

**Understanding the impact of speech-language therapy on the quality of life of people with  
aphasia: A collective case study**

by

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and  
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## **Abstract**

Aphasia is a communication disorder caused by damage to areas in the brain responsible for language, resulting in speaking, understanding, reading, and writing difficulties. Speech-Language Pathologists (SLPs) provide various modalities of therapy for people with aphasia (PWA) through various modalities, including individual and group therapy. There is a paucity of research addressing how different modalities of therapy impact quality of life in PWA, particularly research studies employing qualitative methods. The purpose of this body of work was to gain an understanding of how different modalities of therapy impact quality of life from the perspective of PWA, incorporating qualitative methodology.

This work consists of three integrated manuscripts in addition to introduction, methodology, and general discussion chapters. The first manuscript contributes a current review that examines how quality of life measures are used in studies considering the impact of group therapy on PWA. The second manuscript introduces the concept of supported communication and provides details on how to use these techniques to support the inclusion of PWA in qualitative research. The third manuscript explores the experiences of seven PWA involved in different modalities of therapy, and how each modality impacts outcome measures of language, quality of life, and mood. A collective case study was used to investigate participation in therapy and thoughts and feelings from PWA about their participation. Each case was analyzed using reflexive thematic analysis and concept maps. The themes of Impact of Covid-19, Meaning of Therapy, Comparisons, Social Connections, and Aphasia is a Journey were developed from the analysis.

This dissertation contributes to mixed method research in aphasia and the knowledge base surrounding the impact of different therapy modalities on health-related quality of life. This work has implications for researchers and speech-language pathologists working with PWA. In

addition, this work contributes to methodological and data collection discussions about conducting research with PWA.

Key words: Aphasia, Quality of Life, Health related quality of life, Speech-Language Pathology

## Preface

This thesis is an original work by Carlee Frances Wilson. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Understanding the impact of therapy on the quality of life of people with aphasia”, Pro00097283, 30 July 2020.

Chapter 3 of this thesis has been published as C. Wilson, A. Jones, K. Schick-Makaroff, and E.S. Kim, “Understanding the Impact of Group Therapy on Health-Related Quality of Life of People with Aphasia: A Scoping Review,” *Journal of Speech, Language and Hearing*. I was responsible for the data collection and analysis as well as the manuscript composition. A. Jones and K. Schick-Makaroff contributed to manuscript edits. E.S. Kim was the supervisory author and was involved with concept formation and manuscript composition.

Chapter 5 of this thesis has been published as C. Wilson and E. S. Kim, “Qualitative Data Collection: Considerations for People with Aphasia,” *Aphasiology*, vol. 35, issue 3, 314-333. I was responsible for the data collection and analysis as well as the manuscript composition. E.S. Kim was the supervisory author, contributed to manuscript edits and was involved with concept formation and manuscript composition.

## Dedication

This work is dedicated to people with aphasia, especially those that I have had the opportunity to meet over the past five years.

You have always met me with a smile, and this work would not have been possible without you.

Thank you for being a constant reminder of why I want to work so hard.

*I've learned that people will forget what you said*

*People will forget what you did*

*But people will never forget how you made them feel*

- Maya Angelou -

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(and for the big things too!). I love you and I am so grateful I had you to lean on during this process. I couldn't have done it without you!

Last but not least, I must thank my participants. I am so grateful that my participants were willing to spend their time with me sharing their stories. I have learned so much from each of you, and you have all inspired me to continue this work. Thank you for letting me into your lives, the opportunity to talk with each of you is something I will not soon forget.

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## List of Abbreviations

ADLs: Activities of Daily Living

A-FROM: Living with Aphasia: Framework for Outcome Measurement

ALA: *Assessment for Living with Aphasia*

BNT: *Boston Naming Test*

COAST: *Communication Outcomes After Stroke Scale*

CVA: Cerebrovascular Accident

GHQ-12: *General Health Questionnaire - 12*

HRQL: Health-related quality of life

ICAP: Intensive Comprehensive Aphasia Program

LPAA: Life Participation Approach to Aphasia

MIC: Minimally Important Change

PWA: People/person with aphasia

QOL: Quality of Life

RCT: Randomized Controlled Trial

SAQOL-39: *Stroke and Aphasia Quality of Life Scale - 39*

SLP(s): Speech Language Pathologist(s)

SOAP: Subjective, Objective, Assessment, and Plan

WAB-R: *Western Aphasia Battery – Revised*



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## Chapter 1

### Statement of the Problem

Aphasia is a chronic communication disorder most often resulting from a stroke. It creates communication challenges for people with aphasia (PWA), making it difficult to speak, understand, read, and write. These communication challenges also impact the social lives and in turn the health-related quality of life (HRQL) of PWA. Speech-Language Pathologists (SLPs) can address these communication challenges and provide rehabilitation strategies for communication in therapy sessions and work together with their clients to improve their HRQL.

One framework that SLPs working with PWA use for conceptualizing the impact of aphasia is called the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008). This framework is an adaptation of the ICF, providing more specific context to living with aphasia. Within the A-FROM there are four intersecting domains (Participation in Life Situations, Personal Identity Attitudes and Feelings, Language and Related Impairments, and Communication and Language Environment) with the centre being Living with Aphasia, a concept akin to HRQL (Kagan et al., 2008).

There are many modalities of therapy for PWA, however, some modalities may impact social support and HRQL differently than others. Most PWA in the acute stages begin their journey with therapy working individually with an SLP. Then as they move into more chronic stages, PWA may take part in group therapy, which provides an element of socialization with other PWA. Unfortunately, most research and clinical practice to this point has focused on impairment-based outcomes and has not explored how these different modalities of therapy impact HRQL. Given that the ultimate goal of therapy is to help PWA re-engage with their lives,

it is important to capture the impact of therapy on PWA's feelings about their HRQL. An understanding of how different modalities of therapy impact the HRQL of PWA will ensure they receive the best healthcare possible, while also resulting in an in-depth and impactful understanding of the differences between various modalities of therapy.

The studies contained in this dissertation explore different modalities of therapy for people with aphasia (PWA). Most research attention to date has been focused on how therapy for PWA impacts the language domain. Further, much research on therapy outcomes exists in the quantitative territory; there is a paucity of *qualitative* research addressing how different modalities of therapy impact quality of life in PWA. It is of interest, therefore, to gain an understanding of how different therapy approaches impact health-related quality of life (HRQL) from the perspective of PWA. It is also of interest to determine whether the qualitative information provide similar data as the quantitative measures researchers collect. The connection between how therapy impacts quality of life has not yet been explored using a mixed-method study.

In March 2020, the COVID-19 pandemic began to have major impacts on the everyday lives of Canadians and people worldwide. Businesses were closed to the public, and new health and social distancing protocols were put into place to attempt to stop the spread of the virus. Socialization in a broad sense was restricted, with families and friends not visiting each other in person as they normally would. Some people were able to maintain virtual connections, but this was not the case for everyone. PWA were also not receiving in-person therapy as planned, with both individual and group therapies being cancelled or conducted by SLPs over telehealth. The use of telehealth resulted in more widespread availability of virtual group therapy for PWA, unless the PWA did not have access or ability to use the technology required. These

circumstances make this dissertation a unique contribution to the literature as it examines therapy in the context of a global pandemic.

## **Dissertation Objectives**

My doctoral research aims to investigate how different modalities of therapy (i.e., app-based, aphasia camp, and individual therapy) for PWA impact their quality of life. First it was relevant to conduct a scoping review to understand the status of group therapy and therapy outcomes related to HRQL within the field of aphasiology. This review constitutes the first paper (see Chapter 3). As qualitative methods are not often used with PWA, I explored how to adapt qualitative research methods for conducting studies with PWA. This tutorial paper constitutes the second paper (see Chapter 5) and outlines the intentional approach to my methods and how I used them with PWA. The final paper in this dissertation is a collective case study considering how different modalities of therapy (i.e., aphasia camp, individual therapy, and app-based therapy) impact the HRQL of PWA. Individual therapy and group therapy were selected because there is quantitative research evidence demonstrating the impact of these types of therapy approaches on HRQL (Heart and Stroke Foundation Report, 2017; Northcott et al., 2016; World Health Organization, 2003). App-based therapy was selected because apps represent a relatively new implementation of speech-language therapy; therefore, it is important to explore potential impacts on HRQL. All these modalities of therapy include differing levels of intensity and different levels of human interaction. It is intended that these factors will be described and explored as part of the case study. Prior to completing the final paper, hypotheses were generated in relation to which A-FROM domains would be most relevant to each therapy modality based on what each modality provides. For example, it was hypothesized that aphasia camp would

most impact the participation domain, whereas app-based therapy and individual therapy would most impact the language and related impairments domain.

## **Research Questions**

The purpose of this doctoral work will be to gain an understanding of how different modalities of therapy impact quality of life from the perspective of PWA. Four main research questions will be examined in this doctoral work to understand:

- 1) What is the lived experience of PWA during participation in different modalities of therapy?
  - a) What impact did COVID-19 have on the experiences of PWA?
- 2) What A-FROM domain of functioning is most impacted by these different modalities of therapy?
- 3) How do these modalities of therapy impact the HRQL of PWA?
- 4) How are language and mood outcomes related to HRQL outcomes of therapy for PWA?

Findings from this research will contribute to evidence-based practice by helping SLPs and researchers understand how different types of therapy impact HRQL for PWA. This research will also inform more effective delivery of health services for Canadians with aphasia.

## **Plan of Presentation**

This doctoral dissertation is presented in integrated article format. This work contributes to our understanding of quality of life in people with aphasia.

In chapter one, I introduced important concepts leading to the rationale for this work, the purpose, and the research questions that guided the work. In chapter two, I will introduce and describe aphasia, and situate this work within the literature and current clinical understanding of different modalities of therapy and quality of life.

Chapter three introduces the first integrated article, entitled “Understanding the impact of group therapy on health-related quality of life of people with Aphasia: a scoping review”, published in the journal *Speech Language and Hearing* (Wilson et al, 2021). This article contributes a summary of the known impact of group therapy for PWA on HRQL. This manuscript reflects the state of evidence in SLP, as well as highlights the gap in knowledge in relation to how therapy might impact HRQL. This scoping review informed the design and discussions of this research.

Chapter four describes the methodology and methods selected for this research, and also situates me as a researcher. Case study is discussed as the main methodology and the details of the methods used to conduct the research including recruitment, data collection and data analysis. This chapter complements chapter five, titled “Qualitative data collection: considerations for people with Aphasia” which was published in the journal *Aphasiology* (Wilson & Kim, 2021) and contributes important information for conducting interviews with PWA.

Chapter six consists of another integrated article titled “Understanding the impact of therapy on the health-related quality of life of people with aphasia: A collective case study”. This manuscript provides information about the experiences of PWA in different therapy modalities and how these experiences impacted outcome measures including language, mood and HRQL.

Chapter seven discusses the doctoral work within the context of the field, current research, and future research approaches. This chapter concludes the dissertation and is followed by references.

## Chapter 2

In this chapter, a brief history of aphasia will be followed by a description of the different modalities of aphasia therapy, and a discussion of the state of the current understanding of quality of life in aphasia.

### Aphasia

In the 19th century, Paul Broca used the existing localization theory of language and autopsy evidence to determine that the “3rd frontal convolution” was the location for speech (Eling & Whitaker, 2009; Papathanasiou, Coppens & Potagas, 2017). The theory of localization of language was further developed by Carl Wernicke, who discovered the location of speech perception in the brain, Ludwig Lichtheim, who expanded upon Wernicke’s ideas and Joseph Dejerine, who in the 1900’s defined the “zone of language” (Eling & Whitaker, 2009; Helm-Estabrooks, Albert, & Nicholas, 2004; Howard & Hatfield, 1987; Papathanasiou et al., 2017). These men were foundational in our understanding of language in the brain, and their findings help current researchers and clinicians to understand the connection between brain damage and aphasia. These developments have been foundational to the concept of rehabilitation, which has always been related to optimizing people’s functioning so that they can return to their life before their injury/illness (Stucki, Bickenbach, Gutenbrunner, & Melvin, 2017).

Since the 19th century, many definitions of aphasia have been proposed. At its core, aphasia is a communication disorder caused by damage to the areas in the brain responsible for language, resulting in speaking, understanding, reading, and writing difficulties. Aphasia is considered by many to be a disability, as the level of communication challenges often result in early retirement. Aphasia is different from other communication disorders such as dysarthria, which involves motor speech impairment. People with aphasia can also be diagnosed with

dysphagia (i.e., difficulty swallowing), which SLPs address, however this is out of the scope of this dissertation. Stroke is the most common cause of aphasia; however, it can also result from traumatic brain injury, tumor, and other causes including but not limited to infection and neurodegeneration. As stroke is the most common cause, stroke-induced aphasia will be the focus of this paper and proposed research.

### ***Epidemiology***

Stroke in Canada is the third leading cause of death, and approximately 62,000 Canadians are diagnosed with a stroke annually (Heron, 2007; Statistics Canada, 2017; Heart and Stroke Foundation of Canada, 2016). Most strokes in North America happen to those over the age of 60 (Simmons-Mackie, 2018). By 2036, it is expected that senior citizens will account for 23-26% or more of the population (Statistics Canada, 2021). In fact, 7.1% of Canadians 65-74 report living with the aftermath of a stroke (Public Health Agency of Canada, 2009). As the population ages, an increase in stroke and other neurodegenerative diseases that cause aphasia will also increase (Public Health Agency of Canada, 2010). There are many risk factors for stroke, which in turn may be risk factors for aphasia, such as high blood pressure, diabetes, high cholesterol, a family history of stroke, prior stroke, high levels of anxiety/distress/depression, transient ischemic attacks, smoking, obesity, and sleep disorders (Simmons-Mackie, 2018). Due to improved medical techniques and understanding of rehabilitation post-stroke, people may be living longer after stroke and aphasia, increasing the potential of long-term disability (Simmons-Mackie, 2018).

The incidence rate of stroke is reported as 1.10% in men and 1.21% in women (Kruger et al., 2015). The incidence rate of aphasia is approximately 60/100,000 adults per year, while the prevalence rate is approximately 34% of stroke survivors (Dickey et al, 2010; Flowers et al.,



2016). Mortality from stroke is decreasing with improved medical interventions, however PWA have twice the mortality rate as stroke survivors without aphasia (Laska et al., 2001; Simmons-Mackie, 2018). A large cohort study that considered stroke survivors reported a 12.6% 30-day case fatality, and 23.6% one-year case fatality (Saposnik, 2008). Currently, there are estimated to be over 137,700 people living in Canada with aphasia (Simmons-Mackie, 2018). Hier, Yoon, Mohr, Price and Wolf (1994) reported sex differences in the type of aphasia, but more recent studies have indicated that there are no sex or incidence differences when comparing different types of aphasia (Yao et al., 2015; Engelter et al. 2006; Hier et al., 1994). For PWA, the first six months are when the greatest communication recovery from stroke occurs, however slower recovery continues for years post-stroke (RELEASE Collaborators, 2021).

### ***Pathophysiology***

Different types of strokes (i.e., Cerebrovascular accident, CVA) result in lesions that can cause aphasia and have different functional impacts on the amount of damage done to the brain. In right-handed people with aphasia, CVAs usually occur within the left hemisphere and occur within the supply area of the middle cerebral artery. An ischemic CVA is the result of a blocked artery, which can prevent required oxygen and nutrients from reaching the brain. Arteries can become blocked with a build-up of plaque, made of fat, cholesterol, and other substances (i.e., thrombosis) in the brain or when a build-up of plaque from elsewhere dislodges and gets stuck in the arteries of the brain (i.e., embolism). When the blood flow is not sufficient for the function of brain cells, they begin to die. An ischemic CVA is more common than a hemorrhagic stroke (Virani et al., 2021). Comorbidities associated with ischemic CVA include but are not limited to cardiovascular disease, hypertension, and diabetes.

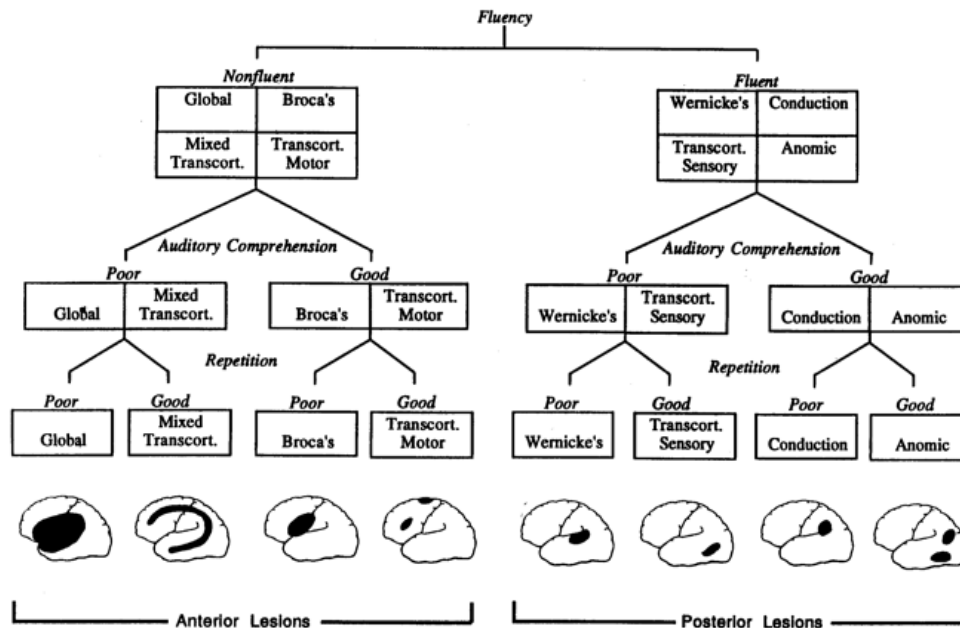
A hemorrhagic stroke is the result of a weak blood vessel that breaks and leaks into the brain tissues. This type of CVA typically occurs in younger patients because it is often due to a congenital malformation rather than plaque build-up. Hemorrhagic strokes can happen either within the brain (intracerebral) or into the tissues separating the brain from the skull (subarachnoid, subdural). Hemorrhagic strokes are often the result of brain aneurysms and malformations of blood vessels. When blood leaks from vessels into the brain, it increases pressure on the brain cells and can cause temporary or permanent damage depending on the amount of blood and amount of time the blood is in contact with the brain cells.

### **Theoretical Models of Aphasia**

Over the years many theories have been used to explain and describe aphasia and its symptoms. The **localization theory** posits that the main areas in the brain responsible for language are situated within the left cortical hemisphere and include Broca's area, Wernicke's area, and the white matter tract that connects them called the arcuate fasciculus. Broca's area is located in the frontal lobe of the left hemisphere, anterior to the primary motor area, and superior to the Sylvian fissure. Wernicke's area is located within the temporal lobe of the left hemisphere, at the posterior end of the Sylvian fissure. **The Boston Classification Model of Aphasia** (see Figure 1) is a simplistic model that shows how these areas may be involved in each type of aphasia and demonstrates the one-to-one correlation between cortical lesion location and symptoms of aphasia.

#### **Figure 1.**

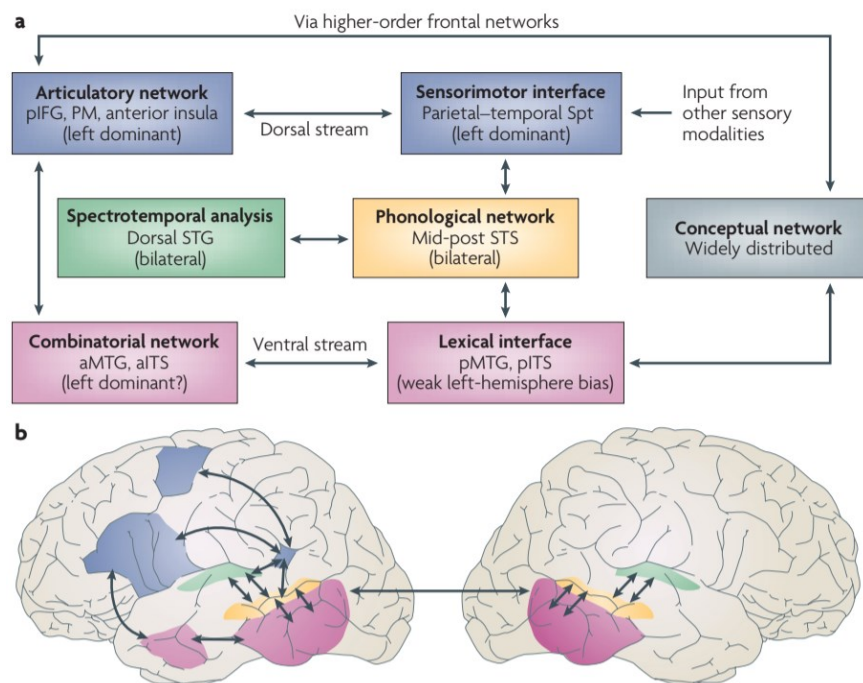
*Boston Classification Model of Aphasia (Beeson & Rapcsak, 1998).*



**The dual-stream model** developed by Hickok and Poeppel (2000) is a more recent and complex model that can be used to explore and understand the neural bases of language. This model proposes a dorsal pathway (also referred to as the *motor* pathway underlying the articulation and speech production component; blue in figure 2) and a ventral pathway (also referred to as the *meaning* pathway supporting concepts and understanding; pink in Figure 2) for the processing of speech production and comprehension (Hickok & Poeppel, 2000). With the increased use of dynamic imaging techniques such as functional magnetic resonance imaging (fMRI) since the early 2000s, we now have a better understanding of the neural mechanisms of aphasia. Specifically, fMRI have shown that when the brain is damaged it results in disruption to several brain regions due to the complex interconnecting networks present in the brain (Helm-Estabrooks et al., 2004; Hickok & Poeppel, 2007; Fridriksson et al., 2018). Due to the synaptic networks and their connections via white matter tracts, we can predict what functional speech impairment would be predicted based on the location and extent of the lesion (Fridriksson et al.,

2018). Researchers have also shown that brain activation is task-dependent, therefore speech processes activate different aspects of the language network, depending on the type of task (Fridriksson et al., 2018; Hickok and Poeppel, 2007). With tasks such as naming, repetition, and grammar, in which processing occurs in both the dorsal and ventral streams, damage to either one of the streams will result in impaired ability to complete these tasks. As these streams are critical to all language processing, their disruption can result in impaired ability to complete these tasks across aphasia subtypes (Fridriksson et al., 2018).

**Figure 2.**  
*Dual Stream Model of Language (Hickok & Poeppel, 2007).*



### **Clinical Features**

The cardinal features of aphasia include anomia (i.e., difficulty with word retrieval) and paraphasias (i.e., errors in naming). Depending on the location and extent of the cortical lesion, PWA may speak in short sentences, substitute words or sounds for other words or sounds, say

illogical words or sentences, or have trouble understanding words or sentences. The location and extent of cortical damage from the stroke can also be correlated with the severity of the clinical features. However, it must be noted that PWA have not lost their intelligence but have difficulty in demonstrating their competence due to communication impairment. More specific cardinal features of communication challenges will now be discussed for broad categories of aphasia, which are based on naming, fluency, auditory comprehension, and repetition (see Figure 1).

### **Fluent aphasia.**

Fluent aphasia includes Wernicke's, Conduction, Transcortical Sensory, and Anomic aphasias. These aphasia types are associated with more posterior brain lesions in the left hemisphere. People with fluent aphasias often use empty speech (i.e., lack of nouns, lots of function words) and paraphasias that are both semantic and phonemic.

### **Non-fluent aphasia.**

Non-fluent aphasias include Global, Broca's Transcortical Motor, and Mixed transcortical and are associated with more anterior brain lesions in the left hemisphere. People with non-fluent aphasias often experience impaired speech prosody and halting speech, and non-fluent aphasia is often associated with depression (Starkstein & Robinson, 1988). One or few word utterances are common, with reduced complexity of grammar (i.e., mostly nouns) and challenges with articulation.

It should also be noted that with recovery, the type of aphasia may change from a more severe profile to a milder profile. A common example of this is moving from a non-fluent aphasia such as Broca's, to anomic aphasia, representing an improvement in speech fluency according to the Boston classification scheme. Other impacts of cortical strokes can include motor or sensory involvement, due to proximity of structures implicated in speech production

and motor strip, resulting in hemiparesis of upper and/or lower extremities. Often PWA are left with chronic aphasia among the other health implications from the impact of a stroke. Due to the long-term disability, PWA often turn to rehabilitation to learn to live with the changes.

