EXPERIENCES AND PERSPECTIVES OF PEOPLE WITH APHASIA WHO ENGAGE IN DISABILITY ACTIVISM

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ABSTRACT

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Acquired neurogenic communication disorders like aphasia have a marked deleterious effect on people with aphasia's (PWA) sense of identity. Consequently, there is an increasing research focus on the ways in which PWA develop a positive and healthy sense of self. At present, there are few studies examining how involvement in activism may mitigate the negative identity-related impacts of aphasia. The purpose of the current investigation was to examine the viewpoints of PWA who engage in activism to better understand how activism might have helped them do the identity work that is often associated with lifelong, adult-onset disability. Moreover, I sought to better understand their views on aphasia, social support, and the current rehabilitation system. I interviewed seven PWA who engage in activism related to aphasia using a semi-structured format. Following the interviews, I transcribed the interviews and analyzed the data by creating themes based on common themes mentioned by the participants.

The participants revealed that they experienced a variety of barriers to their activism efforts. They further stated that their work often focuses on working with and educating other PWA, though education of the public was also a common goal among the participants. The activists displayed complex but generally positive attitudes toward their aphasia and experienced personal benefits from their activism work. Though the level of social support varied across participants, all interviewees cited this factor as an important driver of recovery. The majority of the participants did not view the current rehabilitation system as being client-focused. Related specifically to dealing with the identity-related aspects of living with aphasia, the participants indicated that activism played a role in helping them create new purpose and meaning after their brain injury, motivated them to maintain or form new social circles, and enabled them to develop a position of equanimity regarding their aphasia.

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INTRODUCTION

Aphasia is a communication disorder that can affect an individual's abilities to speak, read, write, and understand language. Often, following the onset of aphasia, individuals experience a loss of identity. Involvement in activism, defined for this study as working to create a positive change, is one way that people with aphasia (PWA) can create a positive outcome and productive life. This research will examine whether activism is effective in helping PWA develop a positive outcome, as well as exploring the PWAs' social support, barriers that they have faced related to activism, their thoughts on the current rehabilitation system, the personal benefits to activism, and their attitudes toward aphasia, public education, and working with and educating other PWA.

CHAPTER 1: BACKGROUND

Aphasia

Aphasia is an acquired communication disorder most commonly caused by a stroke, though other etiologies include tumors, infections, and traumatic brain injuries (National Aphasia Association, 2016). In the U.S., 180,000 people are diagnosed with aphasia each year, while the prevalence of individuals in the U.S. currently living with aphasia is estimated to be 2.4 million people (National Aphasia Association, 2016; Simmons-Mackie, 2018). Aphasia can affect an individual's ability to produce and/or comprehend speech, read, and write (National Aphasia Association, 2016). Each individual's abilities differ because there are many different types and severities of aphasia.

Challenges of Living with Aphasia

Accessibility and Participation. People with aphasia often face barriers related to accessibility. Due to a lack of public knowledge about aphasia, negative attitudes, or communication difficulties, people with aphasia often struggle to access mainstream policies, systems, and services (Howe et al., 2008a, b). Other barriers reported by Howe, Worrall, and Hickson (2008a, b) include inaccessible written information, forms, and signs, a lack of social opportunities, and systems that require verbal communication. In addition to preventing PWA from accessing the services, these barriers in the community likely lead to further isolation and feelings of incompetency among PWA.

This lack of accessibility leads to a lack of participation. PWA report that they often are unable to participate in activities that they previously engaged in due to barriers created by services, policies, and procedures (Howe et al., 2008a). Specifically, individuals who were interviewed cited barriers formed by policies, such as only allowing bank tellers five minutes with each customer, and procedures, such as speaking to a recording on the telephone. These barriers prevent PWA from participating in activities related to daily living.

Related specifically to accessing services, after being discharged from the hospital, PWA often request continuing services to improve their communication; however, additional therapy may not be available (O’Callaghan et al., 2009). Additionally, both individuals with aphasia and their caregivers reported that information and resources were “somewhat difficult” to find across the nation (Hinckley et al., 2013).

Rehabilitation System. PWA report that they highly value the therapy that they receive, as well as, their relationship with their clinician (Parr et al., 1997). However, when examining PWA’s views of the rehabilitation system more specifically, PWA report that therapy ending is often viewed as negative and demoralizing (Lyon, 1996). Having a negative discharge experience may have a long-term negative effect on the individual’ identity because the PWA may feel incompetent or that their language problem was not “fixed” (Hersh, 2009; Shaddon, 2005). Further, Hersh (2009) reported that patients also felt uncertain and confused about their discharge as they were not always sure why therapy ended but they did not feel comfortable explaining their concerns or questioning the therapist. For this reason, Hersh calls for a therapeutic relationship founded on mutual respect which would encourage the clients to be actively involved in the therapy planning and discharge decision.

Work. An onset of aphasia may prevent an individual from returning to work. Approximately 50% of individuals with aphasia between the ages 18 and 65 years of age are unable to return to work following a diagnosis of aphasia (Graham et al., 2011; Tanaka et al., 2014). Additionally, PWA between 15 and 49 years of age demonstrate lower levels of employment when compared to adults of the same age who do not have aphasia (Naess et al., 2009). Research related to casual factors is limited; however, other comorbidities (e.g., cognitive dysfunction, visual neglect), the type of job, and working conditions seem to be important factors related to the PWA's ability to return to work (Graham et al., 2011; Hofgren et al., 2007). When PWA are able to return to work, it is often at a different level or to a job with less demanding tasks (Dalemans et al., 2008). PWAs' ability to return to work is an important factor to consider as an inability to work is a main predictor of health-related quality of life (Hilari et al., 2012). Participants discussed a positive view of their aphasia and levels of social support which may be another reason that they experienced a positive outcome (Hilari et al., 2012).

Activities. There are several types of activities that adults are involved in. Domestic life activities include tasks such as cleaning, shopping, preparing meals, and doing laundry. Following the onset of aphasia, PWA demonstrate a decrease in their participation in domestic activities (Dalemans et al., 2008). Additionally, when examining individuals more than one year after their stroke, one in five PWA need assistance with activities of daily living (ADLs) (Hofgren et al., 2007). ADLs are defined as essential self-care activities, such as bathing, dressing, and feeding (Spector et al., 1987). While leisure activities form an important part of an individual's life, research examining this area related to individuals with aphasia is limited (Dalemans et al., 2008). Examples of leisure activities are talking to friends, bicycling, painting, and dining out. One study examined leisure and education activities of PWA compared to adults of the same age without aphasia and found that PWA most commonly engaged in activities such as watching television and joining therapy groups while adults without aphasia were more likely to talk about activities with friends or attend adult education courses (Davidson et al., 2008). Relatedly, PWA cite experiencing a loss of shared activities as one reason that they lose their friends after aphasia onset (Hilari et al., 2012). Following the onset of their aphasia, the quality and frequency of leisure activities change.

Social Effects. PWA typically reported that their social network shrunk and they had less contact or no contact with their friends following the onset of their aphasia (Howe, 2017). When compared to people without aphasia, PWA participated in significantly fewer social activities (Howe, 2017). Cruice, Worrall, and Hickson (2006) found that PWA who were 12-months post-stroke had fewer social contacts overall, as well as fewer social contacts that they wrote to or called. Further, these PWA were less satisfied with the activities that they participated in and more than 50% reported that they wanted to do more. This effect on social life is important because Howe (2017) found that decreased social networking and poor social support were factors in predicting poor quality of life-related to health for PWA. Further, individuals with aphasia reported that social support is a vital factor for successfully living with aphasia (Hinckley, 2006).

Psychological Effects. Aphasia often results in a large, sudden change in an individual's ability to complete leisure activities, occupation, family activities, activities of daily living, and cognitive tasks (Code & Herrmann, 2003). These changes bring about a variety of emotions for PWA, including anxiety, depression, paranoia, mania, delirium, and apathy (Code & Herrmann, 2003). Specifically, 19.44% of PWA have depression and 22.22% of PWA exhibited subthreshold depression (Ashaie et al., 2019). Subthreshold depression is defined as an in-between stage of having no depression and major depressive disorder and can lead to major depression if not treated. These emotional factors are important to consider because emotional state affects motivation, physical performance, and cognitive and language processing (Code &

Herrmann, 2003). Additionally, the same research shows that mood likely greatly affects an individual's recovery.

Psychosocial Effects. Aphasia does not impact intelligence, ability to make decisions, or general competence (National Aphasia Association, 2016). However, aphasia has a profound impact on the psychosocial dimensions of functioning, self-esteem, and the stroke survivors' sense of self (Shadden, 2005). PWA often report that having aphasia leads to grief, a sense of loss of their old selves, and a struggle to make sense of or find meaning in the sudden and life-changing accident which caused their aphasia (Code & Herrmann, 2003). These changes may occur because language and identity are intertwined (Shadden, 2005).

Effect on Family. When an individual is diagnosed with aphasia, there can be a large effect on the entire family. Spouses of PWA report that they experience changes in their marital relationship, increased responsibilities, and difficulties communicating with the PWA (Michallet et al., 2003). Additionally, when examining both spouses and other family members of PWA, 85% reported negative changes to their physical, mental, and emotional health following the onset of aphasia (Grawburg et al., 2019). Additionally, these family members reported feelings of depression, stress, sadness, and grief. Based on this information, aphasia has great effects on both the PWA and their family members.

Identity. Identity is an individual's sense of self and understanding of who they are related to their defining characteristics, relationships, and place in the world (Taylor, 1994). An individual's identity is created and monitored through social interaction, meaning that individuals with aphasia are vulnerable to a loss or change of identity (Shadden, 2005; Wertsch, 1991). Conversation provides PWA with an opportunity to identify who they are; however, failed social attempts are associated with inadequacy and a depreciation of self-worth (Shadden, 2005). Identity, specifically maintaining status as a competent individual, is also linked to quality of life; thus, a loss of identity is likely to result in decreased quality of life (Shadden, 2005). To overcome these challenges, PWA must make meaning of their new life while finding ways to be competent and empowered (Shadden, 2005). PWA report that to be successful, they must accept that they are a new person with a new life as a result of their aphasia (Hinckley, 2006). The process typically takes a year or more and likely involves a period of crisis in which PWA contemplate their desires and life purpose (Hinckley, 2006).

Activism

Activism refers to the efforts made by individuals seeking to make a positive change in society through social, political, or problem-solving behaviors (Corning & Myers, 2002). Identifying as an activist may be a fairly stable state even if the actions of the activist often change. One focus of disability activists over the past few decades has been the development and promotion of the social model of disability (Sabatello & Schulz, 2014).

Social Model of Disability. The social model of disability was developed by disabled people in response to the medical model of disability. The medical model views disability as a discrete category based on biomedical, scientific, and genetic causes (Sabatello & Schulz, 2014). Those who subscribe to the medical model view disability as something that should be corrected or cured and tend to focus on the inabilities of the disabled person, comparing them to an expected level of health (Sabatello & Schulz, 2014).

