as them. Them guys are fighters. They’re the kind of people I love. I love fighters. I don’t like people who just don’t do nothing.”

Being in an environment where the participants are linked by a common experience helps to foster the sense of re-acceptance into a group of people. Mary, the speech therapist who has

worked with Travis and Mike and also facilitates an aphasia group, explains, “They are participating in conversations where they feel really understood in groups. . . . And accepted by everyone and that they’re all in common groups. I think that . . . helps people feel less frustrated.” The feeling of acceptance is also addressed by Mike, who is three years post-stroke. Mike talks about instances where others have deliberately ignored him to avoid having to speak with him. “A lot of people stand back. . . . If they’re having a problem with me--and they just want to talk to me—they don’t want to talk to me.” Mike’s response to people who looked past him is, “I see people. I’m right in front of them and I’ll tell them, ‘Hey, I am.’” Mike explains that participating in aphasia groups has helped him to feel connected to others because “now I can understand what’s, what I am, and there’s other guys that, other people that are . . . the way I am.” In addition, attending an aphasia group is a way to reclaim autonomy over his life and regain a sense of belonging. He gives an example of how, as an inpatient, he made his wishes known at a time when he had little control over his life:

If they don’t get me going here, and do something, then I need to do it then. And so one day I knew how to do . . . so I knew where it is ‘cause I used to go hunting out there all the time I took off and walked down to [the highway] is where that is on there I knew how to get home. I knew how to do it and I told, that’s why I don’t hear anything from you, I’m going to go. I’m going. . . . They didn’t know where I was.

After leaving the treatment facility, his family decided to have him return home with the help of a visiting nurse and family to provide care.

Josh, Mike’s son, offered his perspective as a caregiver. Josh often accompanied his father on errands early on in recovery to be available to assist with communication. In many

instances, the store clerk or cashier would immediately assume that Mike was unable to communicate or understand what was being said when they heard his speech:

The hard thing is when like he walks up to a cashier . . . and they look at him as if he's mentally challenged, or mentally retarded and it just kind of like screws him up a bit. . . . Right away they don't see him. . . . They don't understand what aphasia is. . . . They try to shut him out. . . . They want to speak to me, not him.

Aphasia groups are places where PWAs who are having similar experiences can go without having to see “the look” that Travis describes or be ignored, as Mike and Josh described. In addition, participation in aphasia groups has helped both Mike and, in turn, Josh accept that there is no “quick fix” after a stroke. Josh expressed that “everyone wanted a quick fix” and that he “wanted to simplify everything, [but] you can't simplify it.”

Martin, who was approximately 14 years post-stroke at the time of the interview, has been living with aphasia the longest of the volunteers. On the day of the interview, Martin gave me a tour of his home. The front bedroom was his office with the typical desk and computer against the wall. Then he opened his closet doors. Inside were several business suits neatly stored in a clear garment bag. He gave a wave of dismissal and then led me through his home. His life, like many others who have survived strokes, was drastically changed. “Before my stroke and after? Completely different. I was a go, go, go individual. And then twelve hours of sleep because of medication.” Martin's stroke occurred when he was in his mid-30s, with a promising accounting career ahead of him. Laura, Martin's mother, offered her perspective as his primary caregiver and commented on his previous ability to find promising employment and to pursue the next step in his career: “He always got a good job. . . . He wanted to pursue a different kind of [job] and that's what he was doing.” She added, “He had a nice life. He did a lot. He traveled.

So, it was a huge change.” He was young and active and there was not an obvious cause of the stroke. Laura considers the possible triggers of his stroke: stress, genetics, or previous injury. For Laura, not knowing what caused the stroke has made it “probably more difficult to accept.” She added:

We have never found out why he had the stroke. He’s had three neurologists They really don’t know what happened. [Martin] thinks it was stress. . . . [The doctors] found nothing that would be genetic, in fact all our kids were all tested, and he didn’t have high blood pressure and he didn’t have high cholesterol and he was really active. He rode his bike; he skied, played golf, so we just don’t know.