### **Speech & Language Therapy for People with Aphasia**

Within the realm of therapy options for people with chronic aphasia, there are two main therapy modalities including *individual therapy*, which occurs one-on-one with the therapist and PWA, and *group therapy*, which occurs with multiple people present. Overall, aphasia therapy helps PWA to improve their language skills; however, the efficacy for each modality and the various options are variable (Fridriksson & Hillis, 2021). It is important to note that when most PWA reach the chronic stage (i.e., six or more months post-stroke), fewer resources are available compared to the acute stages (i.e., one week to one month) after a stroke (Hersh, 2018). When determining whether therapy was successful, clinicians will use different outcome measures that focus on language impairment, as the main focus of therapy is often remediation of the language impairment. The following sections will explain what each model of therapy usually entails, and what outcome measures have been used to assess these types of therapy in the literature.

#### ***Individual Therapy***

In an individual therapy session, a Speech-Language Pathologist (SLP) and their client with aphasia will usually meet in the SLP's clinic space. Individual therapy typically begins with the SLP taking the client's history and completing an assessment battery. This helps the SLP to determine the PWA's areas of strength and challenge and can help with setting SMART goals for the time they have together. Individual therapy can take place at any point along the continuum of recovery, from acute (within hospital) to chronic stages, where therapy can be delivered in rehabilitation facilities or the community setting. The amount of time spent in

individual therapy is based on many factors, such as the PWA's severity of impairment and medical stability, SLP availability, interest in individual therapy, and funding.

Because the focus for both SLP and PWA is often on the language and cognitive impairment, outcome measures used to determine success and completion of goals are often focused on measuring change in impairment. Examples of these outcomes include the *Boston Naming Test-2* (BNT-2; Kaplan, Goodglass & Weintraub, 2001), and the *Western Aphasia Battery-Revised* (WAB-R; Kertesz, 2006). Some SLPs will also use more functional assessments such as the *Communication Activities of Daily Living* (CADL-3; Holland et al, 2018) to capture functional communication effectiveness outside of therapy. Individual therapy is a broad, general term and there are variations in the approaches to individual therapy.

In individual therapy, the SLP will plan activities to work on the areas of challenge for the PWA and will make the activities easier or more difficult as tolerated by the PWA. Some examples of these activities might include reading and writing exercises, naming tasks, and script training. Sometimes family members or friends are invited to a session to teach them about supported communication and how to support the PWA at home. Inviting friends or family to learn can help the PWA transfer new skills and techniques out of the therapy room and into their daily life.

One of the most common activities practiced in individual therapy is *picture naming* (Thomas, Lander, Cox & Romani, 2020) because most PWA have word-finding and/or production challenges that impact their daily life. Increasing their lexical retrieval ability can be both meaningful and productive for recovery of speech and language skills. There are different approaches to picture naming therapy including phonological (e.g., Phonological Feature Analysis; Leonard et al., 2008) and semantic cueing (e.g., Semantic Feature Analysis; Boyle &

Coelho, 1995), as well as a focus on verb networks (e.g., Verb Network Strengthening Treatment; Edmonds et al., 2009). Previous researchers have demonstrated that using a larger number of words and working on more words per hour of therapy improved word retrieval outcomes (Laganaro et al., 2006; Snell et al., 2010; Thomas et al., 2020). Thomas and colleagues also demonstrated that frequent massed practice (i.e., lots of practice in a short amount of time) does not correlate with positive outcomes; however, a larger dosage (i.e., more hours) of therapy is beneficial (2020). In terms of massed practice compared to distributed practice (i.e., lots of practice spread out over time), the research indicates that person-related factors such as motivation and severity of aphasia have an impact on the effectiveness of therapy, so it is unclear which strategy is best (Des Roches, Balachandron, Ascenso, Tripodis, & Kiran, 2015; Dignam et al., 2016; Thomas et al., 2020). It is uncertain how best to approach naming therapy, and so it is easy to see why SLPs may implement several approaches for different PWA.

#### **App-based therapy.**

App-based therapy requires no direct therapist involvement. PWA can use the app independently at home, or the app can be incorporated into an individual therapy program. Because apps are pre-programmed with exercises and stimuli, there are few opportunities to personalize or adjust the content as one would be able to in traditional individual therapy. However, it is possible for an SLP to integrate an app that contains specific exercises (e.g., reading, writing, naming tasks, script training) to supplement individual therapy with the PWA. Doing so adds intensity to the therapy program by adding to the number of hours the PWA is practicing their skill. The option of using apps is becoming increasingly popular with the proliferation of available apps, expansion of app capabilities, increased use of technology in the general population, and continued time constraints of SLPs. An example of an app used in this



way is the *Constant Therapy* app (Constant Therapy Health Ltd., n.d.), which contains speech, language, and cognitive therapy exercises that the clinician can include in a home program for clients. This particular app has a growing evidence base for its efficacy. PWA practicing with this app demonstrated improved accuracy and latency on the app tasks, and better scores on standardized tests than control participants doing therapy without the app (Des Roches et al. 2015).

SLPs can also use an app to take more of a consulting role with a PWA in using therapy apps. In this case, the SLP may suggest the app for the PWA to use, show them how to use it, and monitor progress, but they do not directly complete therapy with the PWA regularly. For example, in the *Constant Therapy* app, PWA can also download and use the app independently without the guidance of an SLP. Using apps in a consultation approach is relatively new and is advantageous for SLPs to consider but requires that the PWA be able to access the technology or have family or friends who are tech-savvy and willing to help. Computer programs and apps that focus on naming have resulted in PWA demonstrating gains on trained items, various standardized measures, and in the maintenance of naming performance (Des Roches & Kiran, 2017; Grasso & Henry, 2019; Kurland, Wilkins & Stokes, 2014). In a randomized control trial of the *Step-by-Step* software, PWA had significant improvement in word-finding when paired with usual care, which is attributed to the use of the app (Palmer et al., 2019).

Regardless of whether the app is used in a clinical setting with a SLP or independently at home, PWA can achieve similar treatment results (Godlove, Anantha, Advani, Des Roches, & Kiran, 2019). For the apps that are currently available to PWA, it appears that most are related to improving speech or language, with some apps including treatment tasks for improving cognition. One possible disadvantage of current apps is that delivery is usually standardized for

all users, which means it can be difficult (but not impossible) for SLPs to tailor the treatment as they would with face-to-face individual therapy (Des Roches et al., 2015; Des Roches & Kiran, 2017). Outcome measures to evaluate progress of therapy with apps can be measured based on progress within the app (such as increased difficulty or number correct), or with outcome measures relevant to the app purpose (e.g., BNT-2 for a naming app). It is possible that using an app to do therapy can have many positive benefits for PWA, including increased independence and being more engaged in therapy. The latter can result in the PWA achieving more functional gains, which has been reflected in improved quality of life scores (Des Roches & Kiran, 2017).

### ***Group Therapy***

Many SLPs follow a Life Participation Approach to Aphasia (LPAA) philosophy when planning and delivering group therapy (i.e., treatment administered to multiple people at one time that meet regularly in a shared real or virtual space)<sup>1</sup>. The LPAA includes five core values related to aphasia service delivery: 1) the goal of therapy should be the enhancement of life participation; 2) everyone affected by aphasia is entitled to service; 3) success is related to life enhancement; 4) intervention should target both personal and environmental factors; and 5) services should be available at all stages of aphasia (Elman, 2016; LPAA Project Group, 2000). Group therapy incorporates these principles of the LPAA by offering services to PWA across the continuum of recovery, and by promoting interaction among PWA to improve participation. When planning group therapy, the SLP will often group individuals based on a shared interest, shared schedule, or shared needs. Group therapy often has an intervention theme, such as a reading group, writing group, choir, or conversation group. These groups, therefore, encourage

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<sup>1</sup> Individual therapy can also be LPAA based, but the nature of the group context lends itself to focus more on social participation, and therefore tends to have a stronger LPAA focus.

interaction around this shared theme, which allows PWA to communicate with many partners in a natural setting. Thus, groups can improve both communication and social aspects of PWA's quality of life, not only within the group setting but also generalized to their life as a whole (Elman, 2004; Elman & Bernstein-Ellis, 1999a, 1999b). Usually, group therapy occurs subsequent to individual therapy, when the individual enters in more chronic stages of aphasia. As a result, specific assessment and outcome measures differ based on the context and needs of the client. Either impairment-based assessments, functional assessments, or some combination of both have been used in different types of therapy. Most research so far has focused on impairment; there is a paucity of research addressing the other areas of functioning for PWA. This includes consideration patient-centred outcomes that explore what is meaningful to PWA. Information and treatment approaches based on the PWA's ability to function outside of therapy should also be considered. Having research that addresses multiple areas of impairment and functioning to quantify the improvements (or lack thereof) seen with participation-focused therapy will allow researchers to better understand how to help PWA and whether a therapy modality such as group therapy would benefit their client.

While participating in group therapy, PWA often share that they have made social connections within the group that are sometimes maintained beyond the therapy sessions (Northcott et al., 2016). The amount of time spent in group therapy is based on many factors, such as the location and availability of group programming, funding or costs, SLP availability, and person-related factors such as attention, motivation, and cognition.

Most research attention has been focused on the impact of group therapy on language impairment, and outcomes in other domains are not always reported. When outcomes from other domains are reported, functional assessments such as the *Communication Effectiveness Index*

(Lomas et al., 1989) are used to capture broad-based areas beyond language impairment including communication (i.e., getting a message in or out) in different situations. Most studies (including RCTs and literature reviews) cite positive changes on communication and language-related outcome measures following group treatment (Attard, Lanyon, Togher, & Rose, 2015; Ciccone et al., 2016; Hoover & Carney, 2014; Hoover, Caplan, Waters, & Carney, 2017; Rodriguez et al., 2013), with only a few studies reporting no changes (Lanyon, Rose & Worrall, 2013). These positive outcomes include PWA saying their communication has improved, they are more confident, and that they talk more (Elman & Bernstein-Ellis, 1999b; Van der Gaag et al., 2005). Based on this evidence, it is recommended that SLPs and PWA explore group therapy options to find the right fit so that they can benefit from group treatment. Group therapy is a broad and general term that can be applied to many versions of therapy that happen with more than one client. Below, variations of group therapy including intensive comprehensive aphasia programs (ICAPs), virtual group therapy, and participation focused therapy will be discussed in more detail.

### **Intensive comprehensive aphasia programs (ICAPs).**

ICAPs are a newer model of therapy that have been gaining in popularity over the last decade. ICAPs are defined as intensive therapy programs that address multiple areas of speech and language through different treatment approaches and formats, and incorporate principles of neuroplasticity by providing an increased intensity of group therapy within a shorter time frame (Rose, Cherney & Worrall, 2013). ICAP groups meet for several hours per day for at least 2 weeks and address various goals throughout the meetings (Rose et al., 2013).

Reviews of ICAP programs have shown different results for who benefits most from ICAP programs in terms of severity and other factors. One retrospective analysis of outcomes of

436 PWA enrolled in an ICAP suggested that people with milder aphasia had greater recovery than those with more severe aphasia; however, all PWA showed some level of improvement on the WAB-R AQ measure (Persad, Wozniak, & Kostopoulos, 2013). Another retrospective analysis with 74 PWA suggested that there were no differences in who benefitted from participation in an ICAP based on severity, type of aphasia, and time post-onset (Babbitt, Worrall & Cherney, 2015). A study of 83 PWA in an ICAP, suggested that age has an impact on improvement, in that younger patients who were longer post-onset of aphasia showed larger gains than older patients with shorter post-onset periods (Babbitt, Worrall & Cherney, 2016). Recent studies by Griffin-Musiak and colleagues (2020; 2021) have also demonstrated proof-of-concept that ICAPs can be successfully implemented in university settings, with positive linguistic and HRQL changes observed in PWA. More research is required at this time to identify person-related and implementation-related features of the effectiveness of ICAP programs.

### **Virtual group therapy.**

Recently with advances in technology, virtual group therapy has been explored for PWA who live in remote locations or communities without an available SLP, which can make it difficult to attend therapy regularly or in person. Doing virtual group therapy allows these PWA to access not only therapy but also a community of other PWA. Most often, virtual groups focus on fostering conversation in addition to activities planned for participants. In one study of a telerehabilitation group for PWA (TeleGAIN), 19 PWA improved in aphasia severity, engagement in communication, and communication-related quality of life after being led through 12 1.5-hour sessions by an SLP (Pitt, Theodoros, Hill & Russell, 2018). At this time, there is a paucity of research about virtual group therapy, and so as this method of treatment delivery

expands due to the global COVID-19 pandemic, more research is forthcoming to explore the efficacy of this service delivery model.

**Participation-focused therapy.**

Participation-focused therapy refers to events where PWA have an opportunity to receive some therapy, but the therapy does not have the formal or continuous schedule of the other types of therapy presented above. The amount of time a participation-focused therapy can take may range from a few hours to an entire weekend. Examples of one-time therapy might include workshops, retreats, and aphasia camps. At this time, few participation-focused therapies have reported outcomes because of the lack of formal delivery of therapy making it difficult to understand what factors resulted in the outcomes. Those that have reported outcomes have used functional outcome measures such as the *Assessment for Living with Aphasia* (ALA; Kagan et al., 2011) as used in Kim and colleagues (2016), narratives as used in Fox and colleagues (2004), clinical discourse assessment as used in Hoepner and colleagues (2019), or activity feedback forms as used in Fox and colleagues (2004).

**Aphasia camps** are an example of an intensive, residential intervention where PWA attend and engage in recreational and therapeutic activities with or without family members/friends. Programming is often delivered by SLPs or an interdisciplinary team of healthcare professionals and/or pre-professional students supervised by licensed professionals. Interventions such as aphasia camps provide an opportunity for PWA to engage with many individuals within a communicatively supportive environment or people who understand aphasia, which allows PWA to enjoy recreation and therapy at the same time. PWA have shown improvements across many domains following participation in aphasia camps, including participation and personal identity as measured by the *ALA* (Kim et al., 2017).

## **Quality of Life in Aphasia**

Understanding quality of life (QOL) of PWA can help to target specific domains and evaluate effectiveness of interventions for the chronic stage of aphasia (Hilari, Wiggins, Roy, Byng, & Smith, 2003). While QOL is a complex construct, pseudonyms such as ‘well-being’ or ‘life satisfaction’ exist in the literature. One detailed example is the definition from the World Health Organization (WHO) which considers QOL to be:

an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (“WHOQOL: Measuring Quality of Life”, 2001, pp.1).

In the literature, QOL and health-related quality of life (HRQL) are often used interchangeably, as there is a common misconception that they have the same definition. They are related terms in that they are both subjective measures related to well-being; however, QOL is a more general term that refers to the experience of being satisfied or happy with life in general which also includes spirituality, creativity, economic security, social and occupation activities, while HRQL is a narrower term that refers to how the health of an individual is related to their well-being and life (Ferrans et al., 2005).

Following a stroke and acquiring aphasia, a multitude of physical, mental, and emotional challenges may affect PWA and impact their HRQL. As highlighted in a systematic review, Hilari, Needle, and Harrison (2012) identified five main factors related to these life changes that have been observed to be associated with a lower HRQL in PWA: communication disability, emotional distress, physical and social activity level, social support, and number of

comorbidities. In addition, fatigue was more recently highlighted by Bullier et al. (2020) as an additional factor. Each of these factors will be described in more detail below.

### ***Communication disability***

In aphasia, there are different clinical levels of severity describing the communication challenges, which are on a continuum from mild to severe aphasia. For instance, *mild aphasia* might refer to someone who can have a conversation but sometimes has trouble finding the right words or difficulty comprehending part of a conversation, whereas *severe aphasia* might refer to someone with limited ability to verbally express themselves or comprehend others.

Severity of communication disability is a relevant construct to HRQL. People with severe aphasia in multiple studies have been reported to have lower HRQL compared to people with mild aphasia and people with mild aphasia have lower HRQL than people who have had a stroke but do not have aphasia (Hilari, 2011; Hilari et al., 2012; Ross & Wertz, 2003). On the other hand, some people with severe aphasia do not always have a lower HRQL than people with mild aphasia (Williamson, Richmond & Redmond, 2011). This evidence demonstrates the complexity of HRQL and the different constructs that need to be considered with HRQL for PWA.

Findings from qualitative studies have reported that PWA feel upset and frustrated when they have difficulty speaking, or when having to speak more slowly (Brown, Worrall, Davidson & Howe, 2010; Cruice, Hill, Worrall, & Hickson, 2010b). The communication difficulties experienced by PWA can make it difficult to communicate basic wants and needs, have a conversation with family or friends, or feel confident asking for help in a store or ordering at a restaurant (including reading from a menu). When PWA have communication abilities taken away from them, they can feel like they are not seen as a whole person, and they also lose the ability to interact with others in the way they have their whole lives, which is a devastating



change (Baker, Worrall, Rose & Ryan, 2020; Dalemans, de Witte, Wade, & van den Heuvel, 2010; Davidson, Howe, Worrall, Hickson, & Togher, 2008).

### ***Emotional distress***

Researchers have identified that emotional distress is felt by PWA (i.e., depression and anxiety; Hilari et al., 2003; Hilari et al., 2012) throughout their journey with aphasia (i.e., throughout acute, and chronic phases; Baker et al., 2020). Some PWA have described feelings such as being bewildered, punished, that they would rather be alone, and wondering what they are good for (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Hinkley, 2006).

In the general population, emotional distress can lead to social isolation, lower self-efficacy, lack of confidence, and suicidal thoughts (Bygstad-Landro & Giske, 2018). These feelings or attitudes might be amplified by the fact that PWA may have fewer people to talk to due to the extra work it takes to communicate with people who have communication challenges, and the extra work to communicate on the part of the PWA (Davidson et al., 2008; Doyle et al., 2003; Johansson et al., 2011). With communication challenges, it may be difficult for PWA to not only let others know that they are having emotional distress, but it can also be difficult to treat as the most common help offered for people experiencing moderate to severe emotional distress is a combination of medication and talk therapy (Baker et al., 2020). Most mental health professionals are not trained to work with PWA and accessing appropriate help for emotional distress may be difficult with mental health professionals who do not have experience working with PWA (Baker et al., 2020; Morrow-Odom & Barnes, 2019). Emotional distress is also related to the communication and language environment domain, as the environment is not set up to appropriately support PWA to communicate their feelings (Kagan et al., 2008). Emotional

distress may decrease over time as PWA see the positive and can set goals to strive for improvement (Brown et al., 2010; Brown Worrall, Davidson & Howe, 2012).

### ***Activity level***

After a stroke, PWA can have challenges that result in a low physical activity level. PWA want to maintain their physical independence and autonomy in activities, including living at home (Brown et al., 2012; Cruice et al., 2010a; Hilari et al., 2012). Limb paresis is common in PWA and can result in mobility limitations that in turn impact the ability to drive, complete activities of daily living (ADLs), work, or volunteer (Baker et al., 2020; Brown et al., 2012; Grohn et al., 2012; Niemi & Johansson, 2013). Loss of these activities can be difficult to manage for PWA, who before their stroke did not necessarily have physical limitations.

Low functional activity level is also a consideration with PWA, who may not have the ability to participate in instrumental ADLs due to communication challenges and emotional distress. Many PWA want to engage in meaningful activities, and they may feel a negative sense of self and that the worst has happened to them if they can't participate (Grohn, Worrall, Simmons-Mackie & Brown, 2012). Some PWA are even afraid of losing function that they have maintained after their stroke, and experience low confidence when in the community, especially when in loud unfamiliar places (Cruice et al., 2010b; Dalemans et al., 2010; Grohn et al., 2012). This can lead to PWA feeling dependent on others, helpless, useless, and limited in their abilities and activities (Brown et al., 2010; Cruice et al., 2010b).

### ***Social support***

In the 11 quantitative studies included in the systematic review by Hilari et al. (2012), social support was not highly associated with HRQL, although the importance of social support and meaningful relationships to their HRQL was expressed in the three qualitative studies

included in the review. Challenges with communication, emotional distress, and low social participation in activities can all impact social support. These variables may have encapsulated the negative impact of aphasia on social support, such that it was not a significant factor in the regression models presented (Hilari et al., 2012).

After a stroke, many PWA have mentioned that they have lost friends, family members and acquaintances that were part of their social network. This was sometimes due to a lack of understanding, people not knowing how to communicate with PWA, others feeling uncomfortable with the large changes they see in their friend or family member, or lack of acceptance/understanding of aphasia (Brown et al., 2012; Brown et al., 2010; Cruice et al., 2010b; Davidson et al., 2008). These situations upset, induced fear, and were a challenge for PWA, and can contribute to a lower HRQL. When others do not make an effort or do not know how to help the PWA in social situations, it can result in PWA feeling isolated and left out (Dalemans et al., 2010). For the PWA, this can mean missing out on social participation such as coffee dates, book club meetings, golf trips, church, and other activities that are relevant to their HRQL.

PWA may also feel like a burden when they need to rely on others to follow along in a conversation (Dalemans et al., 2010). PWA disliked when people showed them pity or sympathy, as they felt that this was not helpful and they did not want others to feel differently about them after their stroke (Brown et al., 2010; Brown et al., 2012). For family members, it can also be difficult to help PWA gain independence to maintain their roles in the family while also providing consistent support and trying to avoid coddling the PWA (Brown et al., 2012; Brown et al., 2010).

### ***Fatigue***

Clinicians have noted over time that PWA have issues with fatigue when communicating and participating in treatment or other activities, resulting in both physical and mental fatigue. Fatigue is a more evident issue in the acute phases of recovery but can be experienced in chronic aphasia as well. A recent study of PWA demonstrated that fatigue is statistically significantly related to QOL ( $R^2 = 0.756$ ,  $P < 0.001$ ) as measured by the *French Sickness Impact Profile 65* (Bullier et al., 2020). PWA have said that when in social situations they can feel like a burden because they may be tired and need to leave the room or go home early (Dalemans et al., 2010). When communicating, PWA may also need more time and to take breaks to reduce their fatigue (Grohn et al., 2012). Fatigue can also act as a barrier to participating in activities that interest the PWA (Grohn et al., 2012).

### ***Comorbidities***

The final significant contribution to HRQL for PWA is the presence of comorbidities. A stroke is a medical event that can have multiple risk factors and complications, in addition to the effects of older age. For Canadians, the most common comorbidities for stroke survivors include hypertension, diabetes, arrhythmias, heart disease, and atherosclerosis (Checchin et al., 2012). These comorbidities impact not only the rate of recovery from stroke, but also the HRQL of the individual. Currently, it is unclear which comorbidities have more of an impact on HRQL for PWA, as personal and environmental factors may play a role in the day-to-day impact (Hilari et al., 2012).

### ***Other factors***

Other factors that have less significance in their contribution to HRQL include cognitive impairment. For PWA who test at a lower cognitive level, it should be considered that many

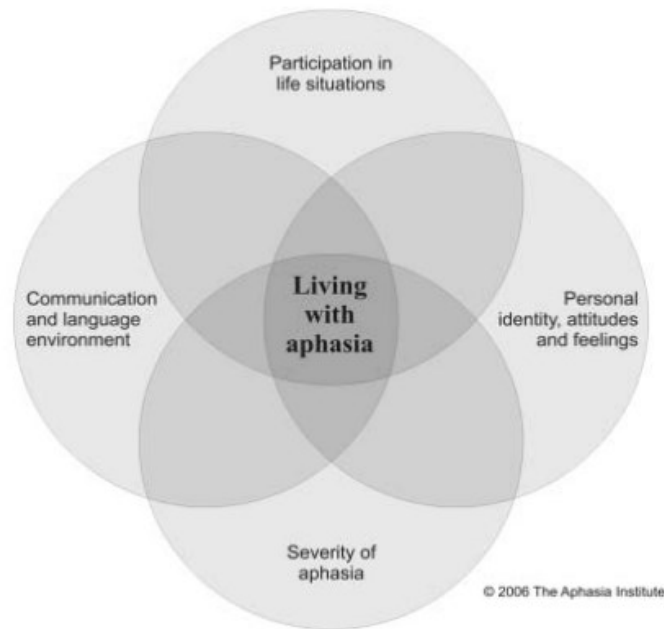
cognitive assessments (such as the *MoCA* or *MMSE*) rely on strong language skills, and so may not be valid to use with someone with a communication disorder (Hilari et al., 2003). Therefore, lower scores on cognitive assessments could be the result of communication challenges confounding the results, rather than a cognitive impairment being present. In the regression models presented in Hilari et al. (2012), other variables that were not associated with HRQL included time post-onset, type of stroke, sex/gender, ethnic background, marital status, SES, employment status, and level of education (Bullier et al., 2020; Hilari et al., 2012).