Often, disabled individuals are not visible in society due to barriers, such as lower employment rates, inaccessible transportation, stigma and discrimination, and lack of access to information (World Health Organization and World Bank, 2011). Disabled people are more likely to experience these barriers if they are women, older in age, and live in rural areas. These barriers create significant difficulties for disabled people related to their daily lives and affect their social and emotional wellbeing (Singleton & Darcy, 2013; World Health Organization, 1980).

In response to the medical model, disabled people created the social model. In North America, the social model of disability uses language that is similar to that used by minority groups and civil rights activists (Hahn, 1988). The Union of the Physically Impaired Against Segregation and Disability Alliance described the social model of disability as follows:

> "In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society." (1976)

This model separates impairment from disability, defining impairment as the person's health condition or disease while disability is a restriction or lack of ability to perform an activity (Singleton & Darcy, 2013; World Health Organization, 1980). The social model states that society is the cause of oppression and discrimination related to disabled people, not the individual's impairment (Shakespeare, 2006). Disability activists typically favor the social model of disability over the medical model because they are rejecting the pity associated with the medical model in favor of the empowerment and equality associated with the social model (Kitchin & Wilton, 2003; Low & Chairman, 2001).

Further, the social model of disability assumes that changes to society are the gateway to improving the position of people with disabilities, rather than the person with disabilities needing to be corrected or cured (Shakespeare, 2006). Additional ideas supported by the social model of disability are that disabled people should be leading the movement and lobbying for changes in society (Shakespeare, 2006). This focus has led to the coining of the phrase, “Nothing about us, without us” (Yeo & Moore, 2003). The social model can be integrated into therapy by recognizing the client as knowledgeable, involving them in decisions related to therapy, and ensuring that they have control over aspects of therapy, such as type of therapy, execution of therapy, and evaluation (Byng & Duchan, 2005)

Activism by People with Aphasia. People with aphasia desire dignity and respect, reporting that they are “competent people, despite their communication difficulties” (Worrall et al., 2011). Several of the individuals interviewed in the cited study mentioned altruistic goals related to helping others, including other PWA. Many people with aphasia reach these goals by becoming activists for others who have aphasia, getting involved with aphasia organizations, or writing books. These activists are needed because, as mentioned previously, there is a lack of public knowledge about aphasia, which contributes to the marginalization of PWA (Howe, Worrall, & Hickson, 2008a, b).

Specifically, an international survey revealed that only 13.6% of the general public reported that they had heard of aphasia, while just 5.4% had “basic knowledge” of aphasia (Simmons-Mackie et al., 2002). An updated survey conducted by Flynn, Cumberland, and Marshall (2009), found that public knowledge of aphasia was extremely low. The public’s lack of knowledge negatively affects people with aphasia because they are unable to reintegrate into their community, which can affect day-to-day activities such as grocery shopping and involvement in family or social events (Sheratt, 2011).

Many activists are involved in aphasia organizations that provide an opportunity to communicate with other PWA. The benefits of involvement with these groups include emotional, informational, and practical support from peers, as well as a sense of belonging and purpose, and the chance to help others (Brown et al., 2010, 2011; Legg et al., 2007).

Benefits of Activism. Engaging in activism is associated with increased levels of well-being (Klar & Kasser, 2009). Further, people with disabilities develop a more positive identity when they advocate for themselves because they are accepting themselves as they are, regardless of society's attempts to marginalize them (Gill, 1997). Based on this information about other disability activists, PWA who engage in activism can reasonably be thought of as people who have come to terms with their disability, developed a new sense of identity, and found some sort of meaning—often positive—in their changed circumstances.

Critical Gap

The Life Participation Approach to Aphasia (LPAA) is a prominent framework used to inform the provision of intervention services to people with aphasia (Chapey et al., 2000). One central tenet of the LPAA is that clinicians should orient to issues such as the impact that aphasia has on psychological and social functioning. Based on the data collected on other disability activists by Gill (1997), we believe that PWA who engage in activism can be seen as representing 'the best-case scenario' in terms of dealing with the psychosocial aspects of their disability.

Therefore, it makes sense for researchers to focus on this group because they could teach both researchers and practicing clinicians about the factors that encourage and discourage the development of a new identity. Additionally, the activists will be helpful in better understanding how PWA engage in activism, cope with challenges, experience social support, and view the rehabilitation system. To understand their experience, researchers must use a critical lens and an insider's perspective (Kelley & Betsalel, 2005). While individuals who have survived strokes may integrate and interpret their experiences differently, there is a common bond between stroke survivors, such that the information provided by activists for aphasia may help other individuals cope with their new diagnosis and the changes that aphasia causes (Kelley & Betsalel, 2005).

Objective

The objective of the present study is to examine activists with aphasia who have come to terms and found a way to return to an active life. The information provided by these individuals can be used to inform future practice for speech-language pathologists. I studied how activists for the rights of people disabled by aphasia draw on their experiences when coping with the psychological and social consequences of a communication disability. The research questions guiding this study were:

- How does involvement in activism activities help people with aphasia develop a positive and integrated sense of self after the onset of aphasia?
- How do aphasia activists view the current rehabilitation system?
- What was the participants’ experience of recovery?
- What was the participants’ experience of engaging in activism?
- How did the participants experience social support?

Research Strategy

I used a qualitative design based on an interpretive phenomenological analysis (IPA) to research the experiences of the activists with aphasia. The goal of qualitative research is to use nonnumerical data to understand the experiences, attitudes, and perceptions of a group of people (Creswell, 1994). Studies that use an IPA-based approach seek to interpret how people make sense of the world around them and their lived experiences (Murray & Holmes, 2014). Typically, these studies use a semi-structured interview to examine in detail how individuals describe stressful situations, how they handle these situations, and the meanings that they attach to the situations (Murray & Holmes, 2014; Smith, 1996). For the interviews that I conducted, I developed a series of questions based on my research questions, however, I also asked follow-up questions based on the participants' answers.

The researcher plays an active role in IPA during the interview by asking related follow-up questions and continues to be active during the analysis process by interpreting the participants' messages. While the participants describe and apply meaning to their experiences, the researcher interprets and deduces the information that is shared to make connections (Smith, 1996). Typically, studies that use IPA have a small, homogeneous sample size due to the amount of data collected and the detailed analysis process (Smith, 1996). This allows the researcher to focus on a target population to best understand their experiences.

Several characteristics of IPA were used in this study, such as semi-structured interviews conducted with a small, homogeneous sample and examining the meaning that individuals apply to their situations. However, the approach of this study does not exactly align with the IPA approach because member checking and lamination occurred. Lamination adds an additional layer of interpretation as different analysts (not the person doing the initial coding) review the transcripts and develop their own schema of codes and themes. In member checking, the participants are provided with the results of the study and asked for feedback to ensure that the researcher accurately captured their viewpoints. For this reason, the approach is better named phenomenological thematic analysis.

Interpretative Phenomenological Analysis

Autism Spectrum Disorder. Numerous studies examining autistic individuals have used an IPA approach. Huws and Jones (2010) used an IPA approach to better understand how people with no prior knowledge or experience with autism spectrum disorder conceptualized the condition. In 2015, the same authors used an IPA approach as to better understand how autistic individuals conceptualized having the disorder. Cridland and colleagues (2014) used an IPA approach to better understand the experiences of autistic girls with autism during adolescence. Further, in 2017, Dewinter and colleagues used an IPA approach to explore the sexuality of adolescent autistic boys. Autistic students pursuing higher education were interviewed about their experiences with success by MacLeod and colleagues in 2017. Additionally, Maloret and Scott (2018) examined mental health unit admissions in autistic individuals following an IPA approach.

Dysphagia. In 2014, Nund, Ward et al. used a qualitative design to study the experiences of caregivers for individuals who developed dysphagia as a result of surgery to treat head and neck cancer. LaDonna et al. (2016) used an IPA research design to examine caregivers of individuals with dysphagia as a symptom of their myotonic dystrophy to better understand the impacts and difficulties of dysphagia. In 2017, Moloney and Walshe studied the impact of living with dysphagia following a stroke through the use of autobiographies.

Parkinson's Disease. In 1996, Habermann studied the day-to-day life of middle-aged individuals with Parkinson's Disease. Bramley and Eatough (2005) used an IPA approach to study the social and personal aspects of having Parkinson's Disease. Giles and Miyasaki (2009) studied individuals with Parkinson's and their caregivers during the palliative stage of the individual's Parkinson's Disease. In 2017, Smith and Shaw used an IPA approach to examine the experiences of people with Parkinson's disease and their partners. Shahmoon and colleagues (2019) used an IPA approach to study how life changed for males with Parkinson's disease after deep brain stimulation.

Stuttering. Klompas and Ross (2004) studied the quality of life of adults in South Africa who stutter using semi-structured interviews. In 2011, Trichon and Tetnowski studied the social impact of self-help conferences for people who stutter. Bricker-Katz et al. (2013) used an IPA approach to examine how stuttering affects individuals in the workplace. In 2018, Tichenor and Yaruss using a phenomenological analysis to better understand individual's perceptions of their stutter. Also, in 2018, Douglass and colleagues used a qualitative analysis and open-ended phenomenological interview questions to examine the change that occurs when individuals shift from covert stuttering to overt stuttering.

Aphasia. Brown et al. (2010) used qualitative approaches to better understand lived experiences related to aphasia. The authors used semi-structured interviews to examine how speech-language pathologists describe successfully living with aphasia. In 2012, they studied individuals with aphasia, family members of those with aphasia, and speech-language pathologists. Similarly, in 2017, Lanyon and colleagues used semi-structured interviews and an IPA framework for data analysis when studying PWA engaging in aphasia support groups. The experiences of SLPs working in an acute hospital setting were studied using an IPA approach in 2016 by Foster and colleagues.

CHAPTER 2: METHODS

Participants

The qualifications to participate in this study included being an activist with aphasia who aged 18 years or older and speaking English as their primary language. Activists were identified using Corning and Myers’ (2002) definition of activists: individuals who are seeking to make a positive change in society through social, political, or problem-solving behaviors. For this study, participants engaged in activism by publishing books or producing movies about their experiences with aphasia or by starting aphasia groups or nonprofit organizations.

I found the participants online through websites and groups created by people with aphasia and their families or through social media sites such as Facebook, Twitter, and Instagram. To identify potential participants, I also used lists of individuals who published written pieces about their experiences with aphasia. Following Institutional Review Board approval, I contacted the participants who self-identified as activists for the rights of PWA via publicly available email addresses from social media accounts or via organization or author websites and invited them to participate in the study. For the individuals who agreed to participate, the virtual interviews were scheduled via WebEx; Webex is a HIPAA-compliant video-conferencing platform (Andricks & Smith, 2020). In some cases, technical difficulties or participant preference led to interviews being conducted over the phone.

In total, seven activists with aphasia were interviewed for the study. The participants engaged in a variety of activism activities, including writing books about their experiences with aphasia, producing a movie about their experiences with aphasia, starting aphasia support groups, and starting a nonprofit organization for PWA. The participants ranged in age from 53 to

71. Specific information about each participant is included below. The participants were assigned pseudonyms.

Elise, 64, is a speech-language pathologist who had a stroke in 2007 that resulted in aphasia. She kept a journal throughout her recovery and used the information to write a book about her experiences. Elise also engaged in spoke publicly about her experiences with aphasia at universities, libraries, churches, and other organizations.