There seems to be a need to find a reason why. “Just the fact, the whole, thing, that he had a stroke. Like [a family member] always said, it could have been one of us instead which would have been a lot more logical.” Laura shared another theory:

One of the doctors said it could have been an injury in childhood that didn’t, nothing happened at the time, but it could have formed. . . . To me, that is a good theory because you know, have you ever hear of kids banging their heads in the crib, rocking the cribs? Well, he did that. And in fact we had to put bumper pads—two layers of bumper pads—up ‘cause he did it for quite a while and you couldn’t make him stop. . . . It’s hard for me to believe it doesn’t [cause any problem]. . . . To me that sounds logical. And of course he could be right about the stress too. He was healthy and active.

Martin talked about stress playing a role in his stroke. He had many stressors in his pre-stroke professional life, but he added that stress continues in his life now, although a different type of stress. His current sources of stress involve his medications, their side effects, and his

communication abilities. “I accepted it. Two things: I was stress, stress, stress, and now a different kind of stress.” He added, “But, it’s still I’m happy go lucky.”

Laura also expresses feelings that he has accepted his circumstances despite the hopelessness he felt immediately following his stroke, “He didn’t even want to live at first—I remember that—and he told his [siblings] first.” She described how he adjusted to his new life: “He just accepted it and made the best of it and we were really proud of him because he’s never acted sorry for himself. I mean, I’m sure he is--I’m sure he regrets you know, like he’d like to go back to [his] old life.”

Throughout the interview, Martin continued to contrast his before-and-after life and affirmed that attending aphasia groups has helped in accept his new pace of life. “I’m a, I was a go, go, go person. But now I’m a ‘Hi, how are you?’ type person. . . . It’s a new life.” Martin added that he felt the greatest advantage of aphasia groups is the opportunity to slow down and “to meet and say hi.” Dan, a speech therapist who was acquainted with Martin through an aphasia group, stated, “When I first met him, I thought he was the leader of the group.” Eventually Martin’s role as group leader diminished. “I don’t know if I’d say resigned, but he’s just accepted it. I know not at first. I know he didn’t,” commented Martin’s caregiver regarding her perceptions of his attitude toward his aphasia. She recounted a story of how a friend had asked Martin if he missed his old life to which he replied “yes, of course he misses his old life. You think he’s going to say, ‘Oh, no. This is fine’? . . . He’s handling it.”

In a study investigating “What People with Aphasia Want,” Worrall et al. (2011) determined that:

It was very common for people to have social goals Social goals were characteristic of later stages of recovery . . . but were also featured throughout their rehabilitation.

Social ease and acceptance were very important goals. People with aphasia were upset by boredom and isolation. (p. 315)

Feeling accepted by a group fostered “social ease” and helped the PWAs progress with their rehabilitation. For Travis, Mike, Will, and Martin, participation in an aphasia group provided social interaction that helped them feel accepted into a community and in turn helped foster feelings of acceptance of their stroke and subsequent aphasia.

Learning and Self-Advocacy: “A One-Man Fighting Team”

Along with the feeling of acceptance that came from attending an aphasia group came a greater understanding of their aphasia. Worrall et al. (2010) observed that one goal of people with aphasia was obtaining information about aphasia:

On a practical level, they needed information about aphasia and stroke to access services and to explain their difficulties to friends or people in the community. In addition, having information allowed people to start taking control and to participate in decisions about their own therapy and their own rehabilitation. (p. 314)

Through group participation, the PWAs reported learning more about their aphasia and gaining a better understanding of their symptoms, the type of aphasia they have, and how the symptoms of their aphasia can change over time. Mary, who has worked with two of the participant PWAs, adds, “I think it helped them learn more and understand more about their own particular set of symptoms, what kind of aphasia they had, and where they were in changing types of aphasia in recovery.” Learning about their symptoms in a group environment also expands their understanding of other people’s aphasia. Learning about others’ symptoms helps participants to look outward, according to Mary, and “help

other people along.” Travis describes how the group grew to include new participants and how he saw himself as someone who could help the new participants:

[I] like helping other people. That’s how I think about it in a way--because I talk pretty good. . . . When [Sandra] came to group last couple of years ago, whatever, about a year, I don’t know, or something, and she see me she pointed, like, ‘what are you doing here? He have no trouble with speech.’ But I do.