### ***Aphasia Health-Related Quality of Life Framework***

The A-FROM conceptual framework is useful to understand HRQL factors that are meaningful and relevant for PWA, the A-FROM conceptual framework should be explored. The A-FROM was not developed as a HRQL model, but rather as a framework for assessment and treatment for SLP. An assessment tool based on the A-FROM is called the *Assessment for Living with Aphasia (ALA)*; Simmons-Mackie et al., 2014). The A-FROM was developed to include factors relevant to PWA, incorporating parts of existing frameworks, including the International Classification of Functioning, Disability and Health (ICF; World Health Organisation, 2001) and the Disability Creation Process (DCP) (Noreau, Fougereyrollas, & Vincent, 2002) (Kagan et al., 2008). The framework was developed with input from PWA, their family members, Speech-Language Pathologists (SLPs), and other rehabilitation professionals to collect ideas about what to include and to refine the framework throughout development (Kagan et al., 2008).

### **Figure 3.**

*A-FROM (Aphasia Framework for Outcomes Measurement; Kagan et al., 2008)*



The A-FROM captures four domains that are relevant to the HRQL for PWA (Figure 3; Kagan et al., 2008). The **Participation in Life Situations** domain refers to PWA participating in their life and doing activities that are relevant to them. This domain captures social support and activity level. Included in the **Personal Identity, Attitudes and Feelings** domain is information about the identity, emotions, and attitudes of the PWA, which can change over time. The personal identity domain captures emotional distress, fatigue, comorbidities, sex/gender, ethnic background, marital status, SES, employment status, and level of education. The **Communication and Language Environment** domain refers to the barriers and facilitators in the PWA’s life. Captured in the communication and language environment domain are activity level and social support. The **Severity of Aphasia** domain (also called the “Language and Related Impairments” domain in other versions of the model) refers to the communication challenges that result from aphasia. The severity of aphasia domain captures communication disability, fatigue, cognitive ability, time post-onset, and type of stroke. Each domain of the A-

FROM is represented in a Venn diagram, illustrating the overlap that exists across domains. In the centre of the diagram where all four domains intersect, a fifth category **Living with Aphasia**, reflects the overall HRQL of PWA (Kagan et al., 2008). According to the A-FROM, HRQL in PWA is a product of one's aphasia severity, communication/language environment, participation in life situations, and their identity, attitudes, and feelings. For example, if two PWA have the same level of impairment, they may be observed to be the same – requiring the same supports and intervention. However, one of the PWA has a supportive family that helps them to practice their speech and attends activities such as bingo together, and the other has personal factors, such as anxiety, that make it hard for them to do chores or activities in the community. With this additional information gained using the A-FROM framework, even though the language impairment is the same, these two PWA require different supports and interventions to reach their goals.

Overall, aphasia can negatively impact all domains of the A-FROM and by extension, HRQL. However, the study of HRQL in PWA is challenging for several reasons. First, available research studies have used different assessments and data collection methods to discover factors related to HRQL. This can make comparison and synthesis of information difficult, as different assessments and methods are likely measuring and exploring slightly different aspects of HRQL. Further, not all methods used are in aphasia-friendly formatting (i.e., in a format with simple language and graphics to help PWA understand), which could also impact the responses of PWA, and therefore, the overall results. Finally, some studies also continue to include proxy responses (i.e., family members, SLPs) instead of or in addition to directly asking PWA about HRQL. It should be noted that the level of evidence for the factors or predictors of HRQL of PWA also requires further exploration and improvement. In my doctoral research, some of these

challenges will be addressed by: 1) using assessments recommended by the core outcome measures for aphasia research (Wallace et al, 2019); 2) using aphasia-friendly formatting for all shared documents; and 3) directly collecting responses from PWA.



## Chapter 3

### Understanding the impact of group therapy on health-related quality of life of people with Aphasia: a scoping review<sup>2</sup>

#### Introduction

Aphasia is a communication disorder caused by damage to the language areas in the brain, resulting in difficulty with speaking, understanding, reading, and writing. Aphasia can result at any age, but most often occurs in elderly individuals after a stroke (Simmons-Mackie, 2018). The majority of strokes happen to those over the age of 60 (Feigin et al., 2014; Simmons-Mackie, 2018). Currently, there are estimated to be millions of people living with aphasia around the world (Simmons-Mackie, 2018; Wittenauer & Smith, 2012). As the population ages, the prevalence of stroke and other neurodegenerative diseases is estimated to increase, resulting in a subsequent increase in associated aphasia (Feigin et al., 2014; Wittenauer & Smith, 2012). Adequate rehabilitation programming to support the quality of life (QoL) of people with aphasia (PWA, i.e., adults with aphasia) is needed to help manage this chronic condition. To explore whether the rehabilitation resource of group speech and language therapy provides a beneficial impact on the QoL of PWA, we conducted a scoping review.

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<sup>2</sup> A version of this chapter has been published: Wilson, C., Jones, A., Schick-Makaroff, K., & Kim, E.S. (2021). Understanding the impact of group therapy on health-related quality of life of people with Aphasia: a scoping review, *Speech, Language and Hearing*, DOI: 10.1080/2050571X.2021.1917216

### ***Resources for people with aphasia***

Most health care funding focuses on rehabilitation in the acute or sub-acute stages of aphasia. Unfortunately, once PWA have utilized acute therapy resources, and enter the chronic stages (four months post-onset or longer), fewer therapy options are available to support their needs. PWA are not receiving adequate follow-up in chronic stages due to a lack of funding and high demand for services by those with more acute needs (Hersh, 2018; Simmons-Mackie, 2018; Wallace, 2010). For communication-related needs, group speech and language therapy (i.e., speech and language rehabilitation treatment delivered to multiple people at the same time in a shared space) is one of the few cost-effective options that people with chronic aphasia have for rehabilitation. To this point, most research attention has been focused on how group speech and language therapy impacts language impairments for PWA, and the impact of group therapy on their QoL is not always considered as a relevant outcome.

Group therapy is an efficient and cost-effective way to provide services to people with aphasia in the chronic stage (Elman & Bernstein-Ellis, 1999). Community programmes, sometimes called aphasia centres, are the way most people with aphasia access group therapy and are often facilitated by Speech-Language Pathologists (SLPs), SLP students, volunteers, or multi-disciplinary teams. A range of activities such as singing, art, ‘toastmasters’ (public speaking), or book clubs can be used in group therapy. These activities contain a social component in that PWA meet others with aphasia and interact within a supported communication environment. The variety of activities offered through group treatment is client-centred, as PWA are provided with various options related to their preferences, interests, and strengths.

Outcomes from group therapy have generally been mixed in terms of language impairment measures (Attard, Lanyon, Togher, & Rose, 2015), however, some researchers have reported positive gains in communication-related outcome measures such as PWA taking more turns speaking and demonstrating an increased ability to participate in discussions (Cicccone et al., 2016; Hoover & Carney, 2014; Hoover, Caplan, Waters, & Carney, 2017; Lanyon, Rose, & Worrall, 2013; Rodriguez et al., 2013). Although an increase in communication participation can be reflective of increased QoL, it is currently unclear whether group treatment has a direct impact on QoL (Kagan, 2011). However, certain aspects related to QoL, such as life satisfaction and social interaction have been shown to improve with group therapy (Armour, Brady, Sayyad, & Krieger, 2019; Attard et al., 2015; Heart and Stroke Foundation, 2017; Lanyon et al., 2013).

Adults with aphasia may have difficulty maintaining social networks and social supports after acquiring aphasia for many reasons including language challenges, loss of shared activities, energy levels, and unhelpful responses from others (Northcott & Hilari, 2011; Northcott, Moss, Harrison, & Hilari, 2016). PWA have more challenges maintaining social contacts and participating in social activities than adults of the same age without aphasia, and PWA have identified social relationships as being particularly important to their well-being (Cruice, Worrall, & Hickson, 2006; Ross & Wertz, 2003). Group therapy is one way that SLPs might be able to help mitigate losses through opportunities to establish new social networks, especially for group members who have a shared experience of living with aphasia (Brown, Davidson, Worrall, & Howe, 2013; Northcott et al., 2016; Vickers, 2010). Understanding how group therapy might mitigate social network losses would require the use of social measures as one of the outcome measures for group therapy.

Systematic reviews of group treatments have examined language outcomes of group therapy for PWA (Lanyon et al., 2013), and perspectives of PWA on these language-focused group therapies (Attard et al., 2015). Lanyon et al. (2013) reviewed group therapy studies of PWA using the World Health Organization International Classification of Functioning, Disability, and Health (WHO-ICF) framework to determine the effectiveness of the interventions. Their review demonstrates that group therapy can be effective for improving specific linguistic processes when these are the target of therapy. Lanyon et al. (2013) also indicated that group therapy may improve social networks. Expanding upon this work, Attard et al. (2015) reviewed qualitative research studies examining the perspectives of PWA who have attended group therapy. They reported that PWA valued their group therapy experiences and their personal growth improved along with their relationships with others. QoL was not directly addressed by these reviews. In previous work, PWA have stated that mental attitudes, emotion, communication, socialization, and participation are all factors that contribute to their QoL (Cruice, Hill, Worrall, & Hickson, 2010; Le Dorze & Brassard, 1995). To our knowledge, no reviews of QoL outcomes, including outcome measures such as social and mood measures, following group therapy have been conducted to date.

### ***Quality of life for people with aphasia***

Understanding QoL for PWA can help in the development of intervention programmes appropriate for the chronic stage of aphasia (Hilari, Wiggins, Roy, Byng, & Smith, 2003b).

Although many definitions of QoL exist with synonyms such as ‘well-being’ or ‘life satisfaction’, most research studies avoid providing a definition. For this scoping review, we took the definition from the World Health Organization (WHO) and consider QoL to be:

an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment ("WHOQOL: Measuring Quality of Life", 2018, p. 1).

Indeed, the components of the WHO-ICF model (disability, activities, participation, contextual factors – personal, environment) are encompassed in this definition of QoL. However, the WHO-ICF model does not currently capture how QoL outcome measurements fit into the construct of QoL within the model (Simmons-Mackie & Kagan, 2007).

The Living with Aphasia: Framework for Outcome Measurement (A-FROM) is a model of real-life outcome measurement in aphasia which draws on the WHO-ICF model, among other models concerning health and disability, which makes the A-FROM well-suited to consider QoL outcome measures concerning aphasia research (Chapey et al., 2000; Kagan et al., 2008). Many measures of QoL used with PWA include questions with references to these A-FROM domains. The A-FROM model assumes QoL for PWA is impacted by the interaction between the communication environment, personal factors (e.g., mood), language impairments, and participation in life activities (e.g., social interactions; Kagan et al., 2008). This framework encompasses the QoL definition from above and looks at the individual as a whole person. For example, physical health may be encompassed within personal factors (i.e., how PWA feel about physical health) or participation (i.e., how physical health might impact participation of PWA). Further, previous research with PWA (Cruice, Worrall, Hickson, & Murison, 2003; Northcott et al., 2016; Northcott & Hilari, 2011) has identified that communication impairments can impact QoL. The A-FROM model can also be adapted to address the group dynamics (i.e., group

environment), personal factors group members may bring, language impairments that vary with each group member, and the activities of group members. Therefore, the model can be applied to each member, as well as to the group as a whole.

However, considering that aphasia is a disease-specific condition, it is also appropriate to examine definitions of health-related quality of life (HRQL). Patrick and Erickson (1993) provide a relevant definition often utilized by HRQL researchers:

The measure in which the assigned value is modified to the duration of the life in function of the perception of physical, psychological and social limitations and the decrease of opportunities due to the disease, its sequels, the treatment and/or the health policies (as cited in Romero, Vivas-Consuelo, & Alvis-Guzman, 2013).

Both HRQL and QoL are multidimensional constructs, and these terms are often incorrectly used interchangeably. The distinctions between the two concepts are nuanced and often confused (see Karimi & Brazier, 2016). For the purposes of this paper, we will use the term HRQL, as this is the term used in our field and will be most familiar to speech-language pathologists.

### ***The current study***

We selected a scoping review as opposed to a systematic review to determine the extent of the emerging evidence and research available concerning HRQL outcomes of group speech and language therapy for PWA (Arksey & O'Malley, 2005; Levac, Colquhoun, & O'Brien, 2010; Munn et al., 2018). In particular, the primary objective of this scoping review was to identify, summarize, and appraise peer-reviewed texts that examine HRQL in PWA attending group therapy. A secondary objective was to understand what HRQL measures were being used

and what these measures tell us about group therapy delivered to PWA. In this examination of HRQL measures, it was also our intention to explore concepts related to HRQL such as social interaction and mood, which when combined, may be proxy measurements to HRQL. It is important to understand how group therapy impacts the HRQL of PWA, as group therapy can often include aspects that reach beyond communication and into general life participation.

## Methods

Our scoping review was informed by Arksey and O’Malley (2005), with updates and modifications by Levac et al. (2010) and Peters et al. (2015). We also followed the guidelines laid out by Tricco et al. (2018) for reporting scoping reviews. The research questions were framed using the PICO process (Table 1).

**Table 1.**  
*PICO Process.*

<b>PICO Process</b>	
P (population)	Adults with Aphasia
I (Intervention)	Group speech-language therapy
C (comparison)	N/A
O (outcome(s))	Measures of: Quality of Life or Health-Related Quality of Life  Also considered are measures of Language, Social, and Mood

The following questions guided the integration of studies:

1. What measures did researchers use to capture HRQL outcomes (including related measures such as social and mood) and language outcomes?

2. What group interventions were provided to PWA?
3. Does participation in group treatment result in a change of HRQL for PWA according to quantitative outcome measures?
4. Does participation in group treatment result in a change of HRQL for PWA according to qualitative descriptions provided by PWA?

### ***Data sources and search strategies***

Search strategies were developed and implemented using the PICO process as outlined in Table 1 by the first author (CW) and a health-sciences librarian for five electronic databases (Ovid Medline, Scopus, CINAHL Plus, PsycInfo, and Embase). The key terms and concepts related to aphasia, group therapy, and HRQL are included Appendix 1.

The initial search of the literature was carried out in June 2019. Following feedback from co-authors an additional database (Scopus) was added to the search, and searches were updated to check for new publications in July 2020. Studies were considered for inclusion if published in a journal before July 31, 2020. Articles were restricted to English and French language. This search was registered with the Open Science Framework (doi: 10.17605/OSF.IO/NJFYA).

The first and last authors developed inclusion and exclusion criteria before the title and abstract screening. The inclusion criteria consisted of (1) Participants were adults in the chronic stage of aphasia (i.e., at least 4-months post-onset; Worrall, 2014); (2) Speech-language therapy had to be provided in a group context and could not be a mix of individual and group therapy. Therapy groups were defined as having two or more members, excluding when the only members of the group are dyads (i.e., two PWA would be considered a group, but two people



consisting of PWA plus their support person is not a group); (3) A generic or condition-specific HRQL outcome measure; (4) A qualitative description of HRQL for studies using qualitative methods. No criteria were put forward concerning the location of the group therapy. No specific outcome measures precluded studies from being included in the synthesis. The exclusion criteria for this review were: (1) Studies with participants diagnosed with Primary Progressive Aphasia or other dementias unless the data of PWA were presented separately. (2) Commentaries, editorials, and grey literature that did not include the use of QoL outcome measures.

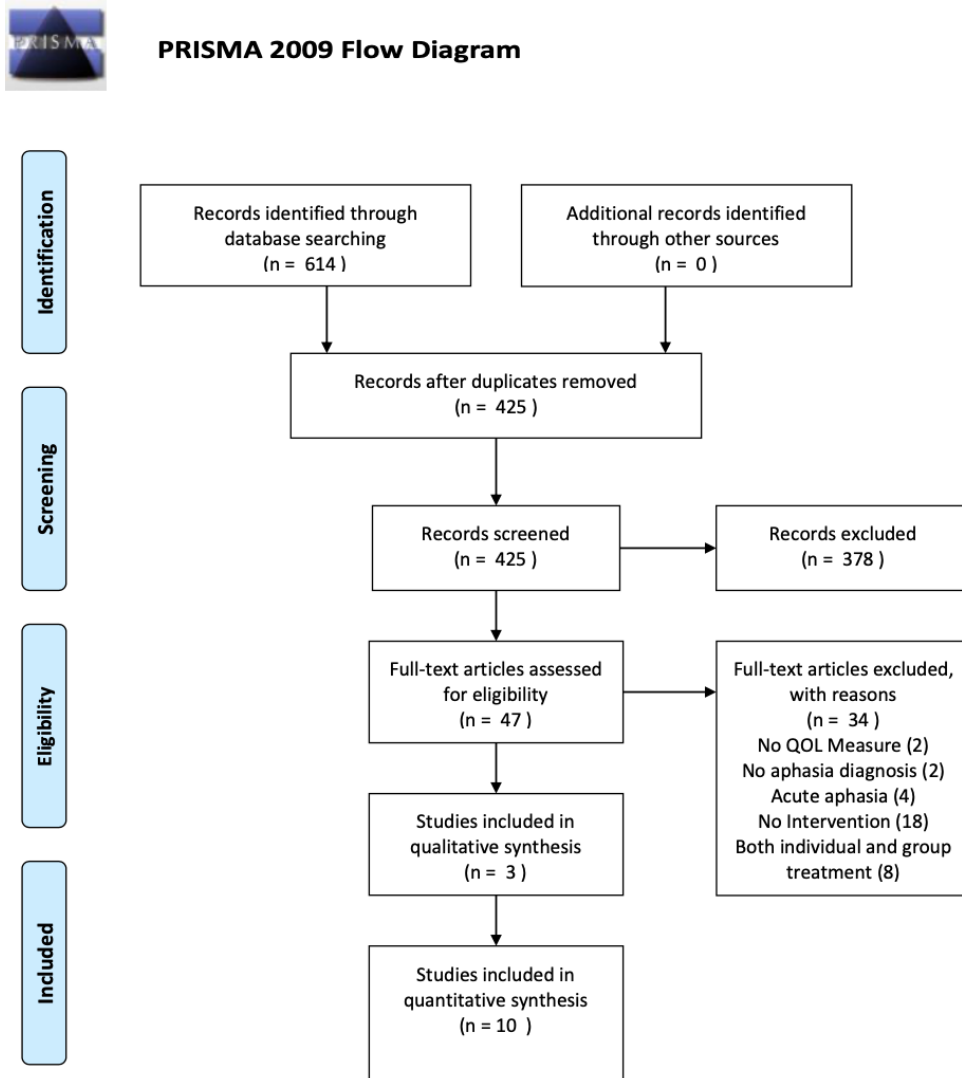
### ***Search***

All citations were uploaded to Covidence (Veritas Health Innovation Ltd., n.d.), and duplicates removed. The search identified 425 unique citations. Titles and abstracts were independently reviewed by a single reviewer (CW) with 47 identified, the full-text screening was completed by 2 reviewers (CW and EK). The inter-rater reliability analysis using the kappa statistic was completed to determine agreement between reviewers (Landis & Koch, 1997). The interrater reliability for the inclusion of full-text papers was moderate ( $\kappa = 0.46$ ). The main disagreements were regarding whether the articles met all inclusion criteria (e.g., did the paper provide aphasia diagnosis? What measure was included that is related to HRQL? Did the qualitative results address HRQL?). Any disagreements or uncertainties regarding inclusion were discussed until an agreement was made. Of these, 34 were rejected (see Figure 4 for details).

The first author (CW) read through each included paper to extract important information (i.e., participant characteristics, interventions, and outcome measures) and the last author (EK) completed checks of extracted material from 10% of papers. The final detailed extraction results are displayed in Appendix 2.

**Figure 4.**

*PRISMA process for identification of included studies.*



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit [www.prisma-statement.org](http://www.prisma-statement.org).

### *Quality assessment*

An analysis of the level of evidence and examination of the effectiveness, appropriateness, and meaningfulness of each qualitative study is provided below using quality appraisal checklists (Schick-Makaroff, MacDonald, Plummer, Burgess, & Neander, 2016).

The articles were reviewed to determine the study design to utilize the appropriate methodological appraisal checklist. The checklists developed by the Joanna Briggs Institute (JBI; Aromataris & Munn, 2020) were selected as they provide evidence-based appraisal tools with study design specific checklists. The methodological quality of each article was independently reviewed and evaluated by 2 authors (CW, EK), and then discussed and agreed upon by the authors for the final appraisal.

Eligibility criteria of participants were provided for all of the studies. The quality of Randomized Controlled Trials (RCTs) were assessed using the critical appraisal Checklist for Randomized Controlled Trials which consists of 13 items regarding the rigour and internal validity (The Joanna Briggs Institute, 2017). Case series studies were assessed using the critical appraisal Checklist for Case Series which consists of 10 questions (The Joanna Briggs Institute, 2017) which addressed participant identification, participant inclusion, and reporting of clinical and demographic information. Previously, pre/post case series were not appraised in reviews due to their less rigorous methodology and lack of appraisal method, but they were appraised in this scoping review (Lanyon et al., 2013; Togher et al., 2009). Qualitative studies were assessed using the critical appraisal Checklist for Qualitative Research which consists of 10 questions (The Joanna Briggs Institute, 2017) that appraised congruency of the study and ethical considerations relevant to qualitative research studies.

### *Classification of studies*

To classify the level of evidence and phase of evidence two authors (CW and EK) reviewed each included article independently using the level of evidence guidelines adapted by ASHA from the Scottish Intercollegiate Guidelines Network (SIGN) (“Assessing the Evidence”, n.d.; SIGN, 2018). Authors then met to discuss their ratings, presented in this paper. To classify the phase of evidence, Robey and Schultz’s (1998) 5-phase model of clinical outcomes that was adapted specifically for aphasia research was used. Objectives and methodology (including sample and design) of the studies were considered in classifying level and phase of evidence; results are presented in Table 2.

**Table 2.**  
*Study design, level, and phase of evidence of included studies.*

<b>Study Design</b>	<b>Article</b>	<b>Level of Evidence</b>	<b>Phase of Research</b>
RCT	DeDe et al., 2019	1b	3
	Zumbansen et al., 2017	1b	3
Qualitative Thematic Analysis	Lanyon et al., 2018	3	1
Qualitative Description	Fogg-Rogers et al., 2016	3	1
	Purves et al., 2013	3	2
Case series	Hoehn et al., 1997	3	1
	Pitt et al., 2018	3	2
	Plourde et al. 2019	3	1
	Ross et al., 2006	3	1
	van der Gaag et al., 2005	3	1
Pilot case series	Attard et al., 2018	3	1
	Brumfitt & Sheeran, 1997	3	1

	Pitt et al., 2017	3	1
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### ***Analysis***

To present a narrative account of the qualitative and quantitative results, we used stage 5 of the framework (‘collating, summarizing and reporting the results’) as described in Arksey and O’Malley (2005) and Levac et al. (2010). Descriptions of the participant, intervention, and outcome measure characteristics were noted. Based on common themes, intervention types were described. Then a framework, based on sections from the A-FROM was developed for the discussion of outcome measures. The A-FROM outcomes model represents HRQL as a construct that incorporates aspects of the Severity of Aphasia, Participation in Life Situations, Communication and Language Environment, and Personal Identity, Attitudes, and Feelings (Kagan et al., 2008). Therefore, these categories of measures were included to capture their contribution to HRQL. This framework allowed us to look for commonalities and gaps across the included studies.

### **Results**

Of the thirteen studies that met the inclusion criteria, the majority were case series (8) along with three qualitative studies, and two RCTs. The results of the qualitative studies will be presented along with the quantitative results in this synthesis. Studies reported sample sizes of the included studies ranges from 4 to 38 PWA. Most studies were from Canada, USA, UK, Australia, and New Zealand (see Appendix 2 for details). We first present the methodological quality and characteristics of included studies, followed by a presentation of the different types

of outcome measures used, quantitative results, and qualitative perceptions according to the three questions of this review.

***Analysis of methodological quality appraisal***

The mean appraisal score for the 2 RCTs was 10 (SD = 1.41); the main issues concerned blinding of participants and therapists who delivered the treatment intervention. The mean appraisal score for the 8 case series studies was 6.13 (SD = 1.64); information was often lacking concerning complete and consecutive inclusion of participants, where the clinic’s participants were recruited from, and how aphasia was measured and identified. The mean appraisal score for the qualitative studies was 7.33 (SD = 0.57). Of the qualitative studies, more information could have been included that contextually located the researcher and discussed their influence on the work. Further details regarding the exact scores for each article are presented in Table 3. Within the studies included in this scoping review, there were six higher-quality studies (defined as 80% or greater on the relevant appraisal checklist) and seven lower quality studies.