Sandra, 57, had a stroke in 1996 that resulted in aphasia. She started a support group for PWA and later a non-profit organization for PWA. The non-profit organization provides resources for PWA and students, hosts support groups for PWA, and publishes a newsletter twice a year containing information and interviews of people related to aphasia and aphasia research.

Ted, 60, is an actor who had a stroke in 2005 that resulted in aphasia. He wrote and produced a movie about his journey with aphasia. Ted engages in public speaking around the world and also speaks to university students about his experiences.

Ron, 69, had a stroke in 2011 that resulted in aphasia. Using a journal that he kept during his recovery, he has written numerous books about his experiences with aphasia. He also has a book for caregivers and medical professionals to educate them about aphasia and aphasia resources. Ron has spoken about his experiences around the county at hospitals, high schools, universities, aphasia groups, book clubs, conferences, and community events.

Judy, 68, is a Classics professor who experienced an accident in 1985 that left her with a traumatic brain injury and aphasia. She kept a journal during her recovery and later wrote a book detailing her experiences. She also speaks to university students and community groups about aphasia.

Stanley, 53, had a stroke in 2015 that resulted in aphasia. After learning that the closest aphasia support group was two hours away from where he lived, Stanley decided to start his own support group. Since then, he has helped start several aphasia support groups while working with his local hospital system.

Ruth, 71, had a stroke in 2005, which resulted in aphasia. Since then, she has started two aphasia support groups that work with local universities. She also has spoken at senior centers, conferences, hospitals, elementary schools, and churches about her experiences with aphasia. During her interview for this study, she was assisted by her husband, **John**. John is heavily involved in Ruth's activism and helped Ruth explain her thoughts and experiences during the interview.

Procedure

Each participant was interviewed one-on-one virtually via WebEx videoconferencing; participants completed the interview in a place of their choosing. After providing informed verbal consent, the participants completed a semi-structured interview consisting of open-ended, nonleading questions that asked about participants' experiences with aphasia and activism (Klompas & Ross; Thompson, 2014). As no other research has examined PWA engaging in activism for aphasia, original interview questions were formulated (Klompas & Ross, 2004). I asked all participants preplanned questions pertaining to aphasia and activism from an interview guide; however, I also asked follow-up questions to elicit more information and explore areas of interest that developed based on the participants' answers (Brown et al., 2010, 2011; Klompas & Ross, 2004; Smith, 1996). The interviews were audio and video recorded with the permission of the participants and transcribed verbatim for analysis (Thompson, 2014).

The interviews took place on WebEx or over the phone. The interviews took no more than 60 minutes to ensure that there was not a large disruption in the participant's schedules and to avoid participant fatigue (Gray et al., 2020). Research shows that virtual interviews do not differ in quality when compared to face-to-face interviews (Cabaroglu et al., 2010; Deakin & Wakefield, 2013). Additionally, participants who complete online interviews have been found to be more open and expressive (Deakin & Wakefield, 2013; Mabragaña et al., 2013).

Interview Guide. I developed an interview guide to elicit detailed answers from the participants. The interview guide included a list of preplanned questions and a list of possible follow-up questions to elicit more information from the participants if needed. The preplanned questions ensured that all interviews elicited information covering the same general areas. However, allowing for follow-up questions provided the interview with flexibility as probes could occur based on each participant's answers (McNamara, 2009).

Supported Conversation for Adults with Aphasia. Supported Conversation for Adults with Aphasia (SCA) is a technique designed to make the PWA feel competent during conversation through the use of strategies employed by the conversation partner (Kagan, 1995). The strategy is composed of two main ideas: acknowledging competence and revealing competence.

In order to acknowledge competence, the communication partner may explicitly state that they are aware that the person with aphasia knows what they are trying to say. Competence may also be acknowledged in more subtle ways; for example, the communication partner will ensure that the conversation is natural and suitable for an adult by using humor, age-appropriate suprasegmental aspects of speech (expressive voice, slow-normal rate of speech, appropriate volume), and verbal and non-verbal (gestures, drawings, writing key-words) supports that they would use in conversation with an adult who did not have aphasia. To reveal competence, the communication partner will confirm throughout the conversation that they understand what the person with aphasia is saying. The communication partner also will incorporate supports to aid the PWA in conveying their message; for example, using yes/no questions, offering answer options, using key-words, written supports, visual resources, or allowing ample time for the person with aphasia to respond.

Before beginning data collection, I completed training on SCA through the Aphasia Institute. Kagan and colleagues (2001) found that SCA resulted in more effective communication during semi-structured interviews. Specifically, the individuals with aphasia provided more information and felt more connected to interviewers who were trained in SCA.

Data Analysis

My thesis advisor and I analyzed the data using NVivo and Microsoft Excel. We used the following framework to analyze the data collected from the participants:

1. We read each transcript separately several times to allow us to become familiar with the data (Bramley & Eatough, 2005; Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Giles & Miyaski, 2009; Habermann, 1996; Huws & Jones, 2010, 2015; Moloney & Walshe, 2017).
2. We coded the data individually using line-by-line open coding (Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Huws & Jones, 2010, 2015; Moloney & Walshe, 2017).
3. When reviewing the line by line coding, we looked for connections between the open codes. If the open codes were related to one another, for example, if they describe different aspects of the same issue, the quotes were united under an axial code (Bricker-

Katz et al., 2013; Huws & Jones, 2010). An axial code is a category label used to arrange open codes.

4. Lamination occurred as both my thesis advisor and I independently coded the data. We met to compare our open and axial codes and attempted to combine them (Biggerstaff & Thompson, 2008; LaDonna et al., 2016; Moloney & Walshe, 2017).
5. We created schemas to identify the major themes that emerged from the data, the ideas within each theme, and the relationship between themes (Bramley & Eatough, 2005; Bricker-Katz et al., 2013; Brown et al., 2010, 2011; Huws & Jones, 2010, 2015).
6. We reviewed the data again to ensure that the schemas accurately represented the data (Bramley & Eatough, 2005; Huws & Jones, 2015).
7. We changed the schemas, as needed (Bramley & Eatough, 2005; Huws & Jones, 2015).
8. We wrote descriptions of each theme to summarize the theme and explain how it relates to the participants (Bramley & Eatough, 2005).
9. We asked the participants to confirm the findings from the analyses in a process referred to as member checking (Bramley & Eatough, 2005; Nund et al., 2014; Trichon & Tetnowski, 2011). All participants were contacted and five of the seven participants provided feedback.
10. Following the completion of lamination and member checking, we revised the schemas based on the feedback we received.
11. After determining the themes from the data, we chose verbatim quotes to support each theme (Bramley & Eatough, 2005; Brown et al., 2010, 2011; LaDonna et al., 2016).

CHAPTER 3: RESULTS

Seven themes emerged from the interviews conducted with the participants. The themes include:

1. Many activists experienced a variety of barriers to their activism efforts.
2. The activists' work often involves working with and educating PWA.
3. Education of the public is often a target in the activists' work.
4. The activists have positive attitudes toward their aphasia.
5. Social support is cited as an important factor in recovery, however, the participants' level of support varied.
6. The current rehabilitation system is not client-focused.
7. The activists experience personal benefits from their activism work.

Figure 1. Themes that Emerged from the Data

Theme 1: Barriers to Activism

Five of the seven participants reported that there were barriers to their activism efforts. These barriers affected the participants' ability to progress toward their goals and help other PWA. Many participants described barriers caused by hospitals. Additionally, several participants described the variety of barriers that occur when starting and maintaining an aphasia group.

Hospitals. Several participants mentioned that hospitals created a barrier throughout their activism experiences because they were not willing to share information or promote the participants' aphasia groups. One participant recalled his and his wife's experience of trying to promote their aphasia support group:

> *"The problem that we found in trying to work with the hospitals is that they felt we were in competition with them. And they really didn't want to give our information out to recent stroke survivors."*
>
> *John*

Another participant, Stanley, reported a similar experience in which the hospitals would not share information about his aphasia group because it had the logo of another local hospital on it:

> *"We have two [hospital systems]. One is [Hospital A] and the other one is [Hospital B] ...and they're competitors. So, one of our people in our meeting, she did the right thing. She said, I went to my doctor for my speech and I gave him a flyer and she was from um [Hospital A]. Well, the flyer in the bottom, it said [Hospital B]. And they said, 'Oh, no, we can't use that.' So, it's a game."*
>
> *Stanley*

Barriers to Running an Aphasia Group. Several participants also expressed specific difficulties related to starting and maintaining an aphasia support group. One participant started a group and invited graduate clinicians from a local university to attend and facilitate the meetings. The group ran into several difficulties related to affording the rent and feasibility for the students:

> *"It was costs, because running the place. It was very tough as far as raising money. And second of all, it was a little rough for the students to leave the campus and come over and then go back and find a parking place and so on."*
>
> *John*

Another participant expressed barriers related to people attending meetings and talks. She stated that transportation or lack of interest could result in poor attendance for groups:

> *"Well I was going to say transportation or a lot of times, people who have aphasia are older, so, they have to have transportation to be able to attend some of these activities that would be helpful and beneficial to them…and….I would say, interest. If you live in a larger community, I think you can get more people to participate in a program, like an aphasia program, but if you're in a smaller community, you might not have as many people attend."*
>
> *Elise*

Not having someone to facilitate the meetings was also stated to be a barrier to maintaining an aphasia group. One participant described the loss of one of the groups he started for this reason:

> *"Her husband got a better job and they had to go to another state. So, when she left, they couldn't find anybody to do the meeting and so they left it alone. So that one's gone."*
>
> *Stanley*

Theme 2: Working with and Educating PWA

The majority of the participants mentioned working with and educating other PWA through their activism work. They were passionate about helping one another, although they do so in different ways through their activism work. Being able to relate to other PWA was an idea that several participants mentioned. Additionally, many participants use their own stories and experiences with aphasia to educate and encourage other PWA.

Relatability. Many of the participants mentioned being able to relate to other PWA. One participant explained that, while their experiences and deficits may be different, PWA can understand each other:

> *"I love to see my friends that have stroke and aphasia. Cause we do fully understand, not fully understanding their deficits per se, but fully understanding how our brain works so*

> *that we can appreciate who we are, even if we can't yet talk or communicate other than body language and other modes of modality of communication."*
>
> *Ron*

Motivation. Several of the participants also expressed that they enjoyed motivating other PWA with their stories and experiences. One participant explained how he uses his experiences with aphasia to encourage others. He stated that he feels PWA are not always informed about the length of time that recovery can take:

> *"This lady, she's on a wheelchair and she had her son with her. And the woman that had the stroke, she couldn't talk that much. And I said, how long have you had your stroke? It was like, three months or something. And so, I went down face to face. And I just told her, I said, you're going to think I didn't have a stroke, but I did and I had aphasia just like you, and you're going to see a lot difference. I said, if I see you, you know, two months from now or a year from now, you watch. And she started crying. You know, it's just I think a lot of times people don't tell that stuff."*
>
> *Stanley*

Another participant shared a similar idea. She explained that she often suggests techniques or strategies that she found helpful during her recovery process. She continues to share that no matter the person's area of deficit, she encourages them to try a variety of activities to facilitate improvement:

> *"I feel that I have a lot to offer to support others because of my experience and sometimes I have some ideas of things that could be helpful; just because of the experience I went through. Some of those techniques that helped me- some of the suggestions that I was given, I've continued to use for other people that have had such situations…Even if you're having a hard time writing, like…hey, try coloring for a while, you know they have all these fancy books and things out now, and, you know, anything that...Whatever your area of difficulty is, you can work on it. You just don't have to say, "I can't do that anymore."*
>
> *Elise*

Theme 3: Public Education

All of the participants discussed some form of public education. Many described the variety of audiences that they have been able to reach through their activism efforts. Others described specific experiences with audiences—such as students and professionals—that they feel have benefitted from learning about aphasia. Another subtheme mentioned by the majority of the participants was the lack of public knowledge about aphasia. Several described negative situations that they have faced because the person they were speaking to did not know about or understand their aphasia. A final subtheme related to public education that was mentioned by the participants was a public figure involved in aphasia activism and why they value her involvement in the journey of aphasia awareness and education.