In this example, Travis became the measure of “normal” [“no trouble with speech”] communication and he alludes to his role as someone who helps the new participants. He explained how he tried to engage a new participant by asking her how a particular recipe is made.

I said, ‘OK, what do I do with them?’ I tried to tell her she put them—but she wouldn’t do it—put them in a pan. But she couldn’t say it, and I wanted her to say it so bad. I was trying to help in a way. . . . But she couldn’t say pan. It’s like argh, damn it.

Travis was relaying an example of how he was trying to elicit communication from a new participant. Travis’s speech therapist stated, “[group therapy] helped them learn more and understand more about their own particular set of symptoms. . . . They felt like they had never been told.” Mary shared the example that as Travis learned more about aphasia he wanted to help others outside of the group setting. He decided to advocate for people with aphasia by offering to speak to new stroke patients at a local hospital to tell them that there was life after stroke. Mary adds “[They are] becoming stronger advocates for [themselves], and stronger teachers with the public about aphasia.” The turning point, when PWAs start to look outward, can be subtle, as Mary describes:

They reach out to other people in the group. They offer advice, or even only just comfort, even just touching one another—patting one another’s hand, that’s how I see [that turning point]. Listening to one another, asking one another questions, giving one another support or suggestions.

Mike has also learned to self-advocate. When communicating with new people, he often presents a card that offers tips on how to communicate with people with aphasia. He states, “This is a part of me and at times I’ll hold that [aphasia card] and I’ll hand it to people when I’m, because I’m have a problem.” He has informed many of the businesses he frequently visits on ways to help both parties communicate. “I go to McDonald’s a lot and they, the reason I go there is because they take care of me. . . . I went through it and they, they gave me everything. If there was a problem, the boss always came over to make sure I was exactly what I was needed and they helped me out a lot [sic].” With his aphasia card in hand and a desire to teach others about aphasia, Mike has become, according to Mary, “a one-man fighting team to get aphasia-friendly businesses.” Mike’s caregiver, Josh, confirmed that being able to advocate for himself has helped Mike “believe in himself. . . . It goes back to being independent. The fact that he’s able to understand what’s going on, take charge [of] it, to be himself.” This move toward independence has not been without challenges for Mike and his caregiver. Mike’s caregiver explained that early in his recovery, “he didn’t want . . . people to really help him out.” Mike’s caregiver revealed, “Overall being a caregiver was like one of the big things that we had a huge problem with—the fact that emotionally it [struck] him that he was reliant on people.”

For Will, participating in an aphasia community was a way to “reach out” to others and seek additional communication support. He has started to reach out because perceives his communication as “moving downhill.”

I'm conscious now that is I start to have a conversation with somebody, that conscious, that speech level is less than what I would like it to be. . . . I can hear conversation. I can, but I'm then when the conversation takes place my level of picking up something and then, you know, move that along, that's, that's changed in me. . . . I'm conscious of a level that I can hear somebody, I can listen to them, but I'm not necessarily, I can't verbal.

For Will, participating in groups also gave him the opportunity to see the range of abilities. He explains "There are different levels of abilities . . . within the group, you know, but I'm beginning to be aware of that I'm, my, I'm not catching up on correct levels of speech that are being given there." This awareness of varying levels of abilities made him examine at his own abilities and how he manages his aphasia: "I'm reaching out to any level that will at least help me or understand who I am, you know, what's going on with me."

Martin's involvement in aphasia advocacy has included attending aphasia conferences as well as visiting aphasia groups. It was important for Martin to express his interest in aphasia groups. "I want to join groups," commented Martin, as he proceeded to name five other aphasia groups that he has visited. Whether a "one-man fighting team" or a person reaching out to help him understand "what's going on" with his aphasia, participation in aphasia groups offers information so that the PWAs can become self-advocates.