**Table 3.**  
*Appraisal of included studies.*

<b>JBI Study Design</b>	<b>Article</b>	<b>Appraisal Score as measured by JBI Checklists</b>
RCT	DeDe et al., 2019	9/13
	Zumbansen et al., 2017	11/13
Qualitative	Lanyon et al., 2018	8/10
	Fogg-Rogers et al., 2016	7/10
	Purves et al., 2013	7/10
Case series	Attard et al., 2018	7/9 *
	Brumfitt & Sheeran, 1997	5/10

	Hoen et al., 1997	3/10
	Pitt et al., 2017	7/9 *
	Pitt et al., 2018	7/9 *
	Plourde et al. 2019	7/10
	Ross et al., 2006	5/10
	van der Gaag et al., 2005	8/10

\* score out of 9 if one question was deemed “not applicable”

***Participant characteristics***

The total number of participants with chronic post-stroke aphasia (i.e., 4 or more months post-stroke) from the 13 included studies was 180. Reported time post-stroke varied, ranging from 4 to 264 months. The age of participants varied with a range of 21–90 years the majority of which were men (64.07%). The level of education was only reported for the two RCT studies with an average of 12 years. Ethnicity/Race was only reported in two studies (Fogg-Rogers et al., 2016; van der Gaag et al., 2005), with the majority (78.26%) of participants reporting a British or European background.

***Intervention characteristics***

This section of the synthesis will only focus on the 12 papers that provided specific information about the group therapy discussed in the article. Lanyon, Worrall, and Rose (2018), interviewed people about participation in group therapy; specifics of the various group interventions PWA attended were not discussed). Characteristics of the group intervention format are in Table 4 and include the number of members, how often they met, how long they

met for, and the duration of the group intervention, as well as who the facilitator was. The cost to attend sessions was not reported in the articles.

**Table 4.**  
*Group intervention characteristics.*

<b>Group Intervention Characteristics</b>	
Intervention Group Size	Range: 2 - 25 ; Mean 7 PWA, SD 5.35
Frequency of meetings	1 per week (11/13); 2 per week (2/13)
Duration of meetings	Range: 1 hour to “half-day”; Mode 1.5 hours
Duration of intervention	Range 7 - 192 weeks; Mean 28.9 weeks, SD 51.64
Group Facilitator(s)	SLP only (4/13) SLP and other professionals (students, volunteers, therapists, social workers, and communication assistants; 5/13) PWA and psychologist (1/13) Choir leader (2/13) Drama teacher (1/13)

### ***Interventions***

Within the 12 articles, eight different **formats** of interventions were employed amongst 24 therapy groups. Most interventions had a focus of improving language or communication through different modalities. All the intervention studies involved communication or social participation as the main aspect of the group therapy. However, the focus of the intervention differed slightly between studies. There were 3 studies where conversation was the focus of the intervention; two used **telerehabilitation for conversation treatment** and had pre-set topics of discussion each week (Pitt, Theodoros, Hill, & Russell, 2017; Pitt, Theodoros, Hill, & Russell, 2018), while one was an **in-person conversation treatment** with pre-set discussion topics (DeDe, Hoover, & Maas, 2019). Three of the interventions were more structured and involved



communication and conversation therapy with **education about identity, stroke, aphasia, and disability** (Attard, Loupis, Togher, & Rose, 2018; Ross, Winslow, Marchant, & Brumfitt, 2006; van der Gaag et al., 2005). Two of the interventions focused on **telling their stories and sharing experiences** and using role-play to practice certain communication situations and skills or activities similar to toastmasters (Brumfitt & Sheeran, 1997; Plourde et al., 2019). One of the interventions had a more casual goal of making friends through **exchanging ideas and providing support** for each other (Hoen, Thelander, & Worsley, 1997). There were also two interventions in which participants sang in a **choir**, where some individuals sang fluently (Fogg-Rogers et al., 2016; Zumbansen et al., 2017), a **drama group** where participants would learn to act (Zumbansen et al., 2017), and a **mentor programme** where PWA were the mentors for students or other PWA (Purves, Petersen, & Puurveena, 2013).

### ***Outcome measures***

In response to the first research question, what measures did researchers use to capture QoL outcomes, a range of outcome measures were used for pre- and post-testing across four broad categories: (1) language and communication, (2) HRQL, (3) mood and personality, and (4) social. A list of disease-specific, generic, and utility measures of HRQL generated from the studies reviewed is included in Table 5. All but one study (Hoen et al., 1997) used a language or communication measure, eight of the studies used HRQL measures, four studies used mood measures, and three studies used social measures.

**Table 5.**

*Outcome measures used in the included studies. References in brackets.*

Measure Category	Generic	Disease-Specific	Utility
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Language & Communication Measures <i>(Primary measures used in reviewed studies)</i>	FCP (Functional Communication Profile) (2)	WAB (Western Aphasia Battery) (1,2,4,6,9,10)	
	S24 (Attitude to Communication Scale) (2)	CETI (Communicative Effectiveness Index) (1,12)	
	AusTOMs (Australian Therapy Outcome Measures - Language Activity Rating Scale) (6)	CAT (Comprehensive Aphasia Test) (3,7,8)	
	COMACT (Communicative Activities Checklist) (8)	MPC (Measure of Participation in Conversation) (1)	
	TLC (Test Lillois de Communication) (13)	CCRSA (Communication Confidence Rating Scale for Aphasia) (1,9)	
	CIU (Correct Information Units) (13)	CAPPA (Conversational Analysis Profile for People with Aphasia) (11)	
	NAVS (Northwestern Assessment of Verbs and Sentences) (3)	MT-86 automatised series & Auditory Comprehension Subtests (Montréal-Toulouse Aphasia Battery) (13)	
	PNT (Philadelphia Naming Test) (3)	ACOM (Aphasia Communication Outcome Measure) (3)	
	Situational Communication Scale (2)		
QoL Measures	Ryff Scales of Psychological Well-Being-Short Form (5)	ALA (Assessment for Living with Aphasia) (1,7,8)	EQ-5D (EuroQol) (12)
	QCL (Quality of Communication Life Scale) (8)	SAQOL-39 (Stroke and Aphasia Quality of Life Measure) (12)	
	ASHA QCL (9)		
	SIP (Sickness Impact Profile-Short) (13)		
	WHOQOL-BREF (4)		
Mood & Personality Measures	RSE (Rosenberg Self-Esteem Scale) (2)	C-SADQ-10 (Community Stroke Aphasic Depression Questionnaire) (1)	
	HADS (Hospital Anxiety and Depression Scale) (2,11)		

	VASES (Visual Analogue Self-Esteem Scale) (11)		
	RLOC (Recovery Locus of Control Scale) (2)		
	VAMS (Visual Analogue Mood Scales) (13)		
Social Measures	MOS SSS (Medical Outcomes Study Social Support Survey) (1)		
	SNCI (Social Networks Communication Inventory) (1)		
	SIPSO (Subjective Index of Physical and Social Outcomes) (4)		
	Lubben Social Network Scale (3)		
Article References: (1) Attard et al., 2018 ; (2) Brumfitt & Sheeran, 1997; (3) DeDe et al. 2019 ; (4) Fogg-Rogers et al., 2016 ; (5) Hoen et al., 1997 ; (6) Lanyon et al., 2018 ; (7) Pitt et al., 2017 ; (8) Pitt et al., 2018 ; (9) Plourde et al. 2019 ; (10) Purves et al., 2013 ; (11) Ross et al., 2006 ; (12) van der Gaag et al., 2005 ; (13) Zumbansen et al., 2017			

**Language and Communication.**

Previous research has demonstrated that there are associations between higher communication abilities and higher HRQL (Cruice et al., 2003). Commonly used language and communication assessments (Western Aphasia Battery-Revised; WAB-R; Kertesz, 2007), Communicative Effectiveness Index (CETI; Lomas et al., 1989), Comprehensive Aphasia Test (CAT; Swinburn, Porter, & Howard, 2005), and Philadelphia Naming Test (PNT; Walker & Schwartz, 2012) were used as part of the primary assessment in 10 studies and helped to demonstrate baseline functioning and change in aphasia severity. Other studies used different language assessments (Appendix 2). All except one study (Hoen et al., 1997) used language or communication measures as a baseline (for qualitative studies) or outcome (for the quantitative studies).

## **Health-Related Quality of Life.**

Not all researchers consistently used the same HRQL measures as their peers. Only two investigative teams used established HRQL measures (WHOQOL-BREF; Harper, 1997) and EQ-5D (EuroQol Group, 1990), while the remaining used either indirect measures from which HRQL could be inferred, or provided qualitative descriptions related to HRQL. More details are provided below.

In two of the qualitative studies (Lanyon et al., 2018; Purves et al., 2013), specific HRQL measures were not used, but researchers provided information related to HRQL through discussion of the quotes from participants. Interview questions for the qualitative studies considered the condition (aphasia), communication, wellbeing, and information about the activities the PWA were participating in. All interviews in these studies were conducted one on one. DeDe et al. (2019) also did not specifically use a HRQL measure but did use a social network measure and a patient report of communication functioning. This information will be addressed in the treatment outcomes section below. Two studies (Brumfitt & Sheeran, 1997; Ross et al., 2006) did not use HRQL measures, but were included because the measures that they used together gave an impression of how the HRQL of participants was impacted by participating in group therapy, and therefore provided proxy information about the HRQL of participants as described below. In the Brumfitt and Sheeran (1997) study, the Recovery Locus of Control Scale (RLOC; Partridge & Johnson, 1989) measure was used to capture the internal and personal beliefs of participants, and they also used a satisfaction scale (five-point Likert scale with seven questions) to determine whether participants were satisfied with the intervention. Although not direct measures of HRQL, the RLOC measure of global self-worth

(Partridge & Johnson, 1989) and satisfaction measures together provide information about how the participants may perceive their HRQL while participating in the study (Margolis & Lyubomirsky, 2018). In the Ross et al. (2006) study, the Visual Analogue Self-Esteem Scale (VASES; Brumfitt & Sheeran, 1999) and Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) were used to consider aspects of psychological well-being, and Conversational Analysis Profile for People with Aphasia (CAPPA; Whitworth, Perkins, & Lesser, 1997) provided information about the language abilities of participants, which can be associated with their communication-related QoL.

### **Mood and Personality.**

Measures of mood and personality can give researchers insight into what personal aspects are relevant to creating a positive group therapy environment (Bays, 2001; Hilari, Needle, & Harrison, 2012). Four of the studies (Attard et al., 2018; Brumfitt & Sheeran, 1997; Ross et al., 2006; Zumbansen et al., 2017) measured mood/personality using tools such as the Rosenberg Self-Esteem Scale (Rosenberg, 1965) and the HADS (Zigmond & Snaith, 1983). The remaining studies (DeDe et al., 2019; Fogg-Rogers et al., 2016; Hoen et al., 1997; Lanyon et al., 2018; Pitt et al., 2017, 2018; Plourde et al., 2019; Purves et al., 2013; van der Gaag et al., 2005) did not evaluate the constructs of mood or personality in their work.

### **Social.**

Three studies (Attard et al., 2018; DeDe et al., 2019; Fogg-Rogers et al., 2016) included the use of social outcome measures (MOS-Social Support Survey; Sherbourne & Stewart, 1991), Social Networks Communication Inventory (SNCI; Blackstone & Hunt Berg, 2003), SIPSO

(Trigg & Wood, 2000), Lubben Social Network Scale (Lubben et al., 2006). Considering that group therapy is a social activity because participants have to interact with others, it is relevant to use social outcome measures to determine whether group therapy can improve the social lives of participants (Elman, 2006; Worrall & Holland, 2010).

### ***Treatment results***

Although the purpose of this review was to examine HRQL outcomes from group treatment for PWA, the included studies had an overall focus on language and communication outcomes with HRQL being a secondary outcome measure. We will briefly touch on the language outcomes here (as language and communication are a part of the A-FROM framework which illustrates the domains contributing to HRQL in aphasia) and then will consider the second research question, does participation in group treatment result in a change of HRQL for PWA according to quantitative outcome measures.

Overall, in the quantitative studies, language, which was the target of the group therapy, improved. However, not all researchers demonstrated a statistically significant change in language measures in their studies. Brumfitt and Sheeran (1997) demonstrated improved communicative behaviour as measured by the Functional Communication Profile (FCP; Sarno, 1975) and evaluations of communicative situations, and participants in the DeDe et al. (2019) conversation group improved their communication functioning as measured by the Comprehensive Aphasia Test (CAT; Swinburn et al., 2005). The Fogg-Rogers et al. (2016) choir group improved in language as measured by the WAB-R (Kertesz, 2007), Both groups of participants in Pitt et al.'s studies (2017, 2018) increased their amount of communication, and Ross et al. (2006) observed a change in conversation although this was not statistically

significant. van der Gaag et al. (2005) observed an increase in communication independence in their participants as measured by the CETI (Lomas et al., 1989), and Zumbansen et al. (2017) found no changes in language profile after group therapy but suggested that their small sample size may have impacted the effect (Zumbansen et al., 2017).

Similar to previous literature, the collection of articles included in this scoping review demonstrate mixed results about whether group therapy has an impact on language outcomes (Attard et al., 2015). It is clear that group therapy resulted in increased frequency and quantity of communication participation in PWA. This improvement in communication was demonstrated across all studies that used language outcome measures, regardless of the type of outcome measure.

HRQL measures seemed to identify generally positive outcomes of group therapy for participants. In the Attard et al. (2018) study, half of the 4 participants reported improvement in their scores for Assessment for Living with Aphasia (ALA; Kagan et al., 2011). Hoen et al. (1997) used the Ryff Scale of Psychological Well-Being (Ryff, 1989) and reported an overall positive change in HRQL related to self-acceptance, independence, and growth. Pitt et al. (2017, 2018) and Plourde et al. (2019) reported an improvement in communication-related QoL. No statistically significant HRQL related changes were reported in the Ross et al. (2006), Zumbansen et al. (2017), and van der Gaag et al. (2005) studies.

It is difficult to determine whether there was a wide-spread improvement in mood and social measures as not all researchers used measures to address these aspects. For example, in the Fogg-Rogers et al. (2016) paper, the interviews indicated that PWA felt an improvement in their mood following participation in the choir, and in the van der Gaag et al. (2005) study participants

felt increased confidence in their communication attempts after the intervention. The Attard et al. (2018), Brumfitt and Sheeran (1997), and Ross et al. (2006) articles used measures that evaluated mental health and participants remained stable without change, but in general, were not at risk of depression before participating in the studies. Attard et al. (2018) found a limited change in the size of the social networks and feelings of social support through the MOS-Social Support Survey and SSCI, as only some participants expanded their social network responses to include members of the group therapy.

### ***Participant perceptions of treatment***

In response to the third research question, does participation in group treatment result in a change of HRQL for PWA according to qualitative descriptions provided by PWA, the ideas about language, communication, and HRQL improving through group therapy presented above can also be expanded upon from the perspective of PWA. The data we extracted from qualitative papers included quotes and analytic notes taken from both results and discussion sections. The Fogg-Rogers et al. (2016) study interviewed PWA from a choir, the Lanyon et al. (2018) study interviewed PWA who had been to group therapy previously, and Purves et al. (2013) interviewed PWA who were acting as mentors and teaching students about aphasia. The researchers all remarked that participants were actively seeking a safe environment to participate in, with the potential to meet others and make friends. Fogg-Rogers et al. (2016) discovered that participating in choir improved feelings of social isolation for PWA. In DeDe et al. (2019), there was no significant change in the social network, however, participants suggested that they were more interested in meeting with old friends than making new ones.



PWA in these studies hoped that participation in group therapy would improve their communication and language. However, because these PWA were in the chronic stage of aphasia, large changes in communication or language were not expected. Therefore, expectations were focused more on meeting others with aphasia, gaining confidence, and having meaningful but structured activities where everyone can participate, and no one is left out. Zumbansen et al. (2017) note that attendance in social activities does correlate with changes in functional communication, which could explain the improved confidence in communication ability PWA felt after group therapy. PWA noted that a facilitator was important to create a structure of turn-taking and prepared topics; but if the facilitator is not genuine, PWA may feel unsupported (Lanyon et al., 2018). According to the participants, laughter and humour in groups helps to demonstrate solidarity, manage identities, cope with awkward moments, mitigate disagreements, avoid topics, and increase the likability of the group members (Lanyon et al., 2018). When PWA are supported, they are excited, have fun, feel that their mood and confidence increase, and they feel valued. All these benefits of group therapy may help to increase the HRQL of PWA.

## **Discussion**

In this scoping review of group therapy for PWA, we sought to examine what measures were being used to capture HRQL outcomes, and whether group therapy had an impact on HRQL of PWA. Few researchers used explicit measures of HRQL when evaluating group therapy with PWA, yet many included different dimensions of HRQL with different types of outcome measures (language, mood, social). Results across studies revealed an unclear impact of group therapy on HRQL based on quantitative measures, but evidence from qualitative studies seemed to suggest aspects of HRQL improved as a result of participation in group therapy.

Studies included in this review incorporated a variety of interventions. As such, the purpose of the groups differed, and outcome measures included in these studies were reflective of the aims targeted by the specific interventions. HRQL and related concepts were often considered secondary to the primary language/communication outcomes.

Overall, the results of the reviewed quantitative studies demonstrated that group therapy had an unclear impact on HRQL for PWA. It was difficult to determine whether group treatment resulted in a change in HRQL of PWA because many researchers did not utilize a standardized HRQL measure. This may be due to the lack of consensus on which measures to use for HRQL, language, mood, and social outcomes. As well, the group therapy was not done with the intention to improve HRQL, and so HRQL was not the main outcome considered for the included studies.

Administering measures of mood can help researchers understand how participants feel and perceive the benefits of group participation. It is also possible that cognitive status has a part in the perception of well-being including cognitive measures could strengthen evidence related to the well-being of PWA (Margolis & Lyubomirsky, 2018). This suggestion is consistent with previous reviews that suggest more information about group participants is required to determine how HRQL can be captured by measures and impacted by group therapy (Attard et al., 2015; Lanyon et al., 2013). The wide variety of outcome measures used in our review make comparison difficult. For example, the study by Hoen et al. (1997) was more focused on psychological well-being, and so they may not have been interested in using a language outcome measure. It is also possible that the measures used were not sensitive enough to capture a change in the chronic stages of recovery. As well, any exploration of therapy outcome is to some extent constrained by the outcome measures selected. The use of both quantitative measures and

qualitative interviews can provide more insight into the experience of therapy and the therapy's impact on PWA.

According to the qualitative results of the included studies, participants reported improved confidence and better mood following participation in group therapy (Fogg-Rogers et al., 2016; Lanyon et al., 2018; Plourde et al., 2019), but this was not always reflected in quantitative pre/post outcome measures as mentioned above. For example, some participants in studies reported no change in HRQL or negative changes in self-acceptance following group therapy. This may have been related to an increased awareness of their impairments through the process of group therapy participation. Therefore, reported HRQL outcomes may not have captured actual changes related to variables of interest. This is where the benefit of qualitative research – asking participants why they feel a specific way – becomes evident. Reading the experiences of PWA, it was clear that there were direct benefits of participation in group therapy, mediated by factors including mood and social engagement. The fact that PWA discussed looking for safe environments to participate and meet others plays into the idea of there being few resources and therapy options available for people with chronic aphasia, and the reduced social networks PWA can experience (Bays, 2001; Brown et al., 2013; Lanyon et al., 2018). The articles reviewed support previous findings that group therapy can have a positive impact on HRQL through satisfaction with therapy and feeling more positive toward the self (Armour et al., 2019; Attard et al., 2015). Due to the limited information available for this scoping review, we looked at a variety of constructs (including satisfaction with therapy) to make inferences regarding HRQL of PWA. We recognize that this is a constraint as these measures are not meant to be used to explore HRQL. However, within the A-FROM model, it is clear that concepts such as satisfaction with therapy, mood, social networks, and language all contribute to HRQL even if

they are not a direct measure of HRQL in the traditional sense. Therefore, the results discussed here, and positive findings from self-reports from PWA are evident and encouraging, but more robust, well-designed and administered studies are required.

The findings from this scoping review contribute to the body of knowledge and identify that aphasia researchers require consistent outcomes of group therapy, in particular for HRQL so that comparison across studies is possible. There is recent evidence that demonstrates speech-language pathologists as a field are moving towards this ideal. A publication by Wallace et al. (2019) outlined the process and decisions of the Research Outcome Measurement in Aphasia (ROMA) consensus statement. This document outlines a recommended set of outcome measures for language impairment (WAB-R, Kertesz, 2007), quality of life (SAQOL-39; Hilari, Byng, Lamping, & Smith, 2003a), and emotional well-being (GHQ-12; Goldberg, 1978) for researchers to use in studies reporting outcomes in PWA. As this consensus statement was published after the majority of papers included in this review, very few of the studies reviewed included the recommended measures. Future researchers should consider following the ROMA consensus statement recommendations when planning which outcome measures to use in research with PWA. Indeed, recent publications have adopted these recommendations (Armour et al., 2019) and we expect future studies will continue to do so. As researchers move forward, it may be advantageous to focus on the use of a specific subset of HRQL measures and specific communication-related measures that are relevant to life with aphasia. As mentioned, some outcome measures used may not be sensitive enough to capture a change, especially a change that is statistically significant, in the chronic stages of recovery. We believe that clinically significant measures, including HRQL measures, may become more important than statistically

significant measures at the chronic stage when evaluating therapy outcomes (Bothe & Richardson, 2011).

### ***Limitations***

Some limitations should be considered concerning this review. As previously stated, many different outcome measures were used across studies, and so categories were assigned to allow for a simplified comparison. Factors that impact HRQL and are aligned with the A-FROM were used for classification of these outcome measures into categories. As part of the inclusion criteria, articles with a combination of group and individual therapy were excluded. Had these articles been included there would have been more evidence to draw from concerning the efficacy of group treatment for improving HRQL, but it would also be unclear as to whether it was the group or individual therapy that made this change.

This review was limited by the availability of characteristics reported in included studies, such as a lack of the use of HRQL measures and variability in the characteristics of participants and the way that characteristics were reported in the included studies. For example, education and race/ethnicity was under-reported, and we suggest that future studies report education, race/ethnicity, and other characteristics of participants such as age and time post-stroke in a clear manner so that in the future more detailed demographic comparisons can be made across studies.

### **Conclusion**

HRQL is becoming a more frequently used measure to evaluate the impact of speech and language-related interventions. It is necessary that SLPs learn more about how to effectively manage HRQL through participation in group therapy, as this is a cost-effective way to help

PWA. We have reported on evidence that suggests PWA are experiencing improved HRQL, confidence, and socialization with peers due to group speech and language therapy, however, we need to continue to measure the constructs related to HRQL more effectively to understand how best to continue group therapy programming (Fogg-Rogers et al., 2016). The 13 studies varied in terms of what comprised group therapy and outcome measures that were used to capture change. Although aphasia groups are associated with the potential to improve HRQL, further research is required to inform practice and support clinicians to establish aphasia groups and use standardized outcome measures to capture change. Currently, group therapy refers to a wide range of activities and purposes, many of which are discussed in this paper. A more specific definition of group therapy, beyond what is provided in this paper, is needed. A more fulsome definition would not only advance the field of aphasiology but assist future reviews.

Further well-designed studies are necessary to improve the level of evidence available concerning our understanding of the impact of group therapy on the HRQL of PWA. From this review is it clear that HRQL measures are not able to capture the entire experience and reasoning behind ratings, and that HRQL is a difficult construct to measure. Using a standard measure of HRQL such as the ALA (Kagan et al., 2011) or SAQOL-39 (Hilari et al., 2003b), as recommended by the ROMA consensus statement (Wallace et al., 2019) will help; however, researchers also need to consider the use of qualitative approaches such as interviews, which can help to provide a rich depiction of group-based speech and language therapy. Mixed method studies may be an approach to consider, to embrace the findings from both qualitative and quantitative research with PWA

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## **Chapter 4**

This chapter outlines the methodology, methods and methodological decisions made for this study. To illustrate this, an overview of case study including the methodology, types, misunderstandings, and strengths is also presented along with the impact of COVID-19 on the research.

### **Situating the Researcher**

Before beginning the MSc-SLP/Ph.D. program, I completed a research-based Master of Science in Health and Rehabilitation Sciences (Speech and Language Science) and volunteered for over 400 hours with SLPs. Many of the questions that have emerged to shape my doctoral work have come from these experiences and will be presented in the following pages.

In my health and rehabilitation science masters, I was introduced to the concept of communication-related quality of life, and I started to think about what quality of life is and what it means. During this time, I was also volunteering on a stroke rehabilitation unit in a hospital and was introduced to aphasia for the first time. As a SLP volunteer, I was able to observe therapy sessions and see how the PWA reacted and dealt with their challenges. I was inspired by how hard the PWA worked to reclaim what they had lost because of their stroke. As aphasia is a communication disorder, and I had a new interest in communication-related quality of life, I started to think about how improving their language and communication abilities MUST improve their quality of life. For some PWA, I saw exactly that, but more often I saw people not making great improvements and still feeling happy about their progress. I also saw people making amazing progress, but not feeling like any successes were ever enough. I realized that I wanted to work clinically and at the same time carry out research related to these clinical questions. From a clinical perspective, I wanted to make sure my clients were feeling happy and successful, and



therefore having an improved quality of life. However, the research did not tell me how to do that, nor did it tell me what the most important factor related to quality of life was for PWA. This led me to explore the concept of quality of life and quality of life measures being used clinically with PWA.