Range of Audiences. The majority of the participants discussed the range of audiences that they work with through their public education efforts. Many of them speak to a wide variety of audiences. With the help of her husband, one participant described the speaking engagements that she has completed:

> *Ruth: "I talk to in Arizona and Las Vegas, a stroke and aphasia conference.*
> *John: "[Ruth] is participating in both, (university), (university), and even (university) all in regards to speaking to groups. And actually, instead of just reading about aphasia, the students are able to witness someone who has aphasia and what it's really like. We have spoken to senior groups, church groups, senior centers, and stuff like that.*
> *Ruth: "And doctors."*
> *John: "And also, during a neurological weekend, in uh (city) she spoke at (hospital name) ...We even spoke a little bit to elementary schools, teaching kids a little bit about stroke and the signs of stroke."*
>
> *Ruth and John*

Another participant described both the range of audiences and the number of presentations he has given since becoming involved in aphasia activism. He also stated that he has transitioned his speaking to being online amidst COVID-19 to allow him to continue educating people about aphasia:

> *"I speak around the country...I've spoken at that church before, but now mostly online. I teach classes at various hospitals that have their own in-house colleges or SLPs in their world and other allied professionals. 50, 60, a year, presentations and classes for the last five years. So, I'm 400 some presentations now to six [thousand] or 7,000 people in the audience. And then the programs."*

Ron

Similarly, another participant described the variety of audiences that she has spoken to in order to educate the public about her personal experiences with aphasia and the signs that someone is having a stroke:

> *"I'm a member of the [state] Speech and Hearing Association, which is a state speech-pathology association, and I was thinking, maybe I could do a presentation…And I ended up speaking with [a university] …and then I spoke at the library, at my church. One of the other groups I used to belong to had several of what they call women's circles, and I would talk to them about stroke, and really the importance of recognizing stroke with the acronym…FAST."*

Elise

Educating Students. Much of the public speaking that the participants engaged in centered around educating students. One participant described her experiences with speaking annually to nursing students:

> *"I talk to the graduate nursing students every semester and I gave them a piece of perspective and…telling my story, and though it may not affect just one person in the class, that's all I want."*

Sandra

Another participant is involved with speech pathology graduate students at two universities near her. During the interview, she stated that educating students is one of the goals for her activism work. Later, her husband went on to state why they feel educating students is important:

> *"Instead of just reading about aphasia, actually, the people- the students are able to witness someone who has aphasia and what it's really like."*

Ruth and John

Educating Professionals. Many of the participants also spoke about educating professionals. One participant described the response that his wife received from speaking about her experiences to doctors at a hospital:

> *"And also, during a neurological weekend, in uh (city) she spoke at (hospital name) And in fact, the funny thing about this, she got a higher rating than the doctors did because hers was down to earth and the doctors were too technical."*
>
> *John*

One participant was a speech-language pathologist and she spoke about why she feels motivated to educate medical professionals:

> *"I had so many feelings of what it was like to go through, that it would be helpful for other people. Especially people that were maybe starting in the speech pathology profession, to know what it was like. To experience that; it is so humbling, you know? I also wanted people to know how sensitive you are to comments that people can make and really just destroy your self-esteem."*
>
> *Elise*

Lack of Public Knowledge. Nearly all the participants described situations related to the general public not being familiar with aphasia. One participant explained how he views people who know about aphasia as existing in their own world:

> *"The world that we have is still quite, what's the word, bisected into the world of stroke and aphasia and the remaining world, which is, you know, 92, 93% are completely unaware. I just want to say, okay guys, you don't know what I know. You're not damaged like me. We live in this little world. I realized that we have to break out."*
>
> *Ron*

Another participant explained the varying reactions that she received when she began interacting with people who did not know about aphasia. She went on to describe an experience that occurred when she was speaking to students; after sharing her story, she experienced a negative reaction from the students:

> *"When I tried to communicate what I went through, an awful lot of people were so helpful and kind, and, and, you know, in a real intimate kind of way of what I had gone through and really caring and thoughtful and wonderful. Some people, especially undergraduate students, I'm afraid, were quite mean. In that, they said that's bullshit, that never happened. You didn't do that, you didn't go through that. You're exaggerating. It couldn't have been that bad."*
>
> *Judy*

Similarly, other participants described a situation that they encountered in public when a waitress did not have the patience or understand why the participant could not fluently order her food:

> *John: Yes. Yes. I mean, we ran into situations where there was a restaurant in [city] that [Ruth], and I have not been to ever since the lady and she was not a young lady. She was like the hand of the waitresses.*
> *Ruth: And older.*
> *John: Yes, she was, she was manager or whatever she was, uh we were sitting there and [Ruth] was trying to say what she wants and she basically [said] 'well, come on lady. I haven't got all day. Either give me the menu, or I'll come back later.' And we have not been to that restaurant since. About ten years.*
>
> *Ruth and John*

Public Figure in Aphasia Education. More than half of the participants mentioned Gabby Giffords, a U.S. senator who has aphasia. One participant, Sandra, described how she felt about Gifford's activism efforts:

> *"Gabby Giffords. She got shot in point-blank range and she said aphasia at the democratic convention speech…. Yeah, she said it and that's really courageous of her"*
>
> *Sandra*

Other participants also discussed how they have been following Giffords in the news and admire her:

> *John: "Gabby Gifford."*
> *Ruth: "I read the book about her stroke. Yeah, very very go-getter…small speech in a last week at…*
> *John: "Democratic Convention."*
> *Ruth: "Yeah."*
> *John: "She spoke."*
> *Ruth: "Yes small but is very powerful"*
>
> *Ruth and John*

Theme 4: Attitudes toward Aphasia

As discussed previously, there are a variety of emotions that individuals experience following the diagnosis of aphasia, many of which have negative outcomes. However, all of the participants interviewed in this study appeared to have a complex attitude in respect to their aphasia. While several discussed challenges that they continue to experience years after their initial diagnosis, they still view their aphasia in a positive light. All of the participants also discussed the acceptance of their aphasia and the changes to their lives that it has caused. Further, many also mentioned a continued focus on trying to improve.

Accepting Changed Reality. All the participants mentioned acceptance of their new changed lives. One participant described the steps that he experienced to accept his new reality:

> *"Four things. first, mourn…mourn because old [Ted] is dead. Second is…is what it is…I can't fix it, but I'm trying to fix every day. And, best I can…Third is…hope…hope is everything. And Finding purpose...I need purpose And, sometimes, I'm through, I'm through, I'm done. But, another day, and OK…again, try."*
>
> *Ted*

Another participant described how she has made peace with her new changed life:

> *"I never would have asked for this, never have anyone asked for this. This is not a good thing. This is not something you want to have happened to you, but your appreciation of life grows enormously... it's a level of appreciation of survival and being alive and having gone through this horrible experience and come out of it quite well. Uh, as I say, I never would have asked for it, but I really love that result. Every now and then something pretty bad happens. And my husband or my son or friends or whatever, say how can you have a smile on your face? And I said, well, you almost die. And you spent months staring at the fucking ceiling. Guess what? This isn't so bad. You know, you really come to appreciate life unbelievably."*
>
> *Judy*

Perseverance. The majority of the participants mentioned that they continue to work to improve, even years after their stroke. One participant described how he disagrees with his doctor's previous predictions about improvement:

> *"They used to say years back, you had about a year and you're going to be where you're at. And obviously, we know that's not true. It's been six years. And every day I get something different, every day for another word."*
>
> *Stanley*

Similarly, another participant described how after regaining the ability to read, she continued to struggle with tracking the text. She was motivated to improve so she challenged herself to become involved in activities that used this deficit. She also discussed the challenge of managing her new hobbies with work and how she continues to try to challenge herself today:

> *"I had a hard time kind of following from one line to the next line and to the next, for, you know like singing and things like that. So, I decided that I was going to try to be [the] liturgist at our church. So I would have to go through and read the uh…the whatever it is, the scripture of that particular day, and so I set a goal for me for doing that, and I still try to do that, and I ended up joining the choir because I always liked music, and I thought, "Can I do all these things and work too?" and, you know, still kept trying to do a little more and a little more and challenge myself in different ways… I still believe in being a lifelong learner, and trying to challenge myself."*
>
> *Elise*

Continued Challenges. Many of the participants still consider themselves to be recovering from aphasia and revealed some aspect of their day-to-day life that still poses a challenge. One participant described how her reading habits have changed with the onset of her aphasia:

> *"I absolutely love reading but what I've noticed lately over the last couple of years, that when I pick up a complicated book where the English is kind of highbrow I'll say, I don't last. I don't make it to the end of the book. So, I start the book. And at some point, I kind of lose interest. It's just more trouble than it's worth. That's not true if I'm reading a young adult book, for example, where the type is maybe a little bit larger or the words are a little bit simpler, I'll make it through to the very end. No problem."*
>
> *Judy*

Theme 5: Social Support

It is well known that social support for PWA is an important factor for recovery. All of the participants described the social support that they experienced following the onset of their aphasia. Support from family was a theme mentioned by all. Many described the support from their friends and community, although the participants' experiences varied. Similarly, the majority of the participants mentioned work, specifically whether or not they were able to return to work and how this affected them. Finally, several participants discussed strategies used during social interactions to support communication. Some described strategies that they use themselves while others explained strategies that are beneficial for people to use when communicating with PWA.