Goals: "Doing it for Myself"

Shadden and Hagstrom (2007) observed that "group interventions can target the sharing of life stories and provide a framework for linking past, present, and future in the lives of persons with aphasia post-stroke" (Shadden and Hagstrom, 2007, p. 334). Being able to process their

experience with their strokes and aphasia through the participation in aphasia groups helped the PWAs recognize their abilities and set goals to further their independence.

Travis's interview was punctuated by comments that reveal his personal goals and independence: "I'm doing it for myself. . . . There's stuff I'm going to do. I'm not trying to prove anyone wrong. I do it for myself." At the time of his interview, he was working with a real estate agent to buy a home. He added, "I see people from buying the mortgages and [they're thinking] 'This guy, he's able to take care of a house?' And I know what he's thinking in his mind. I can see it in their face." However, these setbacks haven't stopped him from proceeding with his plan to be a homeowner. "I'm happier than I've ever been in my life This is the happiest I've ever been in my life." Contrary to his positive attitude, he candidly shared that aphasia for him is:

Terrible. A lot of time you got to pat yourself on the back and do it. I said that word. I said this word. It's hard. It's really hard. People in the beginning don't understand you. . . . It's terrible.

Despite his goals, independence, and the progress he has made, he still struggles with accepting his circumstances:

We're all going to get upset. We all wish we didn't have our stroke. I think about it every day. I wish I could go to bed, get up, my stroke is gone. We all want that. That's our dream, you know. . . . Sometimes I get sad. Sometimes I get depressed. I say, 'Get out of it; you're doing good.'

When asked if has gotten easier to accept, he replied:

Yes and no I guess. Not really. I wish I could talk as good as [before the stroke], but I'm talking much better than I ever did [since the stroke]. So, I'm happy with myself. . . . But,

it's bad as hell. You want to talk to people. I try to tell people, I have trouble talking. It's very frustrating, very frustrating. Because you want to talk to people and you want to and it won't come out right and you want it so bad. Sometimes you, it ain't working, some days it doesn't work. Some days it works good. It's very bad to have aphasia. I know how people feel. I'm different. But I know how they feel 'cause I've been there. I haven't given up and I can understand some people do. I do. I understand that.

Despite his struggles of accepting his aphasia, he manages these negative attitudes in order to continue to work toward his goals: "To me it was like, you had a stroke. Cry about it and start laughing. So I just laugh." Mary describes how group participation helps foster self-confidence so that the participants can learn to look outward, "I think people get to talk about who they used to be and they get acknowledged and validated. . . . They get to talk about how they are trying to be someone different now, and what they are trying to do differently." The acknowledgment and validation they receive from the group is important in shaping goals because it "injects them with more confidence, more self-esteem . . . so they can put themselves out there more, out in the public eye."

Mike, who had a career in construction, is looking for employment; he drives to home improvement and construction product suppliers looking for a job. Despite some physical setbacks and a prescribed weight limit that doesn't allow him to carry a 25-30 pound tool belt, a sheet of drywall and lumber, Josh explains that he "still [knows how to] build a building." Mike, who often touches the side of this head when he talks about his aphasia, adds, "That's the hard part of right now is finding another job because my change. I've changed and I'm not, I know who I am and what it is I have." In addition to providing information about aphasia, participating in an aphasia groups has helped him to become more independent since his stroke. Josh reported

that he “went with him once or twice to know what was . . . going on, to meet the people. . . . He’s apply[ing] himself to go do it. That’s good. . . . Now-a-days he’s going to have to take care of himself.” Mike is acutely aware of the need to take care of himself and be independent and adds, “Now I have to get a job for that.” Mary, the speech therapist who has worked with Mike explains that “they support each other really wonderfully,” and make suggestions to each other, such as “where to go for jobs, where to try to a get a part-time position, what [others] can possibly do.” This support network has helped Mike with his goal by providing both practical advice, “where to go for jobs,” as well as validation and support about regarding his new life post stroke.