### ***Situating myself within this work***

At the beginning of my doctoral course work, I was not sure what epistemological underpinnings I would use to identify myself and my research. Much of my education to this point had been quantitative and firmly in the positivist paradigm (Ponterotto, 2005). Due to my previous research experience, I was comfortable working in this paradigm, but I felt that something was missing from the “big picture” in many projects. Questions without answers. When I began to consider research questions for my doctoral work, the ones that were most interesting to me could not be answered with a positivist approach. It was time to branch out to see what other paradigms could help me answer my questions.

I had taken a qualitative course during my masters, but I was not ready to “pinhole” myself. I needed to learn more about the various paradigms and what they could offer. I took another qualitative course as part of my doctoral course work, and through the readings and discussions of this course, I found myself identifying with pragmatists. Pragmatism essentially allows researchers to use whatever tools help to answer the research question (Morgan, 2007), and I liked the idea of seeing the world through all the lenses available and then picking the one that fits best. I also identified with critical theorists, who aim to reveal how societal and political history impact people’s experiences today (Ponterotto, 2005). With aphasia, society can often misconceive PWA as being less intelligent or incapable, which is not the case. With my interest in HRQL, and with awareness that societal and historical views impact how PWA are viewed

today, the idea of using a critical theory lens was interesting to me.

As I progressed through the program and continued to read more qualitative papers, I noticed that my thinking for my current project was becoming aligned with the constructivist-interpretivist paradigm. Inquiry in the constructivist-interpretivist paradigm aims to understand and put together constructions of the reality of the researcher and research participants (Guba & Lincoln, 2004). Ontologically, I see that there are multiple realities with multiple meanings and subjective views (Finlay, 2006). I aimed to put the stories I would hear from PWA first, however I also realized that I could not entirely separate my interpretation from the stories PWA would tell me.

It can be difficult to choose a paradigm when I am continuing to learn about and explore all that the different paradigms have to offer me as a researcher. I believe that the position I currently hold will change with new experiences and in the process of my growth and development as a researcher, but my doctoral work is situated in the constructivist-interpretivist paradigm.

### **Why Case Study Methodology**

Multiple methodologies were explored and considered to determine what would be the best fit for the research questions/objectives. I liked the idea of becoming immersed in the culture of aphasia and collecting data from multiple sources to allow for an in-depth and detailed understanding of the lived experience of PWA. I also recognized that I needed a method that would fit well within my constructivist-interpretivist perspective and would be something that Speech-Language Pathologists and researchers alike could understand and relate to. After careful reading, discussions, and consideration of other methods that did not properly suit this project, it was decided that a case study methodology would meet my aims. Researchers use a case study

when the phenomenon's variable cannot be separated from the context (Yin, 2009). A case study is also relevant when researchers have 'how' or 'why' questions when behaviour cannot be manipulated because the context is relevant to the phenomena (Yin, 2009). More specifically, a collective case study (Stake, 2006) was selected to investigate the phenomena because it allowed me to explore the individual PWA as cases within each therapy modality, as well as consider the PWA as a group through cross-case analysis.

### **Case Study Methodology**

Case study research has been done throughout history and with many different approaches by both quantitative and qualitative researchers. Qualitative case study research is defined as an exploration of "a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information (e.g., observations, interviews, audiovisual material, documents and reports), and reports a case description and case-based themes. (p. 73, Creswell, 2007)". A case can be a single person, process(es), program, group, institution, community, event, or policy (Merriam, 2009; Stake, 1995, 2000; Yin, 2009). Cases can be bound by time and place (Creswell, 2003), time and activity (Stake 1995), or definition and context (Miles & Huberman, 1994). An inductive approach is used when data and observations are used to generalize and sometimes build theories.

### ***Case study perspectives & types***

There are three main case study researchers that qualitative investigators draw on: Merriam, Yin and Stake. Merriam's approach is more focused on gaining in-depth understanding through thick descriptions and understanding the phenomena through the eyes of the participants (Merriam, 1998, 2009). Yin views a case study as empirical and relies on many data sources and

theories to guide the research (Yin, 2009). In Stake's opinion, the goal of the researcher is to focus on nuances, sequentially, and the whole individual within context. These researchers differ in their ontological perspectives, and as a constructivist, Stake's approach resonated most with how I wanted to conduct my doctoral research. Stake conceptualizes a case study as drawing from "naturalistic, holistic, ethnographic, phenomenological and biographic research methods" (Stake, 1995. p. xi). This fits well with my interest in ethnographic culture perspectives.

Stake has described three types of case studies, which include intrinsic, instrumental, and collective. An **intrinsic case study** is when the case itself is the focus of interest (Stake, 1995, 2000). An **instrumental case study** is when the researcher wants to gain a deep understanding of the case (Stake, 1995, 2000). A **collective case study** is when multiple instrumental cases are compiled to "lead to better understanding, perhaps better theorizing, about a still larger collection of cases" (Stake, 2000, p. 437). For this study, I have chosen to conduct a collective case study, composed of a diverse collection of instrumental case studies to examine how the context of different types of therapies impacts the quality of life of PWA, as well as to better understand any similarities or differences for why different therapies could have different impacts.

### ***Criticisms & misunderstandings of case studies***

Qualitative case studies, like other forms of qualitative research have received criticisms such as the inability to generalize, they are only suitable as a pilot study, and that the researcher's interpretation is overly emphasized (Flyvbjerg, 2006; Merriam, 2009; Thomas, 2011; Yin, 2009). Flyvbjerg (2006) wrote a seminal paper explicitly outlining the misunderstandings of case studies and supporting the use of case studies. The misunderstandings outlined include that context-independent knowledge is more valuable, case studies cannot be generalized and therefore cannot contribute to science, case studies are only useful for generating hypotheses, the

researcher's preconceived notions are easily verified, and that it is difficult to summarize and generalize case studies (Flyvbjerg, 2006). Of course, context-dependent information is valuable for understanding humans, generalization is not the only purpose of science or case studies, and case studies are not limited to only being able to develop hypotheses (Flyvbjerg, 2006).

To attempt to address the relevant concerns for this study, reflexivity (Finlay, 2002) will be used throughout the research process to minimize any tendencies to simplify or exaggerate findings, as well as to keep my inherent bias in check.

### ***Strengths of case studies***

In areas where little research has been done, such as in quality of life for PWA, case studies can bring to light insights and new meanings (Merriam, 2009; Stake, 1995; Yin, 2009). Enhancing our understanding of knowledge and practice in the field can lead to improvements in clinical initiatives and even help to inform new policies. Case studies can be completed without hypotheses or goals that are predetermined (Willis, 2007). This base of information can then be built upon to advance knowledge in the field. Due to this focus on the unique and individual, researchers have the opportunity to collect rich data (Willis, 2007). This is also true of collective case studies that address both uniqueness and common attributes (Stake, 2006). Case studies do not remove the data from the context, and so we can understand behaviours within natural contexts (Willis, 2007), which is an advantage over some other research options. It is important to me as a researcher to have the potential to disseminate my research findings to SLPs in the hope of improving clinical practice. Case studies are the ideal methodology for this goal, because they can enhance understanding of practice by focusing on the uniqueness of the human experience, rather than only common attributes (Merriam, 1998; 2009; Stake, 1995).

## **Methods**

To review, the purpose of this research is to explore how different modalities of therapy impact the HRQL of PWA. My research project used a concurrent longitudinal multiple method (QUAL + quan) collective case study guided by qualitative description methodology to develop comprehensive research findings that will not only stand alone, but also contribute to future larger studies (Creswell, 2016; Sandelowski, 2000; Stake, 1995). In this study, each case was bound by time and activity, as each case is relevant to the specific type of therapy (activity), and the time frame surrounding the therapy experience (time). This study received approval from the institutional research ethics board at the University of Alberta (Pro00097283).

### ***Impact of COVID-19 on the research plan***

In March 2020, the impact of the COVID-19 pandemic was felt worldwide and began to impact Canadians. Businesses were closed to the public, and new health and social distancing protocols were put into place to attempt to stop the spread of the virus. This resulted in PWA not receiving therapy as planned, or SLPs adjusting to conducting therapy over telehealth unless redeployed to assist with more immediate pandemic-related services. The use of telehealth resulted in more widespread availability of virtual group therapy for PWA. Due to the quickly changing and unknown future of SLP services following the pandemic, and uncertainty of the date the pandemic would be eradicated, alternate plans were created to the original research plan to ensure the safety of the participants and the research team. These plans are reflected in the description below.

All three therapy modalities that I studied were delivered in a virtual format. Due to this change, the virtual version of Alberta Aphasia Camp may not have been different from virtual group therapy. Therefore, PWA who had not participated in virtual group therapy were the target for recruitment. The Aphasia Research Lab was participating in an app-based therapy trial where

all elements of the study took place in a virtual environment, allowing for the recruitment of PWA who had not previously participated in app-based therapy. From September 2020 - November 2020, Corbett Clinic completed virtual individual therapy, and PWA who had not completed individual therapy virtually previously were the target for recruitment.

To collect the interview and assessment data, appointments were scheduled with participants via the Zoom online video conferencing platform. Observations were possible via the same Zoom platform, by the researcher observing Alberta Aphasia Camp online sessions, observing individual app-based therapy sessions, and observing individual teletherapy sessions.

In the literature, assessments such as the *Western Aphasia Battery – Revised* (WAB-R, Kertesz, 2006) have been administered over telehealth, and results were highly correlated to in-person administration (Dekhtyar et al., 2020; Hill et al, 2009). Therefore, there were no major concerns with conducting assessments virtually. Qualitative data collection is, however, most often done in person. For example, when conducting interviews, establishing rapport is essential. It is possible that the virtual environment of the interview hindered the process of building rapport, as technical difficulties such as poor internet connections or talking over the other person were conceivable. It also made supported communication more challenging than when in person (Wilson & Kim, 2019).

### ***Recruitment***

PWA were recruited through the client/participant network that consisted of the Aphasia Research Lab, Corbett Clinic, and Alberta Aphasia Camp. Emails with attached posters were used to recruit participants (Appendices 3 & 4). Participants were screened by CW before beginning assessment and interview sessions. The sample of participants was purposefully selected (Creswell, 2007) from the catchment area of the client/participant network (including

urban and rural areas) across Canada. A maximum variation strategy (Creswell, 2007) was sought for cases to collect rich data with significance and different experiences.

### **Participants.**

Recruitment took place over a four-month period (August 2020-November 2020). A total of seven PWA were involved in this study. One PWA withdrew from the study after two phases of data collection, because they felt they could not participate with other responsibilities and activities in their life. Their data was included as interviews had already been transcribed. All participants were 18 years or older and spoke English or French as their primary language. PWA participants were at least 6 months post-stroke to ensure that they were in the chronic phase of aphasia. PWA participated in either individual app-based therapy (the VoiceAdapt trial), participation-focused group therapy (virtual Alberta aphasia camp), or virtual individual therapy (Corbett Clinic). Participants had self-enrolled in their therapy modality before the study began. Consent was obtained by explaining the study to potential participants with aphasia-friendly documents and allowing them to decide if they would like to participate (Appendices 5 & 6).

### ***Compensation.***

Participants were compensated with a \$10 gift card at the end of the study. The compensation funds were derived from the Rehabilitation Medicine Thesis Operating Grant.

### ***Therapy Modalities***

#### **Virtual Aphasia Camp.**

In 2020, Alberta Aphasia Camp took place online via the Zoom platform over three weekend days (Friday September 18 - Sunday September 20; for a total of 6.25 hours). Activities that had been planned for camp (e.g., singing, yoga) were altered to fit the online environment. There were 59 campers total, with 36 PWA, 23 caregivers (friends or family), 20 pre-



professional students from SLP, OT and PT programs at the University of Alberta, and 5 rehabilitation professionals (OT, SLP, PT, RecT).

### **Individual Therapy.**

The Corbett Hall Speech-Language Clinic is situated within the Department of Communication Sciences and Disorders at the University of Alberta. Clients can be referred or self-refer to the program to receive individual speech-language therapy. One-hour assessment and treatment sessions take place two times a week over 12 weeks, for a total of 24 hours. From September to November 2020, Corbett Clinic took place virtually, with two pre-professional SLP students working together to lead the assessments and treatments, while being supervised by a registered SLP.

### **App-based therapy.**

VoiceAdapt is an app-based therapy incorporating principles of Semantic Feature Analysis (Boyle & Coelho, 1995) and Phonologic Components Analysis (PCA; Leonard et al., 2008) into a tablet-based naming app. Participants were asked to use the app for 1 hour each day for 5 weeks (~25 hours).

### ***Materials***

Recordings were uploaded to a secure google drive immediately following data collection, and then removed from the recording device. A virtual notebook was kept for field notes in the same google drive. A detailed description of data collection and procedures is described below.

### ***Data Collection***

According to Stake (1995), data collection begins with our experiences before we even begin to think about a research study and design. Throughout my journey exploring reflexivity,

and my first experiences with PWA, I agree with Stake and would like to acknowledge that these experiences and ideas are part of me and therefore part of my data collection and analysis.

In this study, data collection included the use of assessments of language, mood and HRQL, interviews, observations, and the review of therapy materials. Data collection took place formally within three cases which included the app-based therapy, individual therapy, and aphasia camp. In this study, each case was bound by time and activity, as each case was relevant to the specific type of therapy (activity), and the time frame surrounding the therapy experience (time). Data sources for this study included participants in these different forms of therapy.

For each case, there were three phases of data collection for PWA: before therapy begins, after therapy ended, and at a three-month follow up. Participants were assessed and interviewed at each phase of data collection, with details of the assessments and interview below. Between phases one and two, participants participated in the therapy, and the researcher observed them (details below). Data collection began in September 2020 and finished in April 2021.

### **Quantitative Data Collection.**

Each assessment session was scheduled for 2 hours. The following measures were used at each phase of data collection in line with the recommended core outcome measures for aphasia research (Wallace et al, 2019), *General Health Questionnaire-12* (GHQ-12; Goldberg, 1978), *WAB-R* (Kertesz, 2006), and *Stroke and Aphasia Quality of Life Scale-39* (SAQOL-39; Hilari et al., 2003).

The *GHQ-12* measured emotional well-being in three dimensions including social dysfunction, anxiety and depression, and loss of confidence. Twelve questions were answered by participants using a 4-point Likert scale, which generated summative scores ranging from 0 to

48, with lower scores indicating better emotional well-being. Currently, a value for MIC is not available for the *GHQ-12*.

The *WAB-R* provided an Aphasia Quotient (AQ), which is a disease-specific measure of the linguistic skills of the PWA. It also provided a classification of the type of aphasia according to the Boston Classification Model. The AQ generates a score range between 0 and 100, with scores closer to 100 indicating milder aphasia compared to scores closer to 0. Currently, a value for MIC is not available for individuals (Breitenstein et al., 2022; Gilmore et al., 2019).

The *SAQOL-39* is a HRQL self-report measure of PWA, administered by an interviewer. It includes four subdomains of physical (16 items), psychosocial (16 items), communication (7 items), and energy. Questions were answered by participants using a 5-point Likert scale. The domains and overall score are calculated with a score range of 1 to 5, with higher scores indicating higher HRQL. For the Singapore version of the *SAQOL-39*, MIC is a difference of 0.21 points (Guo et al., 2017).

### **Qualitative Data Collection.**

Each interview was scheduled for one and a half hours and lasted between 39 and 90 minutes, with an average of 59.5 minutes. Both an audio recording device (*Sony digital recorder*) and video recording (*Zoom platform*) were used to record all interviews. I conducted all interviews from a quiet space in my home, and all participants joined the zoom call from a quiet space in their home. It is important to use video recording with PWA, as they often use gestures and facial expressions as part of their communication, which would be missed if only audio recordings were used (Wilson & Kim, 2019). Interview questions for PWA addressed the participant's social life, feelings before, during, and after therapy, and their expectations and the realities of therapy. An interview guide (see appendices 7-9) was used for each interview and

probing questions were developed as the interview unfolded. PWA were provided with the interview guide ahead of the interview in an aphasia-friendly format and were welcome to bring photos or other materials they may need to help them communicate. I also made use of supported communication strategies to assist the PWA as needed (Kagan, 1998; Wilson & Kim, 2019). I took the participants' lead in terms of topics they would like to discuss throughout the interview. Following each interview, I engaged in a debrief with my supervisor during weekly meetings and expanded on field notes. I completed notes through the use of reflective and reflexive journaling, which included details regarding how myself and methods selected influenced the data collection.

Participants were observed for a minimum of one therapy session with the permission of the SLP and participant. Before observations began, the SLPs were also asked to provide a therapy treatment plan before observation that included activities and goals for the session. Observations were focused on how the participant chose to participate in therapy, their overall mood during therapy, and events that occurred while they were participating. I attempted to be a “fly on the wall” in observing these sessions, however, interacted with PWA in the individual therapy and app-based therapy observations to let participants know that I was present and interacted only as needed to ensure the comfort of participants and to be less intrusive. Observations began with prompts from a checklist and notes were expanded as needed. Following each observation, I engaged in a weekly debrief with my supervisor and expanded on field notes through reflective and reflexive journaling, which included details regarding how I and the methods selected influenced the data collection.

## ***Analysis***

Following in the tradition of case study, data collection and analysis occurred simultaneously at the beginning, and then analysis continued after data was collected (Baxter & Jack, 2008; Charmaz, 2006; Stake 1995, 2006). Data analysis took place between September 2020 - November 2021 and attempted to answer the following research questions:

- 1) What is the lived experience of PWA during participation in different modalities of therapy?
  - a) What impact did COVID-19 have on the experiences of PWA?
- 2) What A-FROM domain of functioning is most impacted by these different modalities of therapy?
- 3) How do these modalities of therapy impact the HRQL of PWA?
- 4) How are language and mood outcomes related to HRQL outcomes of therapy for PWA?

### **Qualitative Analysis.**

Within case studies and qualitative analysis, it is possible to adopt various analysis techniques (Merriam, 1998, 2009). Principles of reflexive thematic analysis outlined by Braun and Clarke (2006; 2019) were used to analyse the data, and reflexivity was continued to note how my perspective and experiences shaped the data analysis (Finlay, 2002). This approach was selected to remain consistent with the paradigmatic positions of the researcher and Stake. Braun and Clarke (2006) stated that it is possible to utilize their approach within a constructivist paradigm.

In-depth reflexive thematic analysis was conducted for each case, followed by cross-case analysis (Stake 1995, Stake, 2006, Yin, 2009). Data analyzed for each case included transcribed interviews, observations of therapy sessions and field notes recorded by the researcher, and notes of the review of therapy materials created by the researcher. There were 20 interviews with the seven PWA participants, and 7 sets of observation notes. These pieces of data were not analyzed

separately but were considered alongside each other. This was done to strengthen the findings, as each piece of data came together to complete the puzzle of the case (Baxter & Jack, 2008).

Braun and Clarke (2008) describe 6 phases of thematic analysis. Phases 1-5 were used for the individual case analysis, and phase 6 occurred following cross-case analysis. Phase 1 involved transcribing and reading data, as well as making note of initial ideas. Phase 2 involved creating initial codes throughout the data. Phase 3 involved bringing codes together into themes. Phase 4 involved reviewing and checking the themes while creating a concept map (Daley, 2004; Kinsella, Bossers & Ferreira, 2008) of the analysis. Phase 5 generated names and definitions of each theme. These analyses were related to research questions one, two, and three (i.e., 1. What is the lived experience of PWA during participation in different modalities of therapy?; 2. What A-FROM domain of functioning is most impacted by these different modalities of therapy?; 3. How do these modalities of therapy impact the HRQL of PWA? ). Then themes were refined, and phase 6 from Braun and Clarke (2008) was used to select extracts while writing the manuscript.

### **Quantitative Analysis.**

Quantitative data provided additional descriptive information for the case. Assessments included measures of mood (*GHQ-12*), language (*WAB-R*), and HRQL (*SAQOL-39*) which were used as dependent variables. Independent variables collected from the participants included sociodemographic information (i.e., age, sex, education) and stroke characteristics (i.e., time post-stroke). Each measure was scored according to the published algorithms. Descriptive data of all variables including the three outcome variables were calculated. These analyses were related to research question four (i.e., How are language and mood outcomes related to HRQL outcomes of therapy for PWA?).

### **Crystallization of Data.**

In the cross-case analysis, the researcher “seeks to build abstraction across cases” (Merriam, 2009, p. 195). In order to achieve this, I used strategies of immersion-crystallization, which comes with the understanding that there are multiple truths that are co-constructed (Ellingson, 2009). Borkan (2021) describes eight core elements of immersion-crystallization which include initial engagement (i.e., deciding focus of study and initial impressions), reflexivity, immersion (i.e., getting close to the data), crystallization (i.e., reflection of analysis and interpretation), creative synthesis (i.e., making sense of the data), corroboration and alternative interpretations (i.e., re-examination of data), final interpretations (i.e., reaching point of interpretation saturation), and reporting.

The concept maps (Daley, 2004; Kinsella et al., 2008) developed in phase four (Braun & Clarke, 2008) were used in the crystallization step to visually examine the data from multiple cases, to compare categories and themes, and search for similarities and differences. The quantitative results were also carefully considered in the context of the qualitative results. These analyses are related to research question two (i.e., What A-FROM domain of functioning is most impacted by these different modalities of therapy?) and question three (i.e., According to PWA, how do these modalities of therapy impact their HRQL?).

## Chapter 5

### Qualitative data collection: considerations for people with Aphasia<sup>3</sup>

#### Introduction

Qualitative research methods are well suited for exploring complex social experiences, such as acquiring a communication disorder (Simmons-Mackie & Lynch, 2013). The onset of aphasia often has wide-reaching impacts on all aspects of an individual's functioning. Researchers have traditionally relied on quantitative surveys and questionnaires to gather perspectives on the well-being and opinions of PWA. Often, the surveys and questionnaires were reliant on the report of caregivers and healthcare providers, although recently there has been a shift toward patient-reported outcome measures (PROMs) to capture the perspectives of PWA directly from the source (Damico & Simmons-Mackie, 2003). While a questionnaire may be sufficient for some research questions, other questions require rich contextual information to understand the complex experiences of PWA. An in-depth understanding of their insider perspective may be best captured using qualitative methods of data collection (Damico & Simmons-Mackie, 2003).

As it stands, many researchers and speech-language pathologists (SLPs) who conduct research have been trained with a focus on quantitative methods, and do not have the background knowledge to conduct studies using qualitative methods (Damico & Simmons-Mackie, 2003). Indeed, Elman (1995) called for more researchers to diversify their research and use qualitative methods to improve the understanding of aphasia. Qualitative research requires an understanding

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of various qualitative philosophies, and experience-based learning (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999). Dilollo and Wolter (2004) also recommend that qualitative researchers have excellent writing skills, tolerance for ambiguity, ability to trust others, willingness to change plans or directions in the project, and the ability to commit to finishing the study regardless of the time commitment required in data collection or analysis. Contrary to quantitative research where the researcher is taught to USE various tools, in qualitative research, the researcher IS the tool and must learn how to collect information in a way that effectively answers their research questions (Damico et al., 1999).

Data collection in qualitative research generally involves open-ended questions, which could be particularly challenging for PWA who may have difficulty with verbal expression and auditory comprehension. For someone with a communication difficulty, it could be hard to know where to start an answer, what words to use to accurately describe feelings, and how to organize their thoughts. Moreover, there may be an added social pressure to perform when words are so important to the researcher who wants to understand, and to a PWA who wants to share their story. Since the most popular method of data collection in qualitative research is interviews (Simmons-Mackie & Lynch, 2013), it is essential for researchers to have the proper skills to facilitate an interview with a PWA and explore other options for qualitative data collection that may be less reliant on verbal expression.

A review of qualitative research with PWA published in 2013 (Simmons-Mackie & Lynch, 2013) demonstrates that the number of qualitative research studies in aphasia has increased since Elman first made the call for more qualitative research in 1995. Most studies of aphasia using qualitative methods do not describe a specific qualitative approach to guide the

study, but instead, use a pragmatic approach (i.e., using whatever method is familiar or available to the researcher), which may be either intentional or unintentional. Many of these studies use interviewing to collect data, but it is unclear if interviewing would have always been the best choice to answer the posed research question (Simmons-Mackie & Lynch, 2013). As well, most studies provide little to no information on how they conducted the interviews with PWA aside from mentioning that supported communication techniques were used (Simmons-Mackie & Lynch, 2013). A study by Luck and Rose (2007) stands out, as it is one of the few studies that discuss the issues that arise from trying to interview PWA without making changes to accommodate their communication challenges. Overall, in the current literature, there appears to be a lack of information for researchers on how to transform traditional qualitative data collection techniques to work with populations such as PWA who have communication difficulties.