Family. Support from family was a strong theme that all participants mentioned. All of the participants stated that they felt supported by their families. One participant described the many ways that his siblings and son helped support him following his stroke:

> *"Oh, [social support] helps a lot. It's amazing. I've got, we had five or four brothers and a sister. One of my brothers passed away years back. But anyway, so we got four of us and with my stroke...every one of them came to my house. [my brother] was almost a month in my house and he did all my bills and figured out what's going on with where I'm at and all that kind of stuff. And he's the one who found I went to (Name of university) for that research there, and he found out how to do my phone so I could speak on my phone and do texts that way. But everybody helped, even my kid. He was at that time, I think, seven, he would do a test with me, have words, and I try to say, and he's even given me a grade like A, B, or C or whatever."*
>
> *Stanley*

Another participant described how he felt supported by his family but also revealed the difficulties that his wife faced while supporting him:

> *"My wife, my rock. But sometimes, hard to say what I feel or hard to figure out dinner...But starting again almost. [my wife] said, three children, now fourth"*
>
> *Ted*

Friends and Community. Support from the participants' friends and the community was another theme that was mentioned by all the participants. One participant described how she felt supported by her community:

> *"I have had a tremendous amount of social [support], and all those people, actually came and visited me, and also a lot of people from my church, and, so I was very fortunate, I had a lot of support, I kinda kept my, what do you call it my spirits up, so to speak. So, that was very helpful."*
>
> *Elise*

Another participant discussed the support that he experienced from friends, neighbors, and the members of his church:

> *"I'm really lucky because friends help me. Still help me. Lots of friends, and [my wife's] friends too, help too. Neighborhood, church, and…six months no cooking. And, every day, something different. But eat lots of food…Lots…really good support."*
>
> *Ted*

While many participants experienced high levels of support, not all the participants felt supported by their friends. One participant expressed how his friends did not seem to know what to do when he had his stroke:

> *"When they have a friend that's had a stroke and they don't know anything about stroke anyway, they don't really want to see you. So, one person came. One and brought soup. But the rest of the folks, when I finally get to see them, they were somewhat frightened."*
>
> *Ron*

Work. Many of the participants discussed how their aphasia changed their work situation. Several were unable to return to work. One participant described how she made the difficult decision not to return to work:

> *"I wanted to return to work, but I had to choose disability, and that was hard for me."*
>
> *Sandra*

While another participant discussed how she was able to return to work and felt supported by her colleagues:

> *"I work at a school where all the faculty are psychology professors, so I get a lot of help and understanding in just about everything I go through."*
>
> *Judy*

Strategies for Communication. Strategies to support communication were mentioned by several participants in different ways. Often, in speech therapy, PWA are taught strategies to help them communicate with others. These strategies encourage the person with aphasia to be an active participant in social situations. One participant discussed a strategy that he uses when he is communicating:

> *"Let's say a word that I can get, if I can't say computer or something like that, I'll say, P.C."*
>
> *Stanley*

There also are strategies that people without aphasia can be taught to communicate more effectively with PWA in social situations. Another participant described strategies that she recommends individuals use when communicating with PWA:

> *"Pause, let the person have time to speak, give them eye contact, let them know that you're attending. Not talking to someone really loud after they've had a stroke because you don't need to just suddenly assume that they can't hear anymore. Giving people that pause and that wait time as they try and find the words they're trying to say, and suggesting, is there another word for it?"*
>
> *Elise*

Theme 6: Current Rehabilitation System

Having all received therapy following their stroke and diagnosis with aphasia, the participants' views of the current rehabilitation system were discussed by many. The majority of the participants expressed that they did not feel the current rehabilitation system is client-focused. They expressed how insurance controlled their therapy schedule, how satisfied they were with therapy, and their views on healthcare professionals. The participants' views varied on each topic as some were happier than others.

Insurance. The majority of the participants discussed insurance affecting their therapy. One participant described how much therapy she received and how it was vital for her continued improvement:

> *"I was very fortunate being in the teachers, because we had good benefits, and it got really bad because of the people I was introduced to…the one lady had probably more severe aphasia than me and dysphagia, she was being discharged, you know, and I was able to remain in an inpatient setting with PT, OT, and speech until I was discharged, and then I still qualified for outpatient home therapy, and then outpatient therapy afterwards, and I think that was really crucial for my improvement."*
>
> *Elise*

Most participants were not able to receive as much therapy as they would have liked. Another participant explained how insurance controlled his therapy schedule and ultimately resulted in his decision to stop receiving therapy because treatment would no longer be covered:

> *"I think speech therapy was, I want to say eight months, but we had to spread it out because your insurance, you only get, how many times you can get. And so, we're going to…think I was doing two days a week. And then when we were getting towards the end, we did once a week. And then towards the end, the speech lady, she was wonderful. She asked me and she said, when you're with your insurance is done, are you going to come back? And I, (Name) was her name. I said…Somehow, I figured out how much they pay every visit and I think it was two-fifty. So, I told (name), I said, you know, that's more than my mortgage, you know, and she got it 100 percent. She said ninety-nine percent when the insurance is gone and nobody's going to pay that So, you know, what I would say is a great um great lobby for that is for aphasia, for stroke, or whatever. You know, if the insurance could give more time for that, that would be wonderful."*
>
> *Stanley*

Satisfaction with Therapy. All the participants mentioned receiving therapy and most felt that therapy was worthwhile and helped them improve. One participant described how she felt about her hospital and therapy experiences:

> *"I had great care from the therapists, social workers, aides, nurses, and doctors!"*
>
> *Sandra*

However, another participant did not like speech therapy. She described how she did not think that speech therapy met her wants and needs as a person with aphasia. She felt that she benefitted more from situations in the real-world:

> *"The speech therapy is room with a desk. I want to talk to people, one and one. I am tired for speech therapy is not for me. But every day on your mind and reading, writing, and talk to people."*
>
> *Ruth*

Healthcare Professionals. Several participants expressed thoughts and feelings toward healthcare professionals. One participant expressed his feelings on the limited experiences and education of speech-language pathologists:

> *"The education of SLPs are still limited to the classes you take, your peers, and the few teachers you talk to...It's a small world."*
>
> *Ron*

Another participant described a negative experience that she had with a speech-language pathologist:

> *"Yeah, there were some things that happened that made me feel not very supported. One of them was a provider in our profession. She was a very young, probably a fairly recent grad, and she had told me at one point, not to expect that I would probably go back to work in the same position, I was very very devastated, and I just cried and cried and cried. I can remember making lots of mistakes too, and so I don't hold any type of a grudge, but nonetheless, at that time you're very very fragile; and I wasn't ready to hear that. Some people did make me feel like I was not capable, and, that's just kind of hard on your self-esteem."*
>
> *Elise*

While several participants expressed negative feelings toward healthcare professionals, others reported being satisfied with their care:

> *"I had great care from the therapists, social workers, aides, nurses, and doctors!"*
>
> *Sandra*

Theme 7: Personal Benefits of Activism

Many of the participants discussed some personal benefits that they get from their activism efforts; however, there were a variety of benefits. Some felt that their involvement in activism provided them with a sense of purpose. Others felt that the work they did through activism helped improve areas of difficulty caused by aphasia.

Sense of Purpose. Some of the participants expressed that being involved in activism has provided them with a sense of purpose. Many have turned aphasia activism into their full-time job. One participant described her motivation for engaging in aphasia activism:

> *"I knew I had to do something to help people like me cope with things and make them feel like they get a new normal."*
>
> *Sandra*

Improvements. Several participants also discussed how engaging in aphasia activism resulted in improvements related to their aphasia. One participant described how keeping track of her recovery for her book helped her be aware of her progress:

> *"When I started doing the recordings, and then once I could write, writing down, keeping a journal, it made a huge difference that I could actually see and I could go back and read what I had written a week ago and look how much better I can write now. Not only is my vocabulary larger, but the grammar of the sentences is actually readable and understandable and things like that. So, it made a big difference to me to be able to have proof that I getting better."*
>
> *Judy*

Another participant discussed how he was motivated to improve in order to become involved in aphasia activism efforts:

> *"This is the big question. How can I get better?... It's how do I get better so that I can tell the rest of the world how we all learn and as I get better, again, each step, really a step towards improvement and a step towards realizing I can help more than just me... I'm motivated to help all those other people inside the bubble and outside the bubble to help them get better."*
>
> *Ron*

CHAPTER 4: DISCUSSION

The purpose of this study was to examine how being involved in activist activities related to aphasia helped PWA integrate their aphasia and create a positive identity. Current literature clearly shows that PWA are at risk of experiencing a loss of identity; however, there is a lack of research related to how PWA can cope with and integrate the changes in their life to find a new purpose after the onset of communication disability (Shadden, 2005; Wertsch, 1991). An estimated 2.4 million people are living with aphasia in the U.S. Thus, a pressing need exists for research that examines how these individuals can create new meaning in their lives as people living with a disability (Simmons-Mackie, 2018). To the best of the primary investigators' knowledge, the present study is the only one that explicitly and squarely focuses on how activism can help PWA create a positive identity. The results of this study can inform future research endeavors in this area. Findings from this and other studies should facilitate the development of rehabilitation programs for PWA that orient to the challenging identity-related crises many of these clients face.

The majority of the participants revealed that they experienced barriers to their activism efforts. Hospital systems created a barrier for several participants as these institutions were unwilling to share information with recent stroke survivors. Several other participants discussed the variety of barriers that they encountered when trying to start and maintain aphasia support groups. These barriers included cost, transportation, interest, and the need for a facilitator.

Similar barriers to effecting positive social change have been described in the literature generated by other disability activists. Authors reported that institutional barriers—such as being ignored, inaccessibility, or being unable to find professionals who understood disability—prevented them from engaging in activism (Choi et al., 2019).

The majority of the participants engaged in activism work that involved working with and educating PWA. Several participants discussed how they could relate to other PWA and enjoy sharing experiences through these activities. Additionally, the participants discussed how they use their experiences with aphasia as motivation for other PWA.

This theme is consistent with findings provided in a number of other studies. When Howe and colleagues (2008a, b) interviewed individuals with aphasia, several mentioned that altruistic goals related to helping others—including other PWA—informed their definition of living successfully with aphasia. In the current study, participants, were achieved these goals by becoming activists for others who have aphasia, getting involvement with aphasia organizations, or producing various forms of aphasia-related media.

When examining involvement in aphasia groups, research shows that the benefits of involvement with these groups include emotional, informational, and practical support from peers, as well as a sense of belonging and purpose, and the chance to help others (Brown et al., 2010, 2011; Legg et al., 2007). While the current participants have started the groups, they likely also experienced the benefits of attending the group and felt a sense of community with other PWA.

The participants discussed the wide variety of audiences that they have educated through their activism efforts. Specific foci of the participants' education efforts included teaching students and professionals about aphasia. Research shows that PWA often struggle to access and understand information about their condition and rehabilitation because healthcare professionals do not meet the needs of PWA (Parr, 2007; Ross et al., 2006; Simmons-Mackie & Damico, 2007). Therefore, the activists' attempts to educate healthcare workers have the potential to increase the quality and appropriateness of services provided to people and families living with aphasia.

Several participants also mentioned the lack of knowledge that the majority of the public has related to aphasia. This idea is strongly supported by the literature. Specifically, on an international survey, 13.6% of the general public reported that they had heard of "aphasia," while 5.4% had "basic knowledge" of aphasia (Simmons-Mackie et al., 2002). An updated survey conducted by Flynn, Cumberland, and Marshall (2009), found that public knowledge of aphasia was "extremely low." Clearly, much more work is needed by activists, clinicians, and others to make the public more aware of aphasia and the need to make public and social spaces more accessible to people with neurogenic communication disorders.

All participants expressed a complex set of attitudes towards aphasia. In general, their position towards living with a communication deficit could be summed up as one of equanimity. They appeared to accept that aphasia had changed their lives. Many communicated that persevering and working hard to recover gave them some control over the impact that aphasia had on their lives. Moreover, some participants spoke about how they viewed some aspects of their disability in a positive light.