In addition to seeking communication support from an aphasia group, Will has also made personal goals about learning to live with his aphasia: “Reaching out, grabbing, you know, a verbal contact with that group, and being able to, from it, pick up some more maybe, maybe activity, and so I can, I can better live with this level.” Will’s concerns about his decline in abilities points to his perceptions of his communication abilities. Susan, Will’s former speech therapists shares her perspective:

Their perception is “I sound terrible and I can’t talk to people and I don’t want to,” and then they withdraw. I think an individual’s perception of their abilities really does affect their outcome, how they go back to the community. I think everyone’s different in their perceptions.

Addressing his perception of decline, his wife added, “The more you do . . . the better it’ll be, and maybe that’s why you feel like you’re going downhill because you’re really not pushing [yourself].” For Will, the support of his wife and has played an important role in his rehabilitation. She accompanies him to group sessions, encourages him, and is learning alongside

him how to use strategies to improve communication such as giving him time to reply. Her perspective and contributions expanded upon Will's narrative and revealed the supporting role a caregiver plays in stroke recovery. During his interview, Will talked about a bible study group that he was involved with:

We have a very gifted group in the Sunday school group. . . . And it's a kind of level that under normal circumstances I would even participate in to a much, much greater level. . . . I don't want to expose myself to them and, you know, my level . . . I'm not sure I know what it is.

For Will, working on his personal communication skills goal and learning to "better live with this level" would help him return to this bible study group with more self-confidence. Like Mike, Will's potential to improve his communication and goal to improve how he lives with aphasia is both acknowledged and validated through his participation in aphasia groups, "It's obvious that there are people like me that are out there. There's more people out there than people of what you'd expect."

Worrall et al (2011) identified "control and independence" as a goal of PWAs (p. 315), and this goal is reflected in Travis's goal toward home ownership and Mike's goal to find employment. For Will, his self-esteem is connected to his perceptions of his speech, making his goals about re-establishing his self-identity. The goals expressed by the PWAs reflect how they are incorporating the effects of group participation: the feeling of acceptance and eventually a level of self-acceptance along with information about aphasia so they can learn to self-advocate, to identify their potential, and set goals accordingly.

Chapter 5: Discussion

According to the PWAs interviewed, participation in aphasia groups has helped them to learn to live with their aphasia. Group participation has provided a feeling of acceptance and a place to learn about their aphasia and become self-advocates. These benefits were also evident in personal discussions of future goals.

The theme of acceptance figured prominently in the self-narratives. The aphasia groups provided the opportunity to be part of a community of people brought together by the experience of stroke. Vickers (2010) explored the effects of group participation on social networks and reported that feelings of isolation and reduced social support after a stroke are improved with the participation in a group setting. The aphasia groups in which the PWAs participated helped restore feelings of belonging and inclusion which are often jeopardized after a stroke. The importance of belonging was emphasized by personal examples of the PWAs' experiences of being ignored when a caregiver was present, or being thought of as incapable by others. Travis, Mike, and Josh, Mike's son, all expressed examples of being ignored or thought of as incapable. For Will, his reluctance to return to a church group highlighted how the fear of rejection can be just as powerful as the actual rejection. Participation in aphasia groups helped to repair that isolation. As Legg and Scott (2007) pointed out, participation helped them to "develop beliefs about their capabilities," and "[gave] members access to a group of similar others" (p. 798).

In addition, participating in an aphasia group has helped the PWAs adjust to the impact their aphasia has had on their pre-stroke social interaction: "Alterations in the countless roles and relationships that depend on communication can become the most overwhelming aspect of the coping and grieving process" (Shadden & Agan, 2004, p. 175). The experience of belonging and participating in an aphasia group plays an important role in the renegotiation of self identity.

According to Shadden and Agan (2004), “stroke support groups should provide an ideal forum for renegotiation of identity, because identity by its very nature is social and embedded in interaction” (p. 180). Through aphasia group participation, the PWAs experienced “social ease and acceptance” (Worrall et al., 2010, p. 314), which helped them to begin to manage living with their aphasia.