This tutorial aims to provide a basic understanding of the different data collection methods that should be considered for, and can be used with, PWA regardless of the researcher's epistemology (i.e., their theory of knowledge). It is expected that this content will be informative for researchers and SLPs trying to answer their research questions using qualitative methods of data collection. Specifically, this paper intends to review the strategies and techniques already being used (i.e., focus groups, observation, photovoice and various types of interviews) to help researchers and SLPs embarking on a qualitative study to be prepared for data collection with PWA. It is likely that this information will also apply to data collection with other populations with communication difficulties such as people with dementia, people with degenerative diseases that impact communication, people with developmental disabilities, or non-native English-speaking individuals (Simmons-Mackie, 2018).

## **Approaches to inquiry**

The following section goes into a brief description of some of the qualitative approaches to inquiry that have been identified as relevant to aphasia in the literature (Damico & Simmons-Mackie, 2003; Simmons-Mackie & Lynch, 2013). These approaches include case study, conversation analysis, ethnography, grounded theory, narrative, and phenomenology and are further described in the following pages. It is important that the researcher keeps in mind that there is more than one way to conduct good qualitative research (Creswell, 2013) and that the descriptions below should be understood as a starting point for the types of inquiries that can be done. There are also several other approaches to inquiry that are not included here that do not fit within the scope of this paper (e.g., historical methodology was not included as it usually does not involve interactions with PWA during data collection).

### ***Case study***

According to Creswell (2013), case study research is “a qualitative approach in which the investigator explores a bounded system (case) or multiple bounded systems (cases) over time through detailed, in-depth data collection involving multiple sources of information” (Creswell, 2013). The goal of a case study is to have an in-depth description of a case. One of the differentiating factors of case studies from other qualitative approaches is that they are set within the specific context of that particular case. Case studies are usually framed by “how” or “why” questions (Tellis, 1997). If the researcher has a question that is how or why, with a clearly identifiable case in mind with boundaries and wants an in-depth understanding the researcher should likely pursue a case study. For example, studies such as Davidson, Worrall, and Hickson (2008) and Sorin-Peters (2004) used a case study methodology.

### *Conversation analysis*

The purpose of a conversation analysis is to analyse social interaction through the lens of conversation. The focus in this type of research is on how participants use resources to get their message across (e.g., intonation, gesture, communication devices) and how conversation partners work together. This approach to inquiry makes the assumption that there are patterns and structures to a conversation that allows a researcher to observe or record a conversation, ask how it was achieved, and find the answer within the structure of the conversation by considering turn-taking and negotiations. This type of analysis can be relevant for clinical work and training strategies for communication partners as some examples of potential applications and has been a fruitful methodology for studying the language of PWA. For example, studies such as Goodwin (1995) and Oelschlaeger and Damico (1998) used conversation analysis with PWA.

### *Ethnography*

Ethnographic research focuses on a cultural or social group, which can be large or small, and is populated by people that interact over time. The goals of the research are to describe and interpret the values, beliefs, behaviours, and language of the cultural group and get an insight into the complex social and cultural phenomena. One of the differentiating factors of ethnography is the presence and impact of culture on the observations, and the large amount of time spent doing fieldwork that is a part of data collection. Ethnography has deep roots in anthropology and sociology. Ethnography can be framed by research questions at the outset, or instead, the research may be discovery driven where the questions come later. For example, studies such as Simmons-Mackie, Damico, and Damico (1999) and Hinckley (2005) used ethnographic techniques.

### ***Grounded theory***

The purpose of grounded theory research is to develop a theory or framework shaped by the experiences of the participants. Grounded theory has roots in sociology. The main differentiating piece of a grounded theory study is that the outcome is a theory that may be generalizable, rather than a study of a specific person or group that may not be generalizable. Grounded theory approaches involve interviewing a relatively large number of participants (for example, a researcher might do upwards of 20 interviews; Creswell, 2013). Grounded theories are usually framed by “how” or “what” questions (Tellis, 1997). If the researcher has a question that is how or what and wants to develop or uncover a theory that does not yet exist or is incomplete, a grounded theory should be considered. For example, the study by Andersson and Fridlund (2002) used grounded theory analysis with PWA.

### ***Narrative***

Narrative research (also referred to as biographical studies) has a specific focus on the stories told by individuals and deriving meaning from their experiences. The purpose of narrative research can depend on the researchers’ ontology. For example, some researchers will allow the participants to dictate the topic, while other researchers will provide a topic of interest that they know the participant has experience with and can talk about. Data collection in narrative research consists of having a participant tell their story. This could be their life story, a story about a specific time frame in their life, or even reflections on the causes and effects of certain events, which result in themes. Giving participants space to tell and share their stories can be an empowering experience, especially for PWA who have potentially lost their voice by way of their communication difficulties. For example, studies such as Strong, Lagerway, and Shadden (2018) and Sherratt and Worrall (2019) did narrative research with PWA.

## ***Phenomenology***

Phenomenological studies in qualitative research have their roots in philosophy and focus on describing how humans experience specific phenomena. The researcher and participant explore the emotions, experiences, and responses related to a specific phenomenon (e.g., having a stroke). This research can be done with an individual participant, or with a small group of participants to generalize regarding an experience from various points of view. If the researcher has a research question related to learning about the person's lived experience, it is likely they will want to consider phenomenology. For example, the study by Sundin, Jansson, and Norberg (2002) used phenomenology with PWA.

## **Data collection**

In qualitative research, there are many ways to collect data within the approaches to inquiry discussed above. Usually, the data collection method is traced back to the research question, the approach to inquiry the researcher is embarking on, and the researcher's epistemology. Researchers new to qualitative research are encouraged to investigate all the different approaches to inquiry and epistemologies in qualitative research to determine which approach best fits their research question (e.g., Green & Thorogood, 2018; Hesse-Biber, 2016). Regardless of the approach to inquiry selected or epistemology of the researcher, there are general considerations that should be made before collecting data, including ethical considerations, how to sample and recruit participants, how many participants to include, whether one method of data collection will be enough, as well as how to analyse and report the collected data.

Some data collection methods are present across approaches to inquiry and have been used frequently in qualitative research. These include interviews, focus groups, observation, and photovoice, and will be described below. There will be some discussion of ethical considerations and sampling within each data collection method; however, the information provided is not exhaustive. Readers are encouraged to look to the sources cited in this paper and beyond for more information. Readers are also reminded that in qualitative research, the researcher is the tool and therefore cannot separate themselves from the data that is collected. Therefore, researchers must recognize how their experiences, biases, and perspectives can impact data collection as part of the ethical process.

One way to recognize how the researcher impacts the data collection is through reflexivity which should be done at every point in the research process (i.e., during planning, data collection, and analysis). Reflexivity is an exercise whereby the researcher makes their research process transparent through an examination of their role and subjectivity in the process (Palaganas, Sanchez, Molintas, & Caricativo, 2017). During the planning stage, reflexivity can help researchers to understand their motivation for particular topics and methods and should involve considering the researchers' own relationship to the topic and how their life experiences could impact the direction of the project (Finlay, 2002a). During the data collection and analysis stages, considering aspects of the relationship between researcher and participant, as well as how the participant's stories impact the researcher are important parts of reflexivity. For example, a researcher might consider how they impacted data collection, any power imbalances that were present and how they were dealt with, how the researcher may have influenced participants, how they reacted to participants stories (both what was said and unsaid in the moment), and how the researcher's experiences may impact what they took away as important

pieces of data. (Finlay, 2002a). Researchers are encouraged to read further about reflexivity, as there are many ways to understand and partake in it, beyond what is described here (e.g., Etherington, 2007; Finlay, 2002b; Guillemin & Gillam, 2004).

## **General considerations for people with aphasia**

### ***Supported communication strategies***

To start the data collection in a supportive way, it is recommended that the researcher begins by asking the PWA to state what strategies they use to help them understand, give them permission to ask for help if they get stuck, and ask them if it is okay to try to help if they get stuck (Luck & Rose, 2007). It is recommended that if researchers do not have supported communication training, that they seek it out and refer to established sources prior to engaging in data collection with PWA (e.g., AphasiaAccess, 2017a; AphasiaAccess (Producer), 2017b, 2017c; Kagan, 1998). The main principles of supported communication are to acknowledge that the PWA is competent (i.e., communication difficulty does not mean lack of intelligence), and reveal their competence by ensuring they understand, can respond, and by checking that they have been properly understood (Kagan, 1998). Methods of supporting communication include writing, drawing, using gestures, speaking slowly, and breaking messages down into smaller pieces of information. These are not discrete options, but it is suggested that they are combined to best help the PWA.

Researchers should be prepared with paper and writing utensils at a minimum to support communication by writing keywords, drawing, and offering space for the PWA to do the same. When supporting communication, it is suggested that researchers do not use a whiteboard with PWA, as once the board is erased the information on the board is gone. People, in general, do not



tell stories in a straightforward manner, but often go back and return to previously discussed topics. Having a paper copy of notes used as communication supports to refer to can act as a reference point for the PWA, and therefore support the researchers' understanding of how topics are connected to the current conversation. This is also relevant for multiple meetings, as the researcher may want to bring the papers from previous meetings into future meetings with the same PWA. Another way to facilitate understanding is to have visual aids, such as images relevant to the research questions, ready to use if communication becomes difficult. If researchers do not use supported communication strategies it is possible that they are not capturing the perspectives and opinions of PWA to the fullest extent possible (Luck & Rose, 2007).

Supported communication techniques are important to use when face-to-face, as well as when the researcher is providing information or materials to PWA. When preparing documents for PWA, such as the consent form or the interview guide (if it is intended to be shared), researchers should use aphasia-friendly formatting (see guidelines in Stroke Association, 2012). Suggestions include: using double spaced text, larger font size, black font on white background, bolding the main words, using short and simple phrases, and including images to help their understanding where possible (but avoiding making the materials look "childish"; Brown, Worrall, Davidson, & Howe, 2010; Eames, McKenna, Worrall, & Read, 2003; Hoffmann & McKenna, 2006; Rose, Worrall, Hickson, & Hoffmann, 2011).

Supported communication is particularly important when obtaining consent and explaining the study, notably, if the investigators know the PWA in a clinical capacity, as they may trust an SLP inherently and be unclear on the difference between research and clinical

treatment (Penn, Frankel, Watermeyer, & Müller, 2009). Communication challenges should not prevent PWA from being approached to participate in research, and consent rather than assent should be the gold standard when recruiting PWA (Pearl & Cruice, 2017). The researcher needs the skills to be a communication partner for a PWA to ensure that there are opportunities for PWA to reveal competence. When collecting informed consent there are both straightforward and complex pieces, which requires the researcher to pause to verify comprehension and have effective strategies in place for when there are breakdowns in communication (Pearl & Cruice, 2017).

### ***Eliciting & verifying information from PWA***

The researcher and participant may need to work as partners during data collection to facilitate supported communication, meaning that the researcher may need to offer words or ideas to elicit information that the PWA will either verify or refute. To assist PWA with verbal expression, the researcher may need to break questions down into smaller pieces by using probing questions, encourage their responses (e.g., nodding), and rephrase information that is unclear to be sure they have an accurate understanding of what the PWA is telling them. Sentence starters may also be used to help PWA initiate responses as an alternative to asking questions (Phelan & Kinsella, 2013). For example, having the PWA finish the statement “The best part about therapy is . . .” may be easier for the PWA than asking the open-ended question “What is the best part about therapy?”. However, researchers should make sure that the sentence starters are not leading PWA toward specific responses, as doing so crosses ethical boundaries and will not be informative for the research (Phelan & Kinsella, 2013). Researchers can also avoid leading PWA by using the PWA’s own words when asking questions, thus avoiding “putting words in their mouths”.

The researcher may be required to probe elicited information with yes/no questions to verify that they have understood what the PWA is saying. Using the technique of rephrasing as a supported communication strategy to verify what the PWA is communicating is an important step for the researcher to take to ensure they understand what the PWA has intended to communicate.

### ***Member checking***

The process of member checking is another way to verify information once data collection and primary analysis for the study is completed and involves the researcher taking the results back to participants to confirm its credibility (Creswell & Miller, 2000). Typically, member checking is done by returning the interview transcript to the participant to verify the information, doing a member checking interview, or a focus group (Birt, Scott, Cavers, Campbell, & Walter, 2016; Creswell & Miller, 2000). Simply sending the transcript for a PWA to verify on their own might be confusing or frustrating, even if aphasia-friendly instructions are provided, and so an interview is recommended to discuss whether the findings have accurately captured the lived experience of the PWA. Member checking via individual interviews is essential when conducting case studies. However, a phrase commonly used with aphasia researchers and SLPs is “once you know one PWA, you know one PWA”, meaning that all PWA have unique experiences, strengths, and challenges. This can make member checking a more difficult task for group studies, as combining multiple experiences into a single research article can make participants feel like their individual story is lost. Therefore, using a focus group for member checking rather than individual member checking may be beneficial to ensure that participants know the research is about a group rather than an individual. However, if researchers elect to use a focus group for member checking there are some ethical considerations around

maintaining confidentiality. As soon as participants enter the room of a focus group, they are meeting the other participants, and so this must be well explained to all participants to ensure that they are aware they are losing an aspect of their confidentiality by participating in the focus group.

### ***Silence in research***

SLPs and researchers that work with PWA know to leave space for PWA to think and respond, and so are therefore comfortable with silence. This process becomes particularly important in the qualitative research process. This is because PWA may need more time to process what the researcher has asked and to formulate their response. The researcher being comfortable with silence will allow PWA to have this space. However, researchers should be aware of not letting the PWA get to the point of frustration and so at some point, the researcher may be required to offer communication supports to help them with a response. Knowing when to assist and when to sit with the silence is a skill that takes practice and requires rapport between the researcher and the participant.

### **Interviews**

Interviews are the most common method of data collection in qualitative research (Simmons-Mackie & Lynch, 2013). Although the term “interview” has been defined in different ways over the years from many perspectives, for the purposes of this paper an interview is defined as a conversation driven by a researcher’s need for data, where the researcher and participant “produce language data about beliefs, behaviour, ways of classifying the world, or about how knowledge is categorized” (Green & Thorogood, 2004, p. 87). Traditionally,

interviews take place with one person face-to-face; other interview formats will be discussed below.

SLPs often have training in motivational interviewing which has many of the same principles as qualitative interviewing, and therefore SLPs may be well-suited for qualitative research. Some of these skills and principles include compassion, passion, integrity, resourcefulness, and patience (Dilollo & Wolter, 2004). Also, the foundation of many interview questions may come from the clinical interactions SLPs have with their patients, allowing for the creation of meaningful research questions about their practice and the clients they serve. Building on this idea, SLPs tend to form close client-practitioner relationships with their clients and many of the goals they work on together have personal meaning to the clients. SLPs are cautioned to consider the ethical power implications of these therapeutic relationships and to not abuse them for research purposes. Therefore, SLPs should put on their “researcher hat” and put aside their “clinical hat” during interviews for research purposes (Hunt, Chan, & Mehta, 2011). What this means is that research interviews are not a time for counselling or recommending but should be approached as a time for listening and understanding.

There are many ways that researchers can approach interviews and different types of questions that researchers can ask their participants. In terms of how to approach an interview, researchers might plan out all the questions they want to ask or might have more general ideas of what they want to learn from the participant. Some researchers use a more structured interview, where the researcher may not have met the participant beforehand and do not contribute pieces of their own stories but are more focused on asking the questions (Gubrium & Holstein, 2001). Other researchers might use a less structured interview, where the researcher might work to build

more rapport with the participant ahead of time and conduct the interview more like a conversation where both parties share information (Gubrium & Holstein, 2001). These interviews described exist on a continuum, and it is recommended that researchers practice interviewing before starting data collection to determine what best fits their interviewing style and data collection needs. In terms of the types of questions researchers ask, some may be open (e.g., why do you feel that way?) or closed (e.g., do you feel sad?) questions. While closed questions generally direct participants to a specific answer (e.g., yes/no), open questions leave room for interpretation and discussion. Examples of open questions include descriptive (i.e. tell me about . . .), narrative (i.e. tell me how you came to . . .), structural (i.e. what are all the steps/stages of . . .), contrast (i.e. what are the differences you see between . . .), evaluative (i.e. how do you feel before/after . . .), comparative (i.e. what if . . .), and circular (what do you think XX thinks about what you think about ...) (Spiers, 2017). When selecting research questions, the researcher should consider the depth and breadth of information they hope to gather, whether an interview is the best way to collect the data, and how flexible the researcher is willing to be concerning the number and way questions are asked in each interview.

From reading the work of and having discussions with other aphasia researchers, it seems to be a common consensus that interviews should always be both audio and video recorded. This would allow the researcher to not only have a backup if one type of recording fails, but also provide an opportunity to review both the verbal and nonverbal communication (i.e., gestures, body language, and facial expressions) the PWA was using to express themselves when analysing the data. For example, many PWA will “fingerspell” words instead of saying or writing them, which can be captured on video and help the researcher to determine who came up with the word, whether it was the researcher, the PWA, or both. When considering ethical

implications related to confidentiality and privacy while using video recordings, researchers should take care to ensure participants are aware of additional risks and that data is stored securely (Buchanan & Zimmer, 2018). In the current literature, there is a lack of information about nonverbal communication reported in studies with PWA. Using video and audio recording to capture expressions may require extra effort on behalf of the researcher to interpret the meaning of what is said (or not said), and to help the researcher understand what the PWA is expressing. Gorden (1980) specified four basic modes of nonverbal communication that could be used as a framework to examine video data. The modes of nonverbal communication include: proxemic (use of space between people to demonstrate attitudes), chronemic (how speech is paced and length of silences), kinesic (body movements and postures), and paralinguistic (variation in volume, pitch, and voice quality). Although these categories provide a basic framework, the researcher may also need to go through the video and map emotions and meaning onto the gestures and facial expressions of PWA, which may require additional training to recognize and interpret correctly (Onwuegbuzie, Leech, & Collins, 2010). Kendon (1988) also specified categories of gestures that PWA may use, and these include: iconic (referencing an action or object), metaphoric (referencing something abstract), and deictic (pointing toward what they are referring to) (Kendon, 1988). It is suggested that in the future researchers include information about nonverbal communication analysis in quotations along with verbal communication to give the reader a better picture of what is being expressed so that more severe PWA are not left out of being quoted in research because they may have used more nonverbal communication than verbal communication.

With PWA, it is a good idea to provide an interview guide with aphasia-friendly written questions in advance of the interview. This provides an opportunity for the PWA to familiarize

themselves with the questions and prepare any ideas or write down any notes that they want to talk about during the interview (Johansson, Carlsson, & Sonnander, 2011). It also allows researchers time to think ahead about questions that may require more effort to be understood on behalf of the PWA, and how to help PWA understand all the questions. Some researchers have suggested that an interview can take from 30 minutes to several hours (DiCicco-Bloom & Crabtree, 2006). With PWA there are a few factors to consider when planning how long to schedule the interview. Scheduling a longer interview (i.e., an hour or more) would ensure that the PWA does not feel rushed and that there is adequate time to discuss the questions in as much detail as is required. However, the researcher needs to be mindful of how laborious communication can be for PWA (Johansson et al., 2011), and so they may become fatigued easily in a longer interview and the data may not accurately reflect their thoughts and ideas. If the researcher believes this may be the case, they should consider taking breaks during longer interviews or scheduling multiple interviews. Scheduling multiple interviews also provides an opportunity to build good rapport with the PWA over time, which can be important if the research topic is sensitive in nature.

It can also be an advantage to schedule multiple interviews for PWA who have difficulty with verbal expression, as it is important to be patient and creative with artefacts and other communication supports. For example, if the PWA and researcher are having a discussion and the PWA can't come up with the words or wants to share items such as photos with the researcher to help them understand, then the PWA would have those opportunities if multiple interviews are conducted. The researcher might also want to consider asking the PWA ahead of time to bring any documentation (e.g., medical records or examples of therapy exercises) they have of their experience with aphasia (if available, and relevant to the research question), so that



they can share how the process unfolded and what happened at each stage throughout their experience (Hersh, 2009). This can take some pressure off the PWA to provide exact dates and names; instead of having the PWA describe everything, the researcher can look at the documents and they can work together to create a timeline of events and feelings.

If the PWA has a partner that is their support system, it may be helpful to have them present during interviews to help the researcher understand and get more detailed information about the participant. However, there are some implications that need to be considered that have been observed in interviews in the past. For example, having the partner present could lead to the partner being too supportive by speaking for the PWA, interrupting the PWA, taking the interview down the wrong path, or even the PWA not saying the same things they would say without the partner there. To navigate this, sometimes researchers will also do interviews individually with the PWA, individually with the partner, and then together with both the PWA and partner (Norlyk, Haahr, & Hall, 2015). This allows the researcher to obtain both the PWA's solo perspective and the detailed information they require when the partner is present. However, if the partner will be present for any interviews with the PWA, the researcher should make the partner aware prior to the interview that they are there to provide support but not to interrupt and provide their own perspectives unless specifically requested. The researcher should also consider using the approach to inquiry of conversation analysis, in which it may also be important to note details about how the interviewer, PWA, and any others present interact including finishing sentences or the use of alternative or augmented communication (AAC) devices.

### ***Stimulated recall interviews***

Stimulated recall interviews (also referred to as video-mediated interviews) differ from traditional interviews in that they are meant to elicit data about the thought processes that occurred during the interview or another recorded activity (Gass & Mackey, 2000; Sanders & Dadds, 1992). To achieve this, researchers need to record an interview, conversation or other activity with the participants. Then the researcher and participant watch the recording together and comment on the thoughts, reactions and other internal processes that occurred during the recording. This data is then what is collected and analysed, rather than the initially recorded interaction. This can be helpful for understanding how PWA are feeling in interactions and different situations throughout their lives (Davidson et al., 2008). Watching the video recording can be helpful to aid the PWA with recall, as well as help to elicit the same feelings or thoughts that were present in the initial participation. It is also possible to pause the video at various intervals where the researcher might be curious about a specific facial expression or gesture that wasn't discussed in the initial interaction. Davidson et al. (2008) recommend meeting as soon as possible after the initial interaction to review the recording, which can help to keep the ideas and purpose prevalent.

### ***Alternative interviews***

Alternatives to a traditional face-to-face interview are interviews conducted over the phone, through email, or via videoconferencing software (e.g., Skype). These alternative methods of an interview may allow for more inclusion of PWA from a distance, as it is not always possible if participants live remotely or have mobility challenges that prevent them from participating (Brinkmann, 2018). Interviews over the phone can be difficult with PWA, as the ability to use gestures and other methods to support communication are unavailable. This can

lead to frustration for the PWA and researcher, and for that reason, they are not recommended unless the PWA has good communication skills over the phone. Doing an interview over email would consist of the researcher emailing the PWA questions, having them respond, and then potentially having some back-and-forth discussion to probe their responses further (Minichiello, Aroni, & Hays, 2008). Using email could help to mitigate any difficulties with oral communication, but PWA almost always have difficulty writing and formulating responses compared to their oral communication abilities. Interviews via videoconferencing software are a good alternative to phone and email interviews, as it would allow for nonverbal communication to be captured, and supported communication is possible although unlikely to be as smooth as with in-person interviews. However, not all PWA are computer literate, and so email or videoconferencing methods may not be possible for all PWA. If the PWA lives with or has someone that can help them set up videoconferencing it would make the interview possible. Researchers have brought up issues of ethics and confidentiality when using online services such as email and videoconferencing services (Buchanan & Zimmer, 2018), and so this should be taken into consideration when deciding whether to use these services for data collection.

### **Focus groups**

Another alternative to a traditional one-on-one interview is a focus group interview. Focus group research can be defined as collecting data in a safe space from more than one individual at a time about a specific topic (Krueger & Casey, 2000; Onwuegbuzie et al., 2010). Although the recommended ideal number of participants in a focus group is between six and twelve, recent research has suggested smaller groups (i.e., six or fewer) for more complex topics (Minichiello et al., 2008). Given the complex communication challenges inherent in a focus group of PWA, we recommend smaller numbers per group (e.g., 3–4). Since there are multiple

people providing data in a focus group, it is recommended to have both the interviewer and an assistant present if possible. This way, the interviewer can focus on asking questions and facilitating communication among group members, while the assistant takes notes. Suggested aspects of the focus group to take notes on include: room set up, where people sit in the room, who speaks, the order in which people speak, the general mood in the room, who did and did not contribute, any levels of consensus or lack of consensus, nonverbal communication, as well as group dynamics and the presence of subgroups, if relevant (Minichiello et al., 2008).

A focus group can look very much like an interview where the researcher asks questions and participants respond, but there are also other ways of conducting a focus group depending on the research question. For example, the researcher might present materials to the group such as photos, videos, or newspaper articles for them to look at and discuss (Minichiello et al., 2008). The researcher might also plan group activities to gather the groups' perspectives on the activity itself (Minichiello et al., 2008). It is also possible to conduct a focus group through an online video service to reach remote populations. Much like with an interview, it might be appropriate to send the plan for the focus group to the PWA ahead of time so that they can prepare for the group.