While the participants reported that they have positive attitudes toward their aphasia, several expressed that they have continued struggles. This finding aligns with previous research conducted by Brown and colleagues (2012), which states that PWA may develop positive viewpoints of their aphasia and a focus on improvements as being necessary for living successfully with aphasia. This was echoed by the participants in the current study as they used their successes and experiences to motivate others.

While the short-term negative effects of neurogenic communication disorders are documented (Kauhanen, 2000; Shehata, 2015), the long-term psychological impact of aphasia has not been the subject of intense focus in the rehabilitation literature. At this juncture, it is not possible to predict or explain why some people—such as those interviewed for this study—appear to adjust relatively well to the life-altering changes associated with the onset of aphasia while others develop long-lasting depression and other psychological difficulties. One thing that all the participants we interviewed have in common is their participation in activism. Thus, we might tentatively suggest that there may be a connection between engaging in work of this kind and developing a more positive outlook on aphasia. Future research that examines the interplay between this variable and others (e.g., personality, access to resources, demographic factors) will help clinicians understand how clients navigate the process of living with a communication disability and furnish insights relevant to the life-participation-focused intervention.

All of the participants described how social support promoted their recovery from aphasia. Family support was specifically mentioned by all participants. Several participants were also supported by their friends and communities, although others were not.

The perspectives offered by the participants align well with findings from the relevant literature. The role that social support from friends and family play in the rehabilitation process has been highlighted as a vital factor for successfully living with aphasia (Brown et al., 2012; Hinckley, 2006). With regards to relationships outside the family, friendship bonds may dissolve if the friend in question has little to no understanding of aphasia. In the current study, Ron attributed the loss of friendships to this cause; he stated that his friends did not want to see him after his stroke because they did not know anything about aphasia.

Some participants stated that they were able to return to work; however, others had to retire early or collect disability. Having a purpose—whether this is associated with paid employment or other kinds of work–following the onset of aphasia is listed as an important factor for living successfully with aphasia (Brown et al., 2012). For participants who were unable to return to their previous jobs, their activism work appeared to fulfill some of the needs usually meet by a full-time occupation. Working to advance the interests of PWA appeared to provide them with a sense of purpose and aid in the integration of aphasia into their sense of self. Given the difficulties that most PWA face when they attempt to return to employment, activism may provide opportunities for clients with neurogenic injury to engage in purposeful, meaningful activities outside of the home (Graham et al., 2011; Tanaka et al., 2014). The experiences reported by the participants in this study suggest that clinicians might recommend involvement in activism as a substitute for paid employment.

Participants also discussed their view of the current rehabilitation system. The majority of the participants expressed that they did not feel the current rehabilitation system is client-focused. Interviewees offered a variety of opinions on insurance; although some participants were able to receive what they viewed to be enough therapy, most participants stated that insurance funding was not adequate to meet their perceived needs.

The perspectives and experiences detailed by the participants align with findings from a number of recent studies. Although people with aphasia often request continuing services to improve their communication, additional therapy may not be available in all settings (O'Callaghan et al., 2009). When interviewing SLPs working in the U.S. private sector, Richard and colleagues (2000) reported that insurance companies set 58% of the limits on the amount of therapy provided to PWA. 10 of the 11 interviewed SLPs reported that the limits from insurance companies resulted in insufficient aphasia treatment. Despite aphasia being a life-long disorder, funding for services often dries up a few months after the precipitating medical event (Elman, 1998; Hersh, 2009).

Participants communicated varying levels of satisfaction with therapy and healthcare professionals. Most participants felt that therapy helped them a great deal. One felt that she benefitted more from real-world social interactions, rather than non-functional therapeutic activities. Similarly, several participants expressed negative feelings toward healthcare professionals other than SLPs, while others reported that they were satisfied with their care.

One of the key tenets of the evidence-based practice approach to healthcare is that clinicians should orient to client values and perspectives when providing services (Rubin & Bellamy, 2012). The results of Rubin's and Bellamy's study suggest that, at present, the healthcare funding system in the US may make it extremely difficult to provide evidence-based, client-centered interventions. If evidence-based practices are to become more than just a buzzword, clinicians, PWA, and their families need to advocate for funding systems that provide clients with amounts of therapy that better align with PWA's perceptions of their own needs.

A final theme that emerged from the data concerned the personal benefits that the participants attributed to their activism work. Most participants spoke about how their work provides them with a sense of purpose while others reported that their activism work has helped improve their communication abilities. As mentioned previously, having a sense of purpose is vital to living successfully with aphasia (Brown et al., 2012). Although there is no previous research that specifically examines activists with aphasia, previous research has examined activists with other disabilities and found that engaging in activism is associated with increased levels of well-being (Klar & Kasser, 2009). Furthermore, people with disabilities develop a more positive identity when they advocate for themselves because they accept themselves as they are, regardless of society's attempts to marginalize them (Gill, 1997). These benefits are similar to those described by the current study's participants.

Effect of Activism on PWA's Identity

Research shows that after the occurrence of a life-altering neurogenic injury, a person living with aphasia must accept that they are a new person with a new life as a result of their communication disability (Hinckley, 2006). In essence, PWA need to find meaning in their changed circumstances while maintaining a sense of competence and empowerment (Shadden, 2005). When researchers investigate what these abstract concepts mean to PWA by asking them what living successfully with aphasia means, PWA state that several items played a key role in empowering them to live successfully after surviving a stroke or similar event. An understanding of aphasia, working with other PWA to develop a collective identity, changing the perception of themselves, and continuing to set goals have all been foregrounded by PWA (Hinckley, 2006; Parr et al., 1997).

In the current study, participants spoke about many of these elements when discussing their lives as PWA. They described learning about aphasia so they could educate other PWA. The majority of the participants highlighted working with other PWA as a component of their activism. The participants also explored the ways in which they came to accept how aphasia has changed their lives. Many participants discussed a focus on continuing to improve, even years after the onset of aphasia. Overall, the data we gathered in interviews indicates that participants created a new purpose, maintained or formed new social circles, and developed a position of equanimity with respect to their aphasia.

While the exact nature of the relationship between activism work and adaptive psychosocial outcomes in PWA has yet to be considered and elucidated, the resilient people living aphasia who shared their perspectives with us indicated that activism was an important element of their recovery journey. More detailed investigations of how best to include activism-type components in interventions are warranted.

Limitations and Future Directions

The most notable limitation of the present study is that the participants represented a limited number of PWA who have engaged in aphasia-oriented activist activities. The participants engaged in a wide variety of activism activities, and the data collected is only representative of seven individuals' varying experiences with aphasia activism. While client-centered studies such as this one can contribute to our knowledge of disorders such as aphasia, the extent to which the experiences of these seven participants are representative of the experiences of other PWA who are activists is unknown.

Further research should include a larger sample size that is representative of more PWA who engage in aphasia activism. In the current study, I interviewed a fairly homogeneous group of participants (i.e., all PWA with aphasia who engaged in activism). An appropriate sampling strategy such as maximum variation sampling, by which researchers purposefully attempt to study 'extreme' representations of a category of participant (Palinkas et al. 2016), may refine and expand understanding of the role that activism can play in recovery from aphasia. PWA who have attempted to get involved in activism and gave up engaging in these activities after a time, PWA with different severities and types of aphasia, and PWA who are representative of the racial, gender, and socio-economic classes are just some of the PWA that might be sought out for a study that employs a maximum variation sampling strategy. Systematically varying the types of people interviewed in this way will provide a more comprehensive representation of how PWA use activism to integrate their experiences with aphasia to create a positive outcome and new identity.

To the best of the primary researchers' knowledge, there are no other studies that have examined PWA who engage in activism. Future research that examines in more detail how the complex and multi-facetted institution of activism can be a beneficial mechanism in helping PWA find new meaning in their lives after a neurogenic injury and improve the quality of life-participation focused services offered to PWA.

Practical Implications

The results of this study contribute to the limited body of literature surrounding PWA being activists for aphasia-related issues. Additionally, the results of this study provide insight into the types of changes that PWA can make following the onset of their aphasia to cope with their changed life and create a positive new identity. While further research is clearly required, the results of the current study suggest that one way in which clinicians can support the development of an agentive and healthy sense of self in clients with aphasia is to make clients aware of aphasia-related activism opportunities within their communities. A growing body of literature on making spaces and activities accessible to people with aphasia exists (Simmons-Mackie and Damico, 2001; Kagan and LeBlanc, 2002; Worral et al. 2007). SLPs can draw on studies of this kind to help facilitate their clients' participation in activism.

REFERENCES

Andricks, J., & Smith, S. (2020). *5 Steps to Get Started in Telepractice.* Leader Live. https://leader.pubs.asha.org/do/10.1044/5-few-steps-to-get-started-in-telepractice/full/

Ashaie, S. A., Hurwitz, R., & Cherney, L. R. (2019). Depression and subthreshold depression in stroke-related aphasia. *Archives of Physical Medicine and Rehabilitation*, *100*(7), 1294–1299. https://doi.org/10.1016/j.apmr.2019.01.024

Biggerstaff, D. L. & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology 5,* 173–183. https://doi.org/10.1080/14780880802314304

Bramley, N., & Eatough, V. (2005). The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*, *20*(2), 223–235. https://doi.org/10.1080/08870440412331296053

Bricker-Katz, G., Lincoln, M., & Cumming, S. (2013). Stuttering and work life: An interpretative phenomenological analysis. *Journal of Fluency Disorders*, *38*(4), 342–355. https://doi.org/10.1016/j.jfludis.2013.08.001

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snap-shots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, *24*, 1267–1295. https://doi.org/10.1080/02687031003755429

Brown, K., Worrall, L., Davidson, B., & Howe, T. (2011). Exploring speech-language pathologists' perspectives about living successfully with aphasia. *International Journal of Language and Communication Disorders*, *46*, 300–311. https://doi.org/10.3109/13682822.2010.496762

Brown, K., Worrall, L. E., Davidson, B., & Howe, T. (2012). Living successfully with aphasia: A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International Journal of Speech-Language Pathology*, *14*(2), 141–155. https://doi.org/10.3109/17549507.2011.632026

Byng, S., & Duchan, J. F. (2005). Social model philosophies and principles: Their applications to therapies for aphasia. *Aphasiology*, *19*(10–11), 906–922. https://doi.org/10.1080/02687030544000128

Cabaroglu, N., Basaran, S., & Roberts, J. (2010). A comparison between the occurrence of pauses, repetitions and recasts under conditions of face-to-face and computer- mediated communication: A preliminary study. *Turkish Online Journal of Educational Technology, 9*(2), 14-23.

Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons Mackie, N. (2000). Life participation approach to aphasia: A statement of values for the future. *The ASHA Leader, 5*(3), 4–6. https://doi.org/10.1044/leader.FTR.05032000.4

Choi, I., Haslett, D., & Smith, B. (2019). Disabled athlete activism in South Korea: A mixed-method study. *International Journal of Sport and Exercise Psychology*, 1–15. https://doi.org/10.1080/1612197X.2019.1674903

Code, C., & Herrmann, M. (2003). The relevance of emotional and psychosocial factors in aphasia to rehabilitation. *Neuropsychological Rehabilitation, 13*(1–2), 109–132. https://doi.org/10.1080/09602010244000291

Corning, A. F., & Myers, D. J. (2002). Individual orientation toward engagement in social action. *Political Psychology, 23*(4). http://dx.doi.org/10.1111/0162-895X.00304

Creswell, J., W. (1994). Chapter 9: A qualitative procedure. *Research Design: Qualitative & Quantitative Approaches* (pp. 143-172). Sage Publications.