The aphasia groups also provided education as the PWAs learned about their aphasia as well as other’s aphasia. Worrall et al. (2010) identified one of several goals of PWAs was “information” and reported that:

One of the most commonly reported goals was that of obtaining information. Several people reported that they were apparently not told by their therapists, particularly in the early weeks or months, of the term used to describe their communication difficulty Participants wanted information about aphasia and stroke for themselves and their family. . . . Having information allowed people to start taking control and to participate in decisions about their own therapy and their own rehabilitation. (p. 314)

Group participation helped the PWAs to understanding that their aphasia can change during the course of recovery. They also learned about other types of aphasia. Learning about aphasia helped the PWAs become self-advocates and assert their own voices in their communities and see themselves as productive and capable individuals. This was evident in Mary’s comments about Mike advocating for aphasia awareness in his community. For Will, self-advocacy was seen in his wanting to “reach out” and seek additional support from aphasia groups and speech therapy.

Learning about their aphasia has helped the PWAs learn to live with their aphasia. Mary states, “I don’t know if people ever accept their aphasia . . . I think they learn how to deal with it.

They understand it better and they learn how to live with it.” Worrall et al. (2010) identified “information” as one goal of people with aphasia. Learning about their aphasia prepares PWAs “to access services and to explain their differences to friends or people in the community. In addition, having information allowed people to start taking control and to participate in decision about their own therapy and their own rehabilitation” (Worrall et al., 2010, p. 314). Knowledge about aphasia gives the PWAs a feeling of autonomy over their aphasia. Legg and Scott reported on an aphasia group that they investigated and stated that participation in the group provided the opportunity to learn about “fellow members’ attitudes, abilities and beliefs. Members appear to use this information to compare themselves to these similar others in order to learn about or assess themselves” (Legg & Scott, 2007, p.798). This study revealed how aphasia group participants were specifically applying the information and communication strategies they learned to situations outside of the group setting. Mike, a “one-man fighting team” uses his aphasia card to self-advocate and teach others about aphasia and how to communicate with someone with aphasia. He has used the card in restaurants, in stores, and in stressful situations which can negatively impact his speech. In addition, Travis took steps to help others learn about aphasia when he offered to speak to new stroke patients at a hospital. These participants in my study shared in their own words how they have demonstrated autonomy and the desire to “explain their differences” outside of the group setting (Worrall et al., 2010, p. 314).

The PWAs’ future goals are evidence of how group participation has helped them to learn to live with their aphasia. While all the PWAs expressed some level of acceptance of their communication disorder, the expression of personal goals was a strong reflection of whether a PWA was moving forward in life and learning to live with their aphasia, thus successfully renegotiating their self-identities. Shadden and Agan (2004) reported that “societies value

independence, measure identity in terms of contributions, and reject illness and impairment. By definition, the individual with aphasia no longer fits that social milieu, at least not immediately poststroke” (Shadden & Agan, 2004, p. 174). Successful renegotiation of identity was reflected in the PWAs who acknowledged a new perception of self-identity found in their potential to be productive individuals with contributions to make to society. Those who expressed personal goals were ones who acknowledged the hard work they’ve put into their recovery, the fact that that their lives are different, and still realized their potential. For Travis, that meant working on buying a house. Mike’s goal was to find a job. Will was taking the steps to seek help and improve his speech. These PWAs acknowledged the past, but also realized their future potential and the contributions they can make in their communities.

The themes that the PWAs shared in their narratives were strengthened and enriched by the contributions of their caregivers and speech therapist. The additional perspectives expanded upon the PWAs’ contributions by broadening the experiences with additional perspectives from those who are closely familiar with the PWA. It is however important to acknowledge other factors that may have influenced the themes that emerged from the data, such as age of onset, the time since onset, and where the PWA is in the grieving process poststroke. Martin was the youngest participant in my research and had been living with aphasia the longest. Although Martin expressed a level of acceptance and moving on, his dialog and self-identity remained tethered in the past, frequently repeating the phrase, “I was.” Martin talked about his life pre-stroke life at greater length than other volunteers, suggesting a strong attachment to his previous life and who he was. Although he commented on his feelings acceptance, being an advocate, and travel goals, his perceptions of this aphasia were greatly tethered to how he saw himself before his stroke. According to Worrall et al. (2010), “Younger people with aphasia were particularly