The main outcome of a focus group is that the researcher wants interaction amongst the participants to gather different perspectives, as this interaction is part of what differentiates a focus group from an interview (Krueger & Casey, 2000). It is possible (and quite likely) that within a group of PWA the researcher will find that everyone has different strengths and challenges with their communication; it is the responsibility of the researcher/facilitator of the focus group to accommodate these communication differences. From experience facilitating

groups, this includes being aware of members that may be more assertive or communicate more easily, which could effectively reduce input from other group members whose opinions are also important. Therefore, knowing the individual's communication profile ahead of time or asking each PWA to share strategies that help them communicate as an icebreaker activity can help the researcher to better facilitate the interactions of the focus group members. Sharing communication strategies can also help to build community among the focus group members, and facilitate understanding of each other's challenges, which may increase their willingness to communicate and their ability to assist each other in communicating. One example of a potential strategy for alternative participation is providing PWA with paper and writing utensils to contribute drawings and written answers, and these can be collected after the focus group to be included in analysis. This way, PWA can share their contribution with the whole group, or only share with the researcher. This allows everyone to contribute in a way that is comfortable and can ensure that everyone feels that they were a valuable contributor. Collecting data from a focus group may seem faster than doing several one- on-one interviews, but the transcription and analysis of data can be difficult and time-consuming. Some research questions will also require multiple focus groups with the same or a different group to answer the research question (Minichiello et al., 2008).

## **Observation**

Observation could also be used as a potential data collection method with PWA. Participant observation involves the researcher observing PWA while they are in their natural environment (Gray, 2004; Howe, Worrall, & Hickson, 2008; Spradley, 1980). This could mean observing them in their house, out in the community, at appointments, or during therapy. The data collected consists of observations the researcher makes in relation to their research question,

often referred to as field notes. Field notes usually consist of observations about the physical space, objects noticed in the space, PWA and any other participants involved, actions of the PWA, things that the PWA says, activities the PWA participate in, events that occur during the observation period, goals of the PWA, feelings of the researcher, general tone of the interactions observed, and the amount of time and time of day spent observing (Howe et al., 2008; Spradley, 1980). The frameworks described above for describing nonverbal communication in interviews from Kendon (1988) and Gorden (1980) can also be used to describe the nonverbal communication observed in field notes.

While observing, the researcher can choose to either stay in one spot in the location or follow the PWA of interest as they move through their environment (Polit & Hungler, 1999). Regardless of how the researcher observes, it is ideal if the researcher has a passive role in which they only observe, however it may be required that the researcher participates in an interaction from time to time (Spradley, 1980). For example, Howe et al. (2008) report that in one situation a researcher observing a PWA at the dentist was gestured by the PWA to respond to a question from the dentist on their behalf. By responding to questions and requests like this, it helps to keep the situations as natural as possible (Howe et al., 2008). With observation, it is rare to have a video recording, so the researcher should expand field notes from what was collected in the moment immediately after leaving the observation to increase clarity, as well as to keep the information fresh and as accurate as possible (e.g., Phillippi & Lauderdale, 2018). Field notes can be written, audio recorded, or a combination of both depending on the researchers' preference. The researcher should also attempt to acknowledge their own role in what they observed through the practice of reflexivity by including any biases or experiences they may have that could colour their observations.

It is also possible to observe a group of PWA, such as those participating in an aphasia group or in an online chat forum. To achieve this, the researcher must identify and locate a group to study and find a key informant that can help introduce them to other members of the group of interest. These key informants are also referred to as “gatekeepers”. Building rapport with the gatekeeper and being transparent and clearly explaining the goals of the study is important because good rapport can facilitate the researchers’ entry to observe a group, whereas bad rapport can preclude the researcher from observing the group of interest (Rebeiro, 2001; Witham, Beddow, & Haigh, 2015). After the researcher has permission from the gatekeeper, they would observe the group and take field notes. Field notes, in this case, should include observations mentioned above and depending on the purpose of the study and approach to inquiry selected might also include an attempt to better understand the social and cultural atmosphere of the group and how the group functions together. The researcher might also collect information through casual conversations, images, surveys, and other materials as part of their observation.

The observation method may take multiple visits with individuals or groups, so if the research is taking place over an extended period, conversations or interviews will likely not have a specific and planned structure. PWA should be informed of the research methods beforehand. If the researcher is observing one PWA at a time they would have a direct conversation with the PWA on how the research will be conducted and get their permission to observe them at specific times and locations (as in Howe et al., 2008). If the researcher is observing a group, it might be difficult to tell everyone that could come into the space where the research is being done, and so the researcher should talk to as many people as possible and place aphasia-friendly posters around a location to notify other group members that research observation is taking place. The

gatekeeper may also be willing to help the researcher notify members that observational research is taking place. When relaying information about the study, the researcher should be mindful of explaining the “why” of their research but ensure the information they provide does not cause PWA to change their usual behaviour that the researcher wishes to observe. Depending on the participants, using a video camera to record observations may not be possible, as it may modify the participants’ typical behaviour. However, from experience, it has been observed that most participants become quickly accustomed to the video camera and forget that it is there at some point during the data collection and so researchers are encouraged to try recording sessions whenever possible to capture important non-verbal behaviours. To assist with data collection, the researcher should audio record all interactions where possible, and ensure that PWA are aware that they are being recorded for ethical purposes. Detailed field notes should be taken about the nonverbal communication the PWA are using, so that their visual cues are not missing, or the intended meaning is not changed when listening to the recording later.

### **Photovoice**

Currently, in qualitative research, arts-based methods of data collection are gaining in popularity (Buckingham, 2009). One of these methods is called photovoice, which allows participants to express their point of view and show their reality through photographs (Wang, Yi, Tao, & Carovano, 1998). Photovoice also has other names including photo novella, participant-generated photography, and picturevoice. In previous photovoice research, participants were provided with cameras to take photos of scenes, items, or people that are meaningful to them and are adjacent to the researcher’s questions of interest (Onwuegbuzie et al., 2010). Of course, it is possible for the photos to be shown before the researcher’s questions have been established. For example, a researcher could say they want to learn about the daily life of PWA, and then after



seeing the photos decide where they want to probe for more information about a specific aspect of their daily life portrayed in the photos. Regardless, this method has been demonstrated to provide a rich understanding of the phenomenon and improved interview quality (Brown, Worrall, Davidson, & Howe, 2013; Ulmer, Hux, Brown, Nelms, & Reeder, 2017). In previous photo-voice studies with PWA, participants were given two to four weeks to take the photos, the researchers developed the photos and then the PWA were asked to select the most meaningful photos to share (Auclair et al., 2019; Brown et al., 2010; Wang & Burris, 1997; Wang et al., 1998). The photos are usually used in an interview or focus group setting where the PWA show their photos, and the researcher gains an understanding of the meaning behind the images the PWA share by asking questions. The photos are helpful to elicit discussion and entice PWA to offer additional information around a specific topic of interest, issue, story, or perspective the PWA would like the researcher to know about (Onwuegbuzie et al., 2010).

Originally, photovoice was intended as a participatory action research method, which means that the participants are part of the decision-making process, and the research results are intended to influence policymakers and create a dialogue about changes that participants want to see in their community (Wang & Burris, 1997). Therefore, photovoice specifically has been used to make policymakers aware of issues, but it is possible that it has a wider use than participatory action research as demonstrated by the participant-generated photography studies (e.g., Brown et al., 2010; Onwuegbuzie et al., 2010). Researchers have adopted the idea of photovoice by having participants take photos of their lives to facilitate communication, without the political and dialogue intentions of traditional photovoice (Brown et al., 2010). If the PWA taking part in the research enjoys art and using colours, shapes, and other materials to express their feelings and thoughts it would be worthwhile to consider using photovoice and other arts-based methods

to help them communicate, but this method may not be interesting to all PWA (Brown et al., 2013).

Current technology has made the use of photovoice easier for qualitative researchers. With many PWA owning smartphones, they already always have a means of taking photos. These photos could easily be sent electronically to the researcher. In many cases, PWA already know how to use their cameras or could be taught how to do so. There are also many tools available, such as “selfie sticks,” that can be added to a phone to help augment the photo taking and make it easier to hold if the PWA have any physical limitations, however it is also possible that some PWA would have physical limitations that could not be surmounted by tools. This could lead to partners or caretakers taking photos for PWA, which could lead to misrepresentation of PWA’s experiences (Brown et al., 2013). For PWA who may feel that they have lost their voice to aphasia, photographs can empower them and help them to feel that they have a voice through the images they capture, as well as provide them with ownership and authority in the research process.

Whenever images are included as a part of research, there are ethical considerations. The participants must agree to have their photos published and understand what publication of photos means. If participants do not agree to have their images published, the researcher could ask if it is acceptable to describe the image instead or blur out part of the image such as a face (Phelan & Kinsella, 2013). Although this may be less ideal because the image loses some of its quality and words are not the same as an image, it is necessary to respect the participants’ wishes and privacy, especially since photos can be intimate and reveal more than a participant may have initially intended (Phelan & Kinsella, 2013). It is also possible that participants could be placed

in a false light, unintentionally, through the images and words that the researcher uses to represent them (Phelan & Kinsella, 2013; Wang & Redwood-Jones, 2001). As researchers, it is our responsibility to protect our participants and accurately share their stories, and member checking is one way that researchers can achieve this.

## **Conclusions**

This paper has provided practical, ethical, and logistical considerations and suggestions for researchers and SLPs who are planning to use qualitative data collection methods in their research with PWA. General considerations for data collection with PWA include using supported communication in conversation and using aphasia-friendly recommendations to create documents. Many data collection methods and approaches to inquiry can be utilized with PWA if the researcher is patient and uses some creativity to mitigate the communication difficulties that may arise. Currently, papers reporting qualitative research with PWA do not always explain how they mitigate communication challenges, and it is recommended that in the future researchers report information such as what supported communication strategies were used, and how they refined their research questions to work with PWA. If the way researchers report data collection procedures is unclear, then the credibility and dependability (i.e., rigor) of the data are compromised (Luck & Rose, 2007). Qualitative research with PWA can be challenging due to the communication barrier, but it is important that we continue to collect their stories and give PWA a voice in research by using data collection methods that are suitable for the varying degrees of communication ability present in aphasia.

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## Chapter 6

### **Understanding the impact of therapy on the health-related quality of life of people with aphasia: A collective case study**

#### **Introduction**

Aphasia is a communication disorder, most often resulting from a stroke. In Canada there are estimated to be over 165,000 people living with aphasia (Simmons-Mackie, 2018). People with aphasia (PWA) have challenges with verbal expression, comprehension, reading and writing. Aphasia is considered chronic after six or more months, and during the chronic phase there are fewer resources available for PWA to receive treatment for their communication needs (Hersh, 2018; Simmons-Mackie, 2018; Wallace, 2010). Unfortunately, aphasia is a life-long condition, and PWA are forced to live with the lasting impacts of this communication disorder. Issues that PWA continue to face in the chronic stage include continued challenges with communication, and a lower health-related quality of life (HRQL).

Patrick and Erickson (1993) defined HRQL as “The measure in which the assigned value is modified to the duration of the life in function of the perception of physical, psychological, and social limitations and the decrease of opportunities due to the disease, its sequels, the treatment and/or the health policies (as cited in Romero, Vivas-Consuelo, & Alvis-Guzman, 2013). Wilson & Cleary (1995) developed a conceptual model of HRQL that connects various aspects of health. Their model has five levels (Biological and physiological variables, Symptom status, Functional status, General health perceptions, and overall quality of life) that are interconnected with characteristics of the individual and characteristics of the environment. This model is relevant as the goal of client care is improvement in outcomes, which this model can help researchers to explore.

HRQL is lower for PWA compared to stroke survivors without aphasia (Cruice et al., 2006). Various factors have been linked to a lower HRQL for PWA, including high level of communication disability, emotional distress, low activity level, reduced social support, high levels of fatigue, and a high number of comorbidities (Bullier et al., 2020; Hilari et al., 2012).

Speech-Language Pathologists (SLPs) work with PWA to improve impaired communication domains, with the goal of increasing participation in meaningful activities in their lives. Many SLPs ascribe to the Life Participation Approach to Aphasia (LPAA), which is a philosophy of service delivery where the goal is to assist PWA to function at a level that provides life satisfaction (LPAA Project Group, 2000). The *Living with Aphasia: Framework for Outcome Measurement* (A-FROM; Kagan, 2008), is an adaptation of the WHO-ICF model and the Disability Creation Process developed with input from PWA, family members, SLPs, and other rehabilitation professionals. Within the A-FROM, there are four interconnected domains: Aphasia Severity, Participation in Life Situations, Communication and Language Environment, and Personal Identity, Attitudes and Feelings. “Living with Aphasia”, a concept similar to HRQL, is at the centre of the A-FROM as a product of the overlapping domains. Each domain within the A-FROM can be targeted within a LPAA approach to therapy by ensuring that activities selected in therapy are meaningful and functional in relation to the everyday life of the PWA. As communication is central to the well-being of people, SLPs are uniquely situated to help PWA improve their HRQL given the SLPs’ expertise in communication, training in motivational interviewing, and placement at all stages of the healthcare system. SLPs have considerable agency in terms of what they target in therapy and how it is targeted. Using the LPAA philosophy and A-FROM framework together can help to guide SLPs when considering how to impact the HRQL of PWA. Given that the A-FROM is aphasia specific and is likely to be

familiar to SLPs, this is the model selected for the discussion of HRQL throughout this study. As opposed to Wilson and Cleary's (1995) model, the A-FROM depicts HRQL at the centre of four overlapping domains. As HRQL is the main focus of exploration in the current study, this model was selected.

SLPs can provide therapy in multiple modalities, including individual (i.e., therapist meets with PWA one on one) or group (i.e., therapist leads multiple PWA through activities). One sub-type of individual therapy (app-based therapy) employs technology such as computer programs or tablet-based apps to deliver therapy exercises focused on remediating impaired domains. The different modalities of therapy offer different levels of interaction with both therapists and/or other PWA, which impacts opportunities available for social support through therapy. For example, individual therapy typically comprises consistent interaction with one person (i.e., the therapist) in a therapeutic relationship, whereas group therapy provides consistent interaction with multiple people in both therapeutic and peer roles, depending on the structure of the group. App-based therapy is often combined with individual therapy, or is used in lieu of other therapy approaches, for example when one is discharged from individual therapy.

Positive outcomes have been reported for both individual and group therapies for aphasia. As individual therapy can be easily targeted to address individual goals, improved language outcomes are commonly reported (Brady et al., 2016). App-based therapy has also been shown to improve language and cognitive outcomes (Des Roches et al., 2015; Kiran et al., 2014; Palmer et al., 2019). In general, group-based therapies tend to result in improved confidence and better mood (Fogg-Rogers et al., 2016; Lanyon et al., 2018; Plourde et al., 2019), although a number have also reported improved communication and language outcomes, including increased amount of communication and increased communication independence (Fogg-Rogers et al.,

2016; Lomas et al., 1989; Pitt et al., 2017; Pitt et al., 2018). However, it is relevant to note that group therapy is a very general term that could refer to various iterations of therapeutic and recreational activities done in a group setting. To date, there has not yet been an investigation of how different modalities of therapy (and associated different levels of social interaction) might impact HRQL of PWA. The consideration of quality of life when planning therapy is a newer perspective for most SLPs, but it is an important one to acknowledge, as communication ability is a large factor contributing to HRQL. SLPs are often focused on treatment of the symptoms of a communication disorder, and the consideration of HRQL requires a broader perspective on the impact that treatment can provide.

When considering the state of aphasia research, many foundational studies have used quantitative methodology as opposed to qualitative methodology (Wilson et al., 2021). Many PWA are not included in stroke research, and even research on PWA frequently excludes people with severe aphasia. In both cases, this is due to their communication challenges and lack of aphasia-friendly formatting in recruitment and study materials. In addition, much of the research is quantitative research that focuses on testing hypotheses and measuring variables, whereas qualitative research allows for in-depth exploration of context, concepts, and experiences. Therefore, although quantitative research can help determine *if* a treatment is effective, without talking to participants it can be difficult to understand *why* it was effective and whether the treatment requires changes to be more enjoyable and to achieve further improvement. Qualitative research allows us to explore the “pieces of the puzzle” beyond what quantitative research can provide numerically.

In 2020, COVID-19 resulted in a world-wide pandemic, meaning that in many cases SLP services could no longer safely be delivered in person. This resulted in a massive shift to tele-

therapy (Chadd et al., 2021; Kong, 2021). This shift was a learning process for SLPs and PWA alike, but also provided new opportunities for therapy and conversation groups to take place virtually. Although the shift to virtual provision of therapy was necessary because of the pandemic, questions remain around whether virtual therapy would offer the same level of achievement, engagement and social interaction that is observed during in-person therapy. Kong (2021) indicated that chronic PWA were more adversely impacted due to the change in services and disrupted routines. Research also shifted online to complete remote or virtual data collection, including for the completion of this study. Therefore, this article presents a collective case study of online therapy for PWA during the COVID-19 pandemic.

The purpose of this multiple method (QUAL+quan) collective case study is to report on the lived experiences of PWA during participation in different modalities of therapy to investigate the following research questions:

- 1) What is the lived experience of PWA during participation in different modalities of therapy?
  - a) What impact did COVID-19 have on the experiences of PWA?
- 2) What A-FROM domain of functioning is most impacted by these different modalities of therapy?
- 3) How do these modalities of therapy impact the HRQL of PWA?
- 4) How are language and mood outcomes related to HRQL outcomes of therapy for PWA?

## **Method**

This study used a concurrent longitudinal mixed methods (QUAL + quan) approach, with the qualitative inquiry guided by a qualitative description methodology (Sandelowski, 2000; Creswell; 2016). Approval was received from the institutional research ethics board at the University of Alberta (Pro00097283).



### *Participants*

Seven PWA (6 males, 1 female) who were planning to participate in various therapy modalities were recruited to participate in this study (see Table 6). All participants were 18 years or older and spoke English or French as their primary language. PWA participants were at least 6 months post-stroke to ensure that they were in the chronic phase of aphasia. PWA participated in either app-based therapy (VoiceAdapt trial), group therapy (virtual Alberta Aphasia Camp), or virtual individual therapy (Corbett Clinic individual therapy). One PWA withdrew from the study after 2 phases of data collection as they felt they were unable to find time to complete the assessments and interview; their data was included as assessments had already been scored and interviews had already been transcribed.

**Table 6.**  
*Participant Information.*

Participant Code	Sex	Age at entry to study	Education	Time Post-stroke at time of study	Therapy Modality	Previous Modality Experiences	Stroke Event	Motivations	Current Outlook
PWA001	M	52	14	6 yr	Virtual Individual Therapy	In-person individual therapy, group therapy	Um when I had it-had my stroke...maybe for the first year or one year after my stroke, I saw them, and they said uh um that I-I didn't say very much to them. 'Cause I had hard time. I sat-like there was like uh I don't know, ten friends, and uh-and I was trying to listen to to everybody, and I have a hard time to understand what they're saying, you know. I thought 'Oh my god I'd like to say stuff to them' but I couldn't.	it's just that I am always trying to get better um like you know	what I want to do is, I do want to talk normal or even read or write like uh when somebody's talking to me, they're talking to me I'm understanding that but then I just uh, my head just goes over here [looks to the side away from camera] and I'm not even listening to them anymore because it's starting to uh all blur, you know I'm, you know I just uh I can't I don't know if I can talk to anybody completely
PWA002	M	30	16	10 yr	Aphasia Camp	In-person individual therapy, group therapy	[I] didn't talk, 10 days I wake up in a coma, but I still have my memory. I was mute, and I like can't I can barely see [speak - gesturing pulling words out of mouth] like I can't, like I was stuck. The stroke happened, and I cried and hurt, big like big consequences. I was young, and I had a stroke, and it's affected me drastically. Try to walk, not in the wheelchair but to stand up and trying to walk. It's hard to recognize the seriousness and serious lock and key of my own aphasia, cause it's hard, it's so hard, and I was one of them, I was trying Monday to Friday in [local hospital] and just to like, 2 hours each day, just to like try to talk, and yeah, it's so hard and I'm very, I'm so sad but...I mean like, yeah, it's fine, lots of people are like happy is thankful to be alive.	I mean some part is very sad but mostly it's positive outlook and thanks to my mother, she taught me well and it's the danger of life too, but it's bright side of life	It's some trouble parts but some good parts too and um what can I say it's like just to zig-zag of like different trails and yeah, it's like lots of good meaningful moments and I'm happy and I'm still doing... it's so hard like I'm still have some damage and still have some problems. It's about aphasia, but I don't care about aphasia or stroke but it's so hard and yeah, and it sucks but it's a balancing act, you know. I as hesitant but yeah, I comes to terms of I have aphasia, I have a stroke. It's severe, I'm living right now, but I'm trying to be opposed to keep on motivated, try to different things, different challenges, even if it's hard things to do but yeah... but life goes on and and yeah, it's, that's the way it is.  I think, my point of view, I'm talking more better, more succinctly, ... but I mean yeah, regardless across that 10 year like gap it's like it's huge, big

									improvements...it's improving bit by bit yeah. So I mean the quality of life is like when I was 21 ...And like still struggling like uh to walk and talk and like learn the whole body of language it sucked, it sucks but life is still like better and and keep on reaching so, that's the best I got.
PWA003	M	69	14	2.5 yr	Virtual Individual Therapy	In-person individual therapy, group therapy, app-based therapy	Yeah, when I had last time, I had no couldn't, couldn't much of anything. Just uh just, you know, just telling up a story what's going on. I couldn't I didn't know what was going on. What were they dorrng me and had me uh yeah, during during that block, I didn't know what was going. I don't know.	P: The-the-the I told by the last time was uh two and a half [holds up two fingers and folds third finger down part way to show half]...That's when you start getting, you're on you're-your geuron going uh... That's not it it's uh... learning learning... Yes, and I still feel it's really, I-like it I: You feel like you haven't gotten that upswing yet P: No not anything big yet, who knows, I may never know, I probably never will get... you know?	Yeah, I I don't see much [doesn't say much but listens a lot]. I don't see much to it, but a lot of person a lot of all-around to the whole thing. They have the whole talking listening. You can just sit on it and die on it. That's good for me.
PWA004	M	80	15.5	2 yr	Aphasia Camp	In-person individual therapy, in-person group therapy	[The doctor] said don't take any blood thinner so I said that was my heart doctor and he says the odds are very slim that you get problems, but sure enough they did it uh and I got stroke...I had it what 2 days later something like that ... I had no recollection, like I couldn't couldn't remember my wife or anything like I could visualize her [gesturing as if looking at a picture] but I couldn't remember her name or nothing...but that that's it, so my family was there with me through all the worked with me to - I would've been probably just nothing [without them].	I always wanted to learn. I always wanted to improve myself.	I cannot really complain about my quality of life. You know if I had to drive a car, I would be more independent but since I had the stroke my wife and children do all the driving because I have trouble with my feet and and so, I ruined three cars already with a clutch. So, I had a little accident, and so they said enough of that. To me this is a big... I miss it very much so I can't go anywhere where I want to go and that.  I notice a lot; I speak better and so on. It...gives me confidence. You know like I speak in front of a group you I know it ... it...you have to concentrate on what word you saying and so on and

									your abilities. Everybody's different but ... yeah for me it's challenging because I have to use my brain and that for me helps. I can make myself understood you know people understand me, so for me that's a big step. It's all it all comes together very little but it you just work on it.
PWA005*	M	60	18	1.5 yr	Aphasia Camp	In-person individual therapy,	Uh well um the time uh yeah well, it's kind of difficult because uh, but I thought oh, I'm alive and okay, um but I can't do anything. Uh no I can [holds up and waves left hand] uh the left hand and the right uh left arm uh leg were doing things, but my right arm and my left leg were um, and I can't speak.	well, I have been oh, I'm going back to work	I'm working on it...It's uh it's a problem [laughs] but you know um, and I'm I'm you know like um... I'm a... disability, so that's going on, and it's not progressing as much as I think but...Like um my right hand is okay but um, and that's all I have to worry about, but my speech is like... zero [laughs]. Well not not not zero and I was impressed by the you know like um... the things that um... I was pre- I was able to say, because you know I'm not as bad [laughs]
PWA006	M	47	16	5 yr	App-Based	In-person individual therapy, group therapy, virtual group therapy, app-based therapy	One dash fourteen coma. Talking no talking no [shakes head]...One word. One word. One word. [holds up one finger]	Talking and talking and talking.	[laughs then tears up and says in emotional voice] Sentences. Good. Talking. Good. Talking. More and more.
PWA007	F	51	14	10 yr	App-Based	In-person individual therapy, in-person group therapy	It was uh unreal [laughs] um I couldn't talk, and I couldn't do nothing like yeah. Yeah.	Uh for me is the um challenge so yeah.	I talk right? Now. And um tricks and stuff and yeah. Panic. Because I can't find the words...Tick tick tock you know, oh my god, can't find the words, oh my god.