Cridland, E. K., Jones, S. C., Caputi, P., & Magee, C. A. (2014). Being a girl in a boys' world: Investigating the experiences of girls with autism spectrum disorders during adolescence. *Journal of Autism and Developmental Disorders, 44*, 1261–1274. https://doi.org/10.1007/s10803-013-1985-6

Cruice, M., Worrall, L., & Hickson, L. (2006). Quantifying aphasic people's social lives in the context of non-aphasic peers. *Aphasiology*, *20*(12), 1210–1225. https://doi.org/10.1080/02687030600790136

Dalemans, R. J. P., De Witte, L. P., Wade, D. T., & Van den Heuvel, W. J. A. (2008). A description of social participation in working-age persons with aphasia: A review of the literature. *Aphasiology*, *22*(10), 1071–1091. https://doi.org/10.1080/02687030701632179

Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation*, *15*(4), 325–340. https://doi.org/10.1310/tsr1504-325

Deakin, H., & Wakefield, K. (2013). Skype interviewing: Reflections of two Ph.D. researchers. *Qualitative Research, 14*(5), 603–616. https://doi.org/10.1177/1468794113488126

Dewinter, J., Van Parys, H., Vermeiren, R., & van Nieuwenhuizen, C. (2017). Adolescent boys with an autism spectrum disorder and their experience of sexuality: An interpretative phenomenological analysis. *Autism, 21*, 75–82. https://doi.org/10.1177/1362361315627134

Douglass, J. E., Schwab, M., & Alvarado, J. (2018). Covert stuttering: investigation of the paradigm shift from covertly stuttering to overtly stuttering. *American Journal of Speech-*

Language Pathology, *27*(3S), 1235–1243. https://doi.org/10.1044/2018_AJSLP-ODC11-17-0190

Elman, R. J. (1998). Memories of the ‘plateau’: Health-care changes provide an opportunity to redefine aphasia treatment and discharge. *Aphasiology*, *12*(3), 227-231. https://doi.org/10.1080/02687039808249450

Engell, B., Hutter, B., Wilmes, K., & Huber, W. (2003). Quality of life in aphasia: Validation of a pictorial self-rating procedure. *Aphasiology*, *17*, 383–396. https://doi.org/10.1080/02687030244000734

Foster, A. M., Worrall, L. E., Rose, M. L., & O’Halloran, R. (2016). ‘I do the best I can’: An in-depth exploration of the aphasia management pathway in the acute hospital setting. *Disability and Rehabilitation*, *38*(18), 1765–1779. https://doi.org/10.3109/09638288.2015.1107766

Flynn, L., Cumberland, A., & Marshall, J. (2009). Public knowledge about aphasia: A survey with comparative data. *Aphasiology*, *23*(3), 393–401. https://doi.org/10.1080/02687030701828942

Giles, S., & Miyasaki, J. (2009). Palliative stage Parkinson’s disease: Patient and family experiences of health-care services. *Palliative Medicine*, *23*(2), 120–125. https://doi.org/10.1177/0269216308100773

Gill, J. C. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation, (1*), 39–46. https://doi.org/10.3233/JVR-1997-9106

Graham, J. R., Pereira, S., & Teasell, R. (2011). Aphasia and return to work in younger stroke survivors. *Aphasiology*, *25*(8), 952–960. https://doi.org/10.1080/02687038.2011.563861

Gray, L. M., Wong-Wylie, G., Rempel, G. R., & Cook, K. (2020). Expanding qualitative research interviewing strategies: Zoom video communications. *The Qualitative Report,* 25(5), 1292-1301. Retrieved from https://nsuworks.nova.edu/tqr/vol25/iss5/9

Grawburg, M., Howe, T., Worrall, L., & Scarinci, N. (2019). Family-centered care in aphasia: Assessment of third-party disability in family members with the family aphasia measure of life impact. *Topics in Language Disorders*, *39*(1), 29–54. https://doi.org/10.1097/TLD.0000000000000176

Habermann, B. (1996). Day-to-day demands of Parkinson's disease. *Western Journal of Nursing Research*, *18*(4), 397–413. https://doi.org/10.1177/019394599601800403

Hahn, H. (1988). The politics of physical differences: Disability and discrimination. *Journal of Social Issues*, 44 (1) 39–47. https://doi.org/10.1111/j.1540-4560.1988.tb02047.x

Hersh, D. (2009). How do people with aphasia view their discharge from therapy?. *Aphasiology*, *23*(3), 331-350. https://doi.org/10.1080/02687030701764220

Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*, *93*(1), S86-S95.e4. https://doi.org/10.1016/j.apmr.2011.05.028

Hinckley, J. J. (2006). Finding messages in bottles: Living successfully with stroke and aphasia. *Topics in Stroke Rehabilitation*, *13*(1), 25–36. https://doi.org/10.1310/FLJ3-04DQ-MG8W-89EU

Hinckley, J. J., Hasselkus, A., & Ganzfried, E. (2013). What people living with aphasia think about the availability of aphasia resources. *American Journal of Speech-Language Pathology*, *22*(2). https://doi.org/10.1044/1058-0360(2013/12-0090

Hofgren, C., Björkdahl, A., Esbjörnsson, E., & Stibrant-Sunnerhagen, K. (2007). Recovery after stroke: Cognition, ADL function and return to work. *Acta Neurologica Scandinavica*, *115*(2), 73–80. https://doi.org/10.1111/j.1600-0404.2006.00768.x

Howe, T. J., Worrall, L. E., & Hickson, L. M. H. (2008a). Interviews with people with aphasia: Environmental factors that influence their community participation. *Aphasiology*, *22*, 1092–1120. https://doi.org/10.1080/02687030701640941

Howe, T. J., Worrall, L. E., & Hickson, L. M. H. (2008b). Observing people with aphasia: Environmental factors that influence their community participation. *Aphasiology*, *22*, 618–643. https://doi.org/10.1080/02687030701536024

Howe, T. (2017). Found opportunities for social participation facilitating inclusion of adults with aphasia. *Topics in Language Disorders*, *37*(1), 38–51. https://doi.org/10.1097/TLD.0000000000000113

Huws, J. C., & Jones, R. S. P. (2010). ‘They just seem to live their lives in their own little world’: Lay perceptions of autism. *Disability & Society*, *25*(3), 331–344. https://doi.org/10.1080/09687591003701231

Huws, J. C., & Jones, R. S. (2015). ‘I’m really glad this is developmental’: Autism and social comparisons – an interpretative phenomenological analysis. *Autism*, *19*(1), 84–90. https://doi.org/10.1177/1362361313512426

Kagan, A., & LeBlanc, K. (2002). Motivating for infrastructure change: Toward a communicatively accessible, participation-based stroke care system for all those affected by aphasia. *Journal of Communication Disorders*, *35*(2), 153-169. https://doi.org/10.1016/S0021-9924(02)00062-X

Kagan, A. (1995). Revealing the competence of aphasic adults through conversation: A challenge to health professionals. *Topics in Stroke Rehabilitation, 2, 15-28.* https://doi.org/10.1080/10749357.1995.11754051

Kagan, A., Black, S. E., Duchan, J. F., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using “supported conversation for adults with aphasia” (SCA): A controlled trial. *Journal of Speech, Language, and Hearing Research*, *44*(3), 624–638. https://doi.org/10.1044/1092-4388(2001/051

Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., Threats, T., & Sharp, S. (2008). Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*, *22*(3), 258–280. https://doi.org/10.1080/02687030701282595

Kagan, A., Simmons-Mackie, N., Victor, J. C., Carling-Rowland, A., Hoch, J., Huijbregts, M., et al. (2011). *Assessment for Living with Aphasia. (ALA).* Toronto, ON: Aphasia Institute.

Kauhanen, M.-L., Korpelainen, J. T., Hiltunen, P., Määttä, R., Mononen, H., Brusin, E., Sotaniemi, K. A., & Myllylä, V. V. (2000). Aphasia, Depression, and Non-Verbal Cognitive Impairment in Ischaemic Stroke. *Cerebrovascular Diseases*, *10*(6), 455–461. https://doi.org/10.1159/000016107

Kelley, H., & Betsalel, K. (2005). Travels in Stroke Country: An Ethnographic Photo Essay. *Journal of Contemporary Ethnography*, *34*(2), 170–179. https://doi.org/10.1177/0891241604272644

Kitchin, R., & Wilton, R. (2003). Disability activism and the politics of scale. *The Canadian Geographer/Le Geographe Canadian*, *47*(2), 97–115. https://doi.org/10.1111/1541-0064.00005

Klar, M., & Kasser, T. (2009). Some benefits of being an activist: Measuring activism and its role in psychological well-being. *Political Psychology, 30*(5), 755–777. https://doi.org/10.1111/j.1467-9221.2009.00724.x

Klompas, M., & Ross, E. (2004). Life experiences of people who stutter, and the perceived impact of stuttering on quality of life: Personal accounts of South African individuals. *Journal of Fluency Disorders*, *29*(4), 275–305. https://doi.org/10.1016/j.jfludis.2004.10.001

LaDonna, K. A., Koopman, W. J., Ray, S. L., & Venance, S. L. (2016). Hard to swallow: A phenomenological exploration of the experience of caring for individuals with myotonic dystrophy and dysphagia. *Journal of Neuroscience Nursing*, *48*(1), 42–51. https://doi.org/10.1097/JNN.0000000000000178

Lanyon, L., Worrall, L., & Rose, M. (2018). Exploring participant perspectives of community aphasia group participation: From "I know where I belong now" to "some people didn't really fit in." *Aphasiology*, *32*(2), 139–163. https://doi.org/10.1080/02687038.2017.1396574

Legg, L., Stott, D., Ellis, G., & Sellars, C. (2007). Volunteer Stroke Service (VSS) groups for patients with communication difficulties after stroke: A qualitative analysis of the value of groups to their users. *Clinical Rehabilitation*, *21*, 794–804. https://doi.org/10.1177/0269215507077301

Low, C. (2001). *Controversial speech by British activist: Have disability rights gone too far.* UK Royal National Institute for the Blind.

Luck, A., & Rose, M. (2007). Interviewing people with aphasia: Insights into method adjustments from a pilot study. *Aphasiology*, *21*, 208–224. https://doi.org/10.1080/02687030601065470

Lyon, J. G. (1992). Communication use and participation in life for adults with aphasia in natural settings: The scope of the problem. *American Journal of Speech-Language Pathology*, *1*(3), 7–14. https://doi.org/10.1044/1058-0360.0103.07

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with loss of language after stroke*. Open University Press.