aware of the loss of work and career and often held deep, strong desires to return to some employment” (Worrall et al., 2011, p. 315). Martin strongly associated his identity with his pre-stroke work status, punctuating his narrative with descriptions of how he used to be. His level of acceptance of his circumstances combined with his stronghold on the past suggests that group participation can affect change in a person’s attitude of their aphasia, but perceptions about one’s aphasia can also be strongly influenced by the time of onset and the years post stroke. It is important to note that Martin has been living with aphasia the longest and was the youngest of the volunteers. The age of onset time post stroke are factors that shaped Martin’s perceptions of his aphasia. Therefore, further discussion on how people handle and process their experience of strokes, and subsequently view their communication abilities according to the age of onset and time post stroke is warranted.

The participants in this study all benefited from group participation and some shared personal experiences of how they have demonstrated their feelings of self-acceptance and advocacy outside of the group setting. Although PWAs who did not have experience in group settings or who were no longer involved in group settings were not included in this study, the discourse of aphasia group participation would benefit from interviews with this group of PWAs. This study included two participants who specifically demonstrated advocacy outside of the groups setting. Both Travis and Mike demonstrated their desire to advocate outside of the group and discussed how the groups prepared them to place themselves in the public eye by helping them feel a level of self-acceptance, by providing information about aphasia, and by helping them recognize the contributions they can make. The specific link between group participation and advocacy merits further exploration. Further study could also include those who do not participate in aphasia groups and whether they use strategies to self advocate.

This research contributes to the study of aphasia groups and how they change a PWA's perception by exploring additional viewpoints from the caregivers and speech therapists. To further the discussion, perspectives from multiple members of a family should be explored. In this study, the PWAs' interviews were corroborated by the contributions of their caregivers, who were all family members, with the exception of Travis who did not give consent to interview a caregiver, and their speech therapists who worked with them in either a group setting or in individual therapy. The PWAs' caregivers contributed valuable information about the PWA's experience as well as his or her own. Not only are family members witness to the events of the PWA's rehabilitation, they understand the PWA best, whether communicative understanding, or how the PWA is processing an experience. "Spouses, [and] significant others may be useful in planning and then assessing the efficacy of treatment" (Wallace, 1996, p. 288). Though this research focused on what the caregivers perceptions were of how participation in an aphasia group influenced their loved one's perception of aphasia, their narratives revealed topics that merit exploration, such as: narratives by families processing the experience of rehabilitation, how family dynamics change when a person has a stroke, family members' attitudes about disabilities, and how having a family member as caregiver influences motivation and the rehabilitation process. Wallace (1996) wrote, "The scope of a speech-language pathologist's practice is further broadened when the educational and emotional counseling needs of family members are considered. How well those needs are addressed is a vital consideration in assessing the efficacy of aphasia treatment" (Wallace, 1996, p.288). Thus, the caregivers/family members can offer insight into ways aphasia groups can better serve their communities and augment aphasia treatment.

Chapter 6: Conclusion

This research sheds light on how participation in aphasia groups can affect change in how a PWA perceives his or her aphasia, making it possible for a person with aphasia to learn to live with their communication disorder. The feeling of belonging that the participants gained from participating in aphasia groups helped them realize that they are not alone. In the aphasia groups, they share a common experience with others and they are no longer ignored or avoided by typical speakers. Aphasia education has helped the PWAs advocate for themselves while understanding their own symptoms and learning about other types of aphasia. Acceptance and education have helped the PWAs realize their own potential and set goals accordingly. Understanding how and why group participation can affect changes in perceptions of aphasia can help us understand the recovery process and the elements that help PWAs learn to live with their aphasia.

One limitation to this study is that all the participants shared common traits: they were male, able to successfully communicate their narratives themselves without the use of augmentative technology or caregivers to answer for them, they were all living independently, and were ambulatory. Narratives from female stroke survivors who participate in aphasia groups would enrich the data and merit further inquiry. For PWAs who rely on alternative means of communication and/or are managing a greater range and severity of physical limitations, their experiences with stroke and group participation could potentially reveal different themes or an intensity of a theme that was not expressed by the participants in this study. In addition, varying degrees of ability, side effects of medications, and emotional well-being can affect on how each volunteer perceived his own abilities. Concomitant medical conditions of the participants were unknown, as it was not explored as an excluding criteria to participate in this study. Several

PWAs voluntarily mentioned medical treatment for depression as a part of their recovery, but the topic of depression was not elaborated, nor was it explored as a possible catalyst for any underlying attitudes or feelings. In addition, the age of onset and years post-stroke are two influencing factors in a PWAs' attitudes about self and self-identity. These influential factors merit further exploration. While the narratives do not represent all males with aphasia who participate in a aphasia groups, nor do their experiences in group participation speak for all aphasia groups, self-narratives provide valuable data, in the form of their insights, as to how they process their experience of stroke; therefore, data extracted from their interviews is vital in exploring the "how" and "why" participation in aphasia groups influences perceptions of aphasia. Additional perspectives from the caregivers and SLPs formed a cohesive interpretation data and further enhanced the understanding of how the PWA processed his experience.

However, within the parameters of this research, the themes that emerged from the interviews support the influence that group participation can have on how one perceives his aphasia and learns to live and manage the communication disorder. Their attitudes are reflected in their ability express a level of self-acceptance and acceptance of their circumstances, resulting from the feeling of acceptance found in group participation. The themes align with findings by Worrall et al. (2010), who identified nine goal categories including: communication, information, and control and independence. In addition, the PWAs have learned about their aphasia and have become better equipped to self-advocate, whether through actually tools like the aphasia cards, or through knowledge about the varying signs and symptoms of aphasia.

Participation in an aphasia group can play an important role in the recovery process after a stroke. Stroke survivors are faced with a rehabilitation process without guarantees of a return of skills or improvement of skills and some must redefine their self identities and self-perceptions

due to the consequences of stroke as their lives are no longer what they were before the stroke. Participation in an aphasia group can augment their recovery by helping them learn to live with and manage their aphasia. Legg and Scott (2007) stated, “People with communication difficulties after stroke have a valuable contribution to make” (Legg & Scott, 2007, p. 803). In addition, by volunteering to participate in this research, the PWAs fulfilled the goal of “altruism and contribution to society” as identified by Worrall et al. (2011):

A few people spoke of goals related to improving the lives of others, including other people with aphasia Some participants devoted time to helping speech pathology students by being available for clinical placements, some volunteered in groups, and some wanted to increase people’s awareness of aphasia. (p. 315)

Not only did the participants make valuable contributions through the information gathered from their interviews, their decision to volunteer for this study affirms their desire to teach and advocate outside of the group setting. While individual therapy results in greater gains (Goldfarb & Pietro, 2004) group participation can offer emotional and social re-engagement support that can be applied outside of the group setting as well.

Although each narrative is uniquely that of the participant, cumulatively the narratives offer information that speech language pathologists can apply to how groups are facilitated. As speech language pathologists, we can encourage the expression of self narratives in group settings to help promote the feeling of community and acceptance, the self-confidence and knowledge to self-advocate, and the support and validation to set and take steps toward goals. “I think [participation in groups has] helped them to achieve more control of their self-image and their life in general,” summarizes Dan. Even though levels of acceptance of aphasia will vary, participation in aphasia groups can help prepare and equip stroke survivors to live with their

aphasia. Further study of how age of onset affects perceptions could influence aphasia groups structured for a specific demographic of stroke survivors. In addition, what we learn from the family members and caregivers can help inform and shape how aphasia groups serve their communities. Dan states, “[Caregivers] have a lot to learn . . . They are about as isolated as the person with aphasia is in regards to how to cope with aphasia.” As SLPs we can encourage the narrative experience from both the PWA and the caregiver, and recognize and promote the value of aphasia groups by encouraging participation in aphasia group settings, referring clients to available groups, and promoting volunteerism of SLP students in aphasia groups to gain experience in how groups benefit people with aphasia.

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