Mabraganna, M., Carballo-Dieguez, A., & Giguere, R. (2013). Young women's experience with using videoconferencing for the assessment of sexual behavior and microbicide use. *Telemedicine Journal and E-Health, 19*(11), 866-871. https://doi.org/10.1089/tmj.2013.0008

MacLeod, A., Allan, J., Lewis, A., & Robertson, C. (2017). 'Here I come again': The cost of success for higher education students diagnosed with autism. *International Journal of Inclusive Education.* Advance online publication. https://doi.org/10.1080/13603116.2017.1396502

Maloret, P., & Scott, T. (2018). Don't ask me what's the matter, ask me what matters: Acute mental health facility experiences of people living with autism spectrum conditions.

Journal of Psychiatric and Mental Health Nursing, 25, 49–59. https://doi.org/10.1111/jpm.12438

McNamara, C. (2009). *General guidelines for conducting interviews*. Free Management Library. http://managementhelp.org/evaluatn/intrview.htm

Michallet, B., Tétreault, S., & Le Dorze, G. (2003). The consequences of severe aphasia on the spouses of aphasic people: A description of the adaptation process. *Aphasiology*, *17*(9), 835–859. https://doi.org/10.1080/02687030344000238

Moloney, J., & Walshe, M. (2018). “I had no idea what a complicated business eating is…”: A qualitative study of the impact of dysphagia during stroke recovery. *Disability and Rehabilitation*, *40*(13), 1524–1531. https://doi.org/10.1080/09638288.2017.1300948

Murray, S. J., & Holmes, D. (2014). Interpretive Phenomenological Analysis (IPA) and the ethics of body and place: Critical methodological reflections. *Human Studies*, *37*(1), 15–30. https://doi.org/10.1007/s10746-013-9282-0

Naess, H., Hammersvik, L., & Skeie, G. O. (2009). Aphasia among young patients with ischemic stroke on long-term follow-up. *Journal of Stroke and Cerebrovascular Diseases*, *18*(4), 247–250. https://doi.org/10.1016/j.jstrokecerebrovasdis.2008.10.005

National Aphasia Association. (2016) Aphasia fact sheet. National Aphasia Association. https://www.aphasia.org/aphasia-resources/aphasia-factsheet/

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2013). The lived experience of dysphagia following non-surgical treatment for head and neck cancer. *International Journal of Speech-Language Pathology,16*(3), 282-289. https://doi.org/10.3109/17549507.2013.861869

Nund, R. L., Ward, E. C., Scarinci, N. A., Cartmill, B., Kuipers, P., & Porceddu, S. V. (2014). Carers' Experiences of Dysphagia in People Treated for Head and Neck Cancer: A Qualitative Study. *Dysphagia*, *29*(4), 450–458. https://doi.org/10.1007/s00455-014-9527-8

O'Callaghan, A. M., McAllister, L., & Wilson, L. (2009). Sixteen years on: Has quality of care for rural and non-compensable traumatic brain injury clients improved? *Australian Journal of Rural Health*, *17*, 119–123. https://doi.org/10.1111/j.1440-1584.2009.01054.x

Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*(1), 98–123. https://doi.org/10.1080/02687030600798337

Parr, S., Byng, S., & Gilpin, S. (1997). *Talking about aphasia: Living with loss of language after stroke*. McGraw-Hill Education (UK).

Richard, C., Katz, B., Hallowell, C., Code, E., Armstrong, P., Roberts, C., Pound, L., & Katz, R. (2000). A multinational comparison of aphasia management practices. *International Journal of Language & Communication Disorders*, *35*(2), 303–314. https://doi.org/10.1080/136828200247205

Ross, A., Winslow, I., Marchant, P., & Brumfitt, S. (2006). Evaluation of communication, life participation and psychological well being in chronic aphasia: The influence of group intervention. *Aphasiology, 20*, 448–497. https://doi.org/10.1080/02687030500532786

Rubin, A., & Bellamy, J. (2012). *Practitioner's guide to using research for evidence-based practice*. John Wiley & Sons.

Sabatello, M., & Schulz, M. (2014). A short history of the international disability rights movement. *Human rights and disability advocacy*, 13-24.

Shadden, B. (2005). Aphasia as identity theft: Theory and practice. *Aphasiology*, *19*(3–5), 211–223. https://doi.org/10.1080/02687930444000697

Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, *2*, 197-204.

Shahmoon, S., Smith, J. A., & Jahanshahi, M. (2019). The lived experiences of deep brain stimulation in Parkinson's Disease: An interpretative phenomenological analysis. *Parkinson's Disease*, *2019*, 1–7. https://doi.org/10.1155/2019/1937235

Shehata, G. A., El Mistikawi, T., Al Sayed, K. R., & Hassan, H. S. (2015). The effect of aphasia upon personality traits, depression and anxiety among stroke patients. *Journal of affective disorders*, *172*, 312-314. https://doi.org/10.1016/j.jad.2014.10.027

Sherratt, S. (2011). Written media coverage of aphasia: A review. *Aphasiology*, *25*(10), 1132–1152. https://doi.org/10.1080/02687038.2011.577285

Simmons-Mackie, N., (2018). Aphasia in North America: Frequency demographics, impact of aphasia, communication access, and service gaps. *Aphasia Access.* https://www.aphasiaaccess.org/white-papers/

Simmons-Mackie, N., Code, C., Armstrong, E., Stiegler, L., & Elman, R. J. (2002). What is aphasia? Results of an international survey. *Aphasiology*, *16*(8), 837–848. https://doi.org/10.1080/02687030244000185

Simmons-Mackie, N., & Damico, J. S. (2001). Intervention outcomes: A clinical application of qualitative methods. *Topics in language disorders*, *22*(1), 21-36. https://doi.org/10.1097/00011363-200111000-00004

Simmons-Mackie, N., & Damico, J. S. (2007). Access and social inclusion in aphasia: Interactional principles and applications. *Aphasiology, 21*, 81–97. https://doi.org/10.1080/02687030600798311

Singleton, J., & Darcy, S. (2013). ‘Cultural life’, disability, inclusion and citizenship: Moving beyond leisure in isolation. *Annals of Leisure Research*, *16*(3), 183–192. https://doi.org/10.1080/11745398.2013.826124

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*(2), 261–271. https://doi.org/10.1080/08870449608400256

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). Sage Publications, Inc.

Smith, L. J., & Shaw, R. L. (2017). Learning to live with Parkinson’s disease in the family unit: An interpretative phenomenological analysis of well-being. *Medicine, Health Care and Philosophy*, *20*(1), 13–21. https://doi.org/10.1007/s11019-016-9716-3

Spector, W. D., Katz, S., Murphy, J. B., & Fulton, J. P. (1987). The hierarchical relationship between activities of daily living and instrumental activities of daily living. *Journal of Chronic Diseases*, *40*(6), 481–489. https://doi.org/10.1016/0021-9681(87)90004-X

Tanaka, H., Toyonaga, T., & Hashimoto, H. (2014). Functional and occupational characteristics predictive of a return to work within 18 months after stroke in Japan: Implications for rehabilitation. *International Archives of Occupational and Environmental Health*, *87*(4), 445–453. https://doi.org/10.1007/s00420-013-0883-8

Taylor, C. (1994). The politics of recognition. In A. Gutman (Ed.), *Multiculturalism* (pp. 25-73). Princeton University Press.

Thompson, D. (2014). Talk to me, please!: The importance of qualitative research to games for health. *Games for Health Journal*, *3*(3), 117–118. https://doi.org/10.1089/g4h.2014.0023

Tomkins, B., Siyambalapitiya, S., & Worrall, L. (2013). What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology*, *27*(8), 972–991. https://doi.org/10.1080/02687038.2013.811211

Trichon, M., & Tetnowski, J. (2011). Self-help conferences for people who stutter: A qualitative investigation. *Journal of Fluency Disorders*, *36*(4), 290–295. https://doi.org/10.1016/j.jfludis.2011.06.001

Union of the Physically Impaired Against Segregation [UPIAS] & the Disability Alliance (1976). *Fundamental principles of disability.* London, England: Union of the Physically Impaired Against Segregation & the Disability Alliance

Wertsch, J. V. (1991). *Voices of the mind: A sociocultural approach to mediated action*. Harvard University Press

Worrall, L., Rose, T., Howe, T., McKenna, K., & Hickson, L. (2007). Developing an evidence-base for accessibility for people with aphasia. *Aphasiology*, *21*(1), 124-136. https://doi.org/10.1080/02687030600798352

World Health Organization (WHO). (2001). *International classification of functioning, disability and health (ICF)*. World Health Organization.

World Health Organization. (1980). International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease, published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976. World Health Organization. https://apps.who.int/iris/handle/10665/41003

World Health Organization & WHOQOL Group. (1998). The World Health Organization Quality of Life Assessment (WHO- QOL): Development and general psychometric properties. *Social Sciences and Medicine, 46*, 1569–1585. https://doi.org/10.1016/s0277-9536(98)00009-4

World Health Organization and World Bank. (2011). World Report on Disability. http://www.who.int/disabilities/world_report/2011/report/en/index.html

Worrall, L. E., Howe, T., O'Callaghan, A., Hill, A. J., Rose, M., Wallace, S. J., … Rohde, A. (2013). The World Report on Disability as a blueprint for international, national, and local aphasia services. *International Journal of Speech-Language Pathology*, *15*(1), 106–112. https://doi.org/10.3109/17549507.2012.721004

Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, *25*(3), 309–322. https://doi.org/10.1080/02687038.2010.508530

Yeo, R., & Moore, K. (2003). Including Disabled People in Poverty Reduction Work: "Nothing About Us, Without Us." *World Development*, *31*(3), 571–590. https://doi.org/10.1016/S0305-750X(02)00218-8

APPENDIX A: INTERVIEW GUIDE

- Welcome
  - Thanks for participating
  - I know about aphasia and activism from an outsider's perspective but I want to know about it from the perspective of the real experts...the people who have lived through it
  - By activism, I mean working to create a positive outcome for people with aphasia. In your case… (book, group, etc.)
- Troubleshooting plan
  - If we get disconnected, participant will rejoin my meeting room
- Review consent form (5 min)
- Interview (40-50 min)
  1. Tell me the story of your stroke/accident that caused aphasia
     a. When did this happen?
  2. Describe your level of social support following your diagnosis of aphasia
     a. Who were the people in your life who supported you?
     b. Can you describe some specific examples of how they supported you?
     c. Is there anyone who didn't support you how you would have liked?
     d. How/Why/When did you feel unsupported?
  3. How much therapy did you receive after your stroke?
     a. How long did you receive therapy?
     b. Do you currently receive any therapy?
  4. What is life like for you post-stroke?
     a. How often do you get out?
     b. Are you able to do what you want?

Okay, those questions were about living with aphasia. Now I want to focus on what you do as an activist.

  5. Can you describe any experiences you've had of engaging in activism?
     a. What kinds of activities related to activism are you engaged in?
     b. When did you start advocating for people with aphasia?
     c. Can you describe how and why you became involved in aphasia activism?
     d. What specific areas/goals have you worked on in activism?
  6. What does aphasia activism mean to you?
     a. Why is it important to you?
  7. What are barriers to activism that you have faced?
  8. How did activism affect your recovery from aphasia?
     a. What are some specific ways activism has improved your quality of life?
  9. Are there any negatives to being an activist? If so, what are they?
  10. Are there any positive aspects to having aphasia?
     a. What would those be?
- Thank you, reminder that they will be re-contacted for member checking (5 min)