\* indicates participant who withdrew from the study before assessment and interview 3.

### ***Recruitment***

All participants were contacted via email to be invited to participate in this research prior to beginning each therapy modality. Participants had self-enrolled in their therapy modality before recruitment began. PWA were recruited through the client/participant network that consisted of the Aphasia Research Lab, Corbett Clinic, and Alberta Aphasia Camp. The sample of participants was purposefully selected (Creswell, 2007) from the catchment area of the client/participant network (including urban and rural areas). All participants had been involved in both in-person individual and group therapy prior to taking part in this study, and many of the participants had used an app during previous therapy sessions. None of the participants had participated in teletherapy versions of these therapy modalities. Each participant took part in only one of the three therapy modalities for this study.

### ***Therapy Modalities***

#### **Virtual Aphasia Camp.**

Alberta Aphasia Camp is a therapy modality that takes place over one weekend in a rustic location, providing an enriched communication environment, and both recreational and therapeutic activities for both PWA and their family members. In 2020, Alberta Aphasia Camp took place online via the Zoom platform over three weekend days (Friday September 18 - Sunday September 20; for a total of 6.25 hours). Activities that had been planned for camp (e.g., singing, yoga) were altered to fit the online environment. There were 59 campers total, with 36 PWA, 23 caregivers (friends or family), 20 pre-professional students from SLP, OT and PT programs at the University of Alberta, and 5 rehabilitation professionals (OT, SLP, PT, RecT). Throughout the weekend campers were put into different breakout rooms depending on the

activities they had pre-selected to participate in (see Appendix 10). Within each breakout room activity, campers had opportunities to meet and interact with other PWA, caregivers, SLPs and the pre-professional students. There were also large group activities where campers would interact with everyone in attendance. All students and supervisors had training related to supporting communication and supporting PWA in the online environment.

### **Individual Therapy.**

The Corbett Hall Speech-Language Clinic is situated within the Department of Communication Sciences and Disorders at the University of Alberta. Clients can be referred or self-refer to the program to receive individual speech-language therapy. One-hour assessment and treatment sessions take place two times a week over 12 weeks, for a total of 24 hours. An example of a treatment session plan is available in Appendix 11. From September to November 2020, Corbett Clinic took place virtually, with two pre-professional SLP students working together to lead the assessments and treatments, while being supervised by a registered SLP.

### **App-Based Therapy.**

VoiceAdapt is an app-based therapy incorporating principles of Semantic Feature Analysis (Boyle & Coelho, 1995) and Phonologic Components Analysis (PCA; Leonard et al., 2008) into a tablet-based naming app. The efficacy of this app was investigated in a randomized controlled trial (Kim et al., 2021) enrolling participants from July 2020 – November 2021. Participants were asked to use the app for 1 hour each day for 5 weeks (~25 hours). Use of the app consisted of looking at images presented by the app and following auditory and written prompts to provide details about the image. For example, if participants were in the PCA condition and were shown the image of a dog, they would be asked to name the picture, say a rhyming word, the first sound, another word that starts with the same sound, the last sound, and

the number of syllables. Meanwhile if participants were in the SFA condition and were shown the image of a dog, they would be asked to name the picture, say what category/group it belongs to, what is associated with it, what actions it does, what properties it has, and where you would find it. A research assistant completed a weekly check in on participants during the trial to ask about any technical difficulties with the app and whether they were able to complete the training each day.

### ***Data Collection***

All data collection sessions were conducted and recorded through Zoom software (Zoom Video Communications Inc., 2021). Data collection included assessments, interviews, observations, and the review of therapy materials. Data collection took place formally within three cases which include group therapy, individual therapy, and app-based therapy described above. In this study, each case was bound by time and activity, as each case is relevant to the specific type of therapy (activity), and the time frame surrounding the therapy experience (time).

Participants were individually assessed and interviewed at three time points: before therapy began (baseline), after therapy ended (post-intervention), and at a 3-month follow up. Observations and review of therapy materials took place between pre-therapy and post-therapy assessments and interviews.

### **Qualitative Data.**

Participants were observed for a minimum of one therapy session with the permission of the SLP and participant. The first author (CW) used an observation chart to make notes (see Appendix 12). Observations were focused on how the participant chose to participate in therapy, their overall mood during therapy, and any events that occurred while they were participating.

Each participant was interviewed by the first author (CW). Interviews were scheduled for one and a half hours; they lasted between 39 and 90 minutes, with an average of 59.5 minutes. Both an audio recording device (*Sony digital recorder*) and video recording (*Zoom platform*) were used to record all interviews. All PWA decided to complete the interviews independently (i.e., without a care partner present). Interview questions for PWA concerned the participant's social life, feelings before, during, and after therapy, and their expectations and the realities of therapy. Semi-structured interview guides including questions and prompts (Appendices 7-9) were sent to participants before the interview as recommended by Wilson and Kim (2021).

### **Quantitative Data.**

Quantitative data provided additional descriptive information for the case. The following measures were used at each of the three assessment periods based on the recommendations of the core outcome measures for aphasia research (Wallace et al., 2019): *General Health Questionnaire-12* (GHQ-12; Goldberg, 1978), *Western Aphasia Battery-Revised* (WAB-R; Kertesz, 2006), and *Stroke and Aphasia Quality of Life Scale-39* (SAQOL-39; Hilari et al., 2003). Variables provided by participants included sociodemographic data (i.e., age, sex, education), and stroke characteristics (i.e., time post-stroke, brain hemisphere where stroke occurred).

Although a variety of outcome measures are used in aphasia treatment research, there is a lack of consensus on what is considered a 'successful' result (Breitenstein et al., 2022). Over time, outcome measures have been considered in terms of statistically significant change (i.e.,  $p < 0.05$ ), and sometimes researchers have considered a minimally important change (MIC; i.e., longitudinal change (de Vet & Turwee, 2019)), which can be seen as more relevant to clinical work. Gilmore and colleagues (2019) calculated average effect sizes for several commonly used



outcome measures in aphasia treatment research from studies employing both within and between group designs. For example, a change of 5.03 points on the WAB-R is provided as a benchmark indicating mean score difference. However, this benchmark is relevant for mean group change studies, and is not appropriate for use in measuring individual change, which is observed in this study. In addition, outcome measures and exploring the statistical and MIC differences don't indicate what is meaningful from the perspective of PWA and therefore doesn't mean that a meaningful change has happened in their lives (Breitenstein et al., 2022). In this study we are choosing to evaluate the impact of MIC in relation to the perspectives of PWA when evaluating outcomes following different therapy modalities.

The *WAB-R* provided an Aphasia Quotient (AQ), which is a measure of the linguistic skills of the PWA. It also provided a classification of the type of aphasia according to the Boston Classification Model. The AQ provides a score range between 0 and 100, with scores closer to 100 indicating milder aphasia compared to scores closer to 0. Currently a value for MIC is not available for the *WAB-R* (Breitenstein et al., 2022).

The *SAQOL-39* measured the quality of life of PWA through four subdomains of physical, psychosocial, communication, and energy. Questions were answered by participants using a Likert scale. The subdomains and total score are calculated with a score range of 0 to 5, with higher scores indicating higher HRQL. MIC is a change of 0.21 points for the Singapore version of the *SAQOL-39* (Guo et al., 2017). Since an MIC for the original version is not currently available, this study will use the MIC reported by Guo and colleagues.

The *GHQ-12* measured emotional well-being in three dimensions including social dysfunction, anxiety and depression, and loss of confidence. Questions were answered by participants using a Likert scale, which provided scores ranging from 0 to 48, with lower

numbers indicating better emotional well-being. At this time a value for MIC is not available for the *GHQ-12*.

### ***Data Analysis***

#### **Qualitative.**

In-depth reflexive thematic analysis was conducted for each case, followed by cross-case analysis (Braun & Clarke, 2006 & 2019; Stake 1995, Stake, 2006, Yin, 2009). Analysis began with the transcription of interviews including gestures and facial expressions and writing field notes after each interview. Then the data was coded in Microsoft Word, using comments to denote different codes. The first author (CW) independently coded all interviews. The first author also trained seven additional research team members, who each independently coded 3 interviews. The approach to coding was collaborative with the intention of finding consensus less important than developing a rich reading of the data (Braun & Clarke, 2019). Therefore, codes were discussed, defined, and refined as needed. Each code was then put on a digital sticky note, and the sticky notes were sorted into groupings of similar ideas. These groupings were then reviewed to see if the overall themes matched the codes, and diagrams of the analysis were created. This process was completed for each set of interviews from each participant. Then the codes from interviews of each case were combined and examined. Finally, data from all three cases was cross analysed through comparison of codes and themes.

#### **Quantitative.**

All outcome measures were scored by the first author (CW) following the guidelines provided in the administration manual for each assessment. To achieve a fuller depiction of the impact of therapy on language, HRQL and mood outcomes, descriptive statistics were used to

examine individual scores for each participant to describe the change seen in scores over the three timepoints.

**Results**

The qualitative results are presented first and organized by case, followed by quantitative results which are organized by outcome measure, and finally a discussion of how the data and cases are interrelated through crystallization. Throughout this section, the four research questions will be addressed through the discussion of qualitative and quantitative results.

***Qualitative Results***

The lived experiences of PWA during participation in different modalities of therapy are described below to answer research questions one and 1a, “*What is the lived experience of PWA during participation in different modalities of therapy?*” and “*What impact did COVID-19 have on the experiences of PWA?*”. Themes used to describe the experiences included: Impact of Covid-19, Meaning of Therapy, Comparisons, Social Connections, and Aphasia is a Journey (Table 7). Some of these themes were present across cases, while others were unique to each case. Each relevant theme will be discussed within each case below.

**Table 7.**  
*Reflexive Thematic Analysis Results.*

Overall Themes	Example Codes	Relevant Case(s)
Impact of Covid-19	Isolation, limited interaction, environmental barrier	Virtual Aphasia Camp Individual Therapy App-Based Therapy
Meaning of Therapy	Learning, work, fun, happy, hope, important, change, good days	Virtual Aphasia Camp Individual Therapy App-Based Therapy

Comparisons	Preferred modality, mix of modalities, same experience	Virtual Aphasia Camp Individual Therapy App-Based Therapy
Social Connections	Caregiver, hobbies, support, empathy for PWA, willing to try, drive to connect	Virtual Aphasia Camp
Aphasia is a Journey	Impact of stroke, rising to challenges, strategies, acceptance, hope, reactions of others, personal feelings, drive to improve, balancing act	Virtual Aphasia Camp Individual Therapy App-Based Therapy

***Impact of COVID-19***

Given this study was completed during the COVID-19 pandemic, it is not surprising that the impact of COVID-19 was a theme arising from the analysis. The following quotes from participants provide context into what changed for PWA in their lives during the pandemic, and how they felt about the pandemic. PWA004 discussed how his social interactions had been limited due to the pandemic, “Yeah it has changed it a lot. I don’t go to stores hardly any at, nowhere, rarely I go to stores. I used to like to go to stores so I can see the people and so on. I don't see my family really...I have family here and so it's a it's a big change”. PWA007 had a similar experience “Shuttered. Shut in. Yeah. Yeah. Netflix and chill [laughs]”. PWA006 described how the pandemic changed an activity they regularly engaged in,

“P: Volunteer XXX[hospital] volunteer...Coffee, water.

I: Very cool. And not anymore?

P: No. Before healthy good. Before after ... C [typing on AAC device] COVID. COVID.

I: It ruined that volunteering for you, hey?

P: Yeah. [now] TV. Speech device”.

The social environment was also changed by COVID-19 mandates, which made communication challenging. PWA001 stated, “when I wanna go to the uh store or the stores or anything um you know of course uh we have to wear a mask now that's bothering me”. Even at home it seemed that PWA003 had a hard time putting COVID-19 aside, “Uh [sighs] How do I say that? We ate that all the time. It's always, always on my life. The cov-the comi [COVID]. Can't step back”. With all of the challenges that COVID-19 presented, PWA002 seemed to sum up everyone's feelings on the topic, “Yeah, I mean it's terrible what happened like I mean the whole world is like ruined now but I mean it's here now so...I accept it”.

### **Virtual Aphasia Camp.**

Virtual Aphasia Camp participants had thoughts to share regarding what they expected to happen before attending camp, with PWA004 saying, “Well, I'm looking forward to it! [big grin on face] ...I don't know what's gonna happen really” PWA002 saying, “I don't know, we'll see. I'll like let you know, but it's like it's first time so it's uh, should be a fun time”, and PWA005 saying, “I'm hoping that it was, that it's going to be interesting”. One participant, PWA002, had been thinking about attending camp in person in previous years but decided that virtual aphasia camp was a better fit, “ I was um hesitant because it's like it's far away to drive...And that's why it's I like um yeah zoom is very best and like driving to one hour and half and like and like drive back it's like I don't like want to camp and like 3 days I mean kinda like I live like my home my home and it's that what I want to bed and like sleep with um at camp it's kinda like scary I mean”.

A prominent theme was called **Social Connections** and detailed how PWA felt about the interactions that took place over the weekend. During aphasia camp, campers often enjoy

meeting and talking to each other throughout the weekend. It was anticipated that at virtual aphasia camp, campers could continue with social interactions even through the virtual format. However, this worked for some activities better than others, “No like I love taking like um different songs but like all at mute so like what's the point of singing” (PWA002). The experience of being muted throughout many camp activities at virtual aphasia camp was described by PWA002 and PWA004 (respectively), “I listen, I was muted, so like I eat breakfast and try to listen to it but yeah...like the zoom camp is all like muted and then like the first real conversation [was Sunday] which is fine I suppose...but it's like, it's like, still it's like it's 3 hours, and like in one tiny resemblance of like my own situation” and “The only thing I would have liked a little bit more [conversation]. Talking you know, I missed that a little bit, it could've been more...you can communicate better you know somehow”. PWA004 expanded on this in the interviews by discussing the difficulties with making friends virtually, “No, I don't know how we could make friends, uh you know what I mean, it-it's very hard uh, you know, you have to know somebody a lot better”.

PWA also provided information on how they viewed themselves in different social situations at camp. Even though being muted for activities was not ideal in terms of building friendships, many participants enjoyed the aspect of getting to meet other PWA, and see their challenges, “I'm and so I'm feeling sorry for myself yeah but it's not it's not able to feel sorry for myself, because I saw the people that are worse off than me... I thought oh, I'm you know um well I'm kind of disabled [grimaces] and not quite the same, and the aphasia camp is like oh, there's worse, and there's yeah there's and I'm lucky to be at camp” (PWA005). Meeting others with aphasia allowed PWA005 to compare deficits and see either where they would like to work more or where they were doing well. PWA004 had a favourite day of camp, “oh Sunday was

really, I thought was the greatest...yeah, I-I liked what happened on Sunday. I think they... it was a little bit livelier. It was uh... uh music and-and everything. I-I thought it, well I remember it's yeah sort of; I really enjoyed the Sunday". On Saturday all campers with aphasia were invited to share their story, "I shared my story, and um the... you know um people shared their story, and it was um... um... um... encouraging. So okay, I shared my story, and you know um and they shared their story and okay it was um um um it was, yeah it was sharing" (PWA005). Traditionally this has been an impactful and meaningful activity for all campers, and the campers at virtual aphasia camp enjoyed it as well.

In terms of **Comparisons**, it was mentioned that online therapy was less preferred, less intimate, and that interactions can be more difficult online, "Lots of students and lots trying has aphasia and try to interact, but zoom is much much harder so" (PWA002). In comparing online aphasia camp to other online group therapies, PWA004 and PWA005, respectively, felt that "no it wasn't that much different really" and "not especially, because um there's different things that I uh that that that going, and I don't know that it's all that different". When asked to compare group and individual therapy, PWA005 preferred the dynamics in group therapy, "Um one-on-one uh you have to... um...learn that okay, it's going to be one-on-one, and group therapy is like it's...it's more relaxed *[laughs]*...And I can get my words out".

The final theme for aphasia camp, **Aphasia is a Journey**, discusses the impact of attending Virtual Aphasia Camp in each PWA's journey with aphasia. When asked about whether aphasia camp had an impact on HRQL, PWA002 said, "Probably not really, I mean a little bit but yeah, it's, before it's been 10 years...so yeah, maybe, I think, but generally it's more of like other individuals of like just to talk". PWA004 felt that camp helped him take away new knowledge, "It made me richer and what I saw and the things I perceived, uh... you know, like

the drawings and the PP [Primary Progressive Aphasia].” Although the impact on HRQL may not have been felt by the campers, both PWA005 and PWA004 made comments that demonstrated their enjoyment of camp and what it meant to them. PWA005 said, “I can be open to the things at camp that um are... uh going, like um uh no see um... [points at head] I can um hm... be... [moves hand to help find the words] um uh cognisant of the other people at camp, and I don't have to be oh I'm uh uh... I'm being oh uh um... hm um... I'm being... uh uh... um... excluded from camp or uh and I'm feeling oh, camp is no it like uh [sighs] uh I feel lucky to be at camp”. PWA004 said, “I mean the people should be commended for what they did, I mean, for the first time you know, everything is new and you know, oh yeah it was amazing, all the goodies we got here... It made me richer and what I saw and the things I perceived” (PWA004).

### **Individual Therapy.**

Before starting their individual therapy, PWA001 and PWA003 did not have expectations or goals for their sessions, but PWA001 mentioned, “I wanna get better”. Although this was not part of a theme for individual therapy, this quote represents a common sentiment among participants.

All participants had experienced in-person therapy previously, so it was natural to make **Comparisons** of the in-person and online therapies. PWA003 mentioned that it would be nice to be in person, but that he thought online therapy would be fine, “I like well it would be nice to open again, but we just can't do it”. After his block in therapy, PWA001 discussed his experience of comparing online and in-person therapy,

At the beginning, it was uh frustrating because um I thought I would be more having more hard time to understand but uh that's not true it was I I learned from them uh like I did on the computer. Then the uh the uh in person you know to see for me to be there at uh... at shoot I can't... The clinic. So, I yeah yes there is little



bit different but uh um I don't think it was so much different um cause they they did it pretty good... the difference is is um I didn't have to drive there. Um and it didn't cost me any uh money um in the um...the parking, yes. That's right. Yeah, so that's nice uh but I do like at the same time I do like it because I like 'cause its um get out of my house...it works either way so.

PWA001 and PWA003 preferred the virtual individual therapy (as stated by PWA001) compared to group therapy, "I think I have I would have to say I do like to be by myself probably because um I'm more, hm I hate to say this but I'm more embarrassed, or I'm not too sure if embarrassed is the right. Um, not embarrassed, kind of uh [*holds up hands*] scared type of thing to see them...I just didn't feel as well with the groups than by myself so".

The main theme arising from participants who engaged in individual therapy was **Aphasia is a Journey**, which for these participants describes the emotions and experiences of participating in therapy over time. At the beginning of therapy, PWA003 found it difficult but toward the end he felt everything was going better. When asked what they thought of therapy, PWA001 said, "I thought it was really good and um you know and it's exactly what I wanted to um uh to see them to um help me out. And cause they're they're asking me right right out to me you know. And uh um so you know that's that made me so much better I wouldn't say it's better of me but its uh so much better cause I have something to to um read [script] um read it if I do have any problems you know". PWA003 said, "Yes good, good for me". PWA001 did have some hesitations about participating in therapy online, "Cause they're they're great people uh this time I mean they're always you know everybody I met uh for the um ... the um... the student teachers or whatever they wanna call them um they I've always had a good time with them yeah. But these people it's kind of maybe a little bit different cause it's on the uh computer so. It was they were all pretty good. And uh it felt really good with them." but seemed to have a

successful time in therapy. When asked about whether individual therapy had an impact on HRQL, PWA003 said, “Oh, I think we are, yes, we are, yes” and PWA001 said, “Yeah, I do feel so much better for myself”. Both participants also discussed the improvements and changes they saw in themselves with PWA001 saying, “I’m really enjoying it because it’s uh because it’s, it’s um, something’s happening, you know?” and PWA003 mentioning, “it is it’s I it’s nice to know something about it before but I never, you know, I am different dude than before. It is not the same as it was before.”

### **App-Based Therapy.**

The main theme for app-based therapy, **Aphasia is a Journey**, details participants thoughts on the app and how they felt while using it. When asked what they thought about using the app, PWA006 said, “Good. Speech good [holds up app on tablet, nods and smiles] ...Improving, improving. Talking. Easier. More words, more words!”. PWA006 did not want to stop using the app when the trial was over. In contrast, PWA007 did not have the same experience, “Um it was okay um. It was frustrating- frustrating but... Yeah, but have to um... have to um make it more work um on um it”, as she references challenges she experienced with the app. However, PWA007 did feel that the app was worthwhile despite the challenges, “yes um um really have to concentrate on the words and um um yeah. Um it was it was a good plan” and that it taught her something new, “Um yeah um ... um rhyme rhyming [laughs] yeah rhyming. I never do that before [scratches head].”

In consideration of **Comparisons** made regarding app-based therapy, PWA007 made a poignant remark, “[smiles and laughs] but um hmm hear me you know”, referring to how the app did not always ‘listen’ or ‘hear’ her when she was talking to it, whereas a person will almost always hear you and try to listen. PWA006 did not have the same frustrations with the app, “P:

Speech good. Uh speech good. I: Yeah. Is one better than the other? [holds hands at different levels] P: No, no. I: They're both the same. [holds hands at same level] P: Same. [nods]”.

PWA006 also preferred the app to group therapy, “XXX[conversation group], no. I: No. App is better than XXX[conversation group]? P: Better, and better. I: Okay. Is that because you have more practice? Talking? P: Talking and talking and talking. I: Yeah. And in XXX[conversation group], sometimes it's more listening. P: Listening.”

When asked about whether the app-based therapy had an impact on their HRQL, PWA006 said, “Mm, yes no. [scrunches face] I: Yes no. So, kind of the same? P: Same.” and PWA007 said, “Hmm... Um ... yes. Um I think I uh um words right. So yeah. Yeah.”. Both participants however, noted the impact of the app-based therapy on their language and communication, as PWA006 said, “Good. Ss-speech good [gesturing away from mouth].” and PWA007 said, “The same. The same [as before].” but did mention that she felt “proud” of the work she put in while using the app.

### ***Quantitative Results***

The results from assessments of language (WAB-R), HRQL (SAQOL-39) and mood (GHQ-12) that were completed pre, post and follow-up relative to therapy are presented in Table 8 below. The results below include information about minimal clinically important differences (MIC), as defined by each measure (King, 2011). For the *WAB-R*, a clinically relevant improved difference is a score change of 5.03 points (Gilmore et al., 2019). For the *SAQOL-39*, a MIC is a score change of 0.21 points (Guo et al., 2017).

**Table 8.**

Numerical results of language, HRQL and mood assessments. \* denotes MIC

Therapy Modality	Participant	WAB-R AQ			SAQOL-39												GHQ-12		
		Score range 0-100			Score range 0-5												Score range 0-48		
		Pre	Post	Follow-Up	Pre-intervention (Baseline)				Post-intervention (Post therapy)				Three Month Follow-Up				Pre	Post	Follow-up
				Total	Physical	Communication	Psychosocial	Total	Physical	Communication	Psychosocial	Total	Physical	Communication	Psychosocial				
Virtual Aphasia Camp	PWA002	70.4	80	80.1	4.59	4.31	4.43	4.94	4.69	4.63*	4.57	4.81	4.79	4.75*	4.71*	4.88	2	3.5	4
	PWA004	78.9	84.1	83.6	3.59	3.63	4	3.38	3.99*	3.81	3.93	4.19*	3.64	3.5	4.29*	3.5	14	11	12
	PWA005	82.9	90.3		3.51	4.44	2.71	2.94	3.51	4.63	3.71*	2.31					14	12	
Individual Therapy	PWA001	65.2	73.7	79	3.49	4.94	3.43	2.06	3.95*	4.81	3.29	3.38*	3.89*	4.88	3.14	3.25	19	6.5	17.5
	PWA003	42.3	50.6	56.7	2.85	3.5	1.85	2.63	3.19*	4.16*	1.71	2.88*	3.33*	4.25*	0.88	2.94*	16	16	13
App-Based	PWA006	61.4	57.7	55.9	3.09	3.93	2.93	2.31	1.44	1.5	2.1	1.1	2.71*	2.71	2.86	2.63*	26	10	11

<b>Therapy</b>	PWA007	86.4	90.5	76.7	3	4.13	3.14	1.88	3.3*	3.9	3.29	2.8*	2.77	3.81	2.86	1.69	17	19	25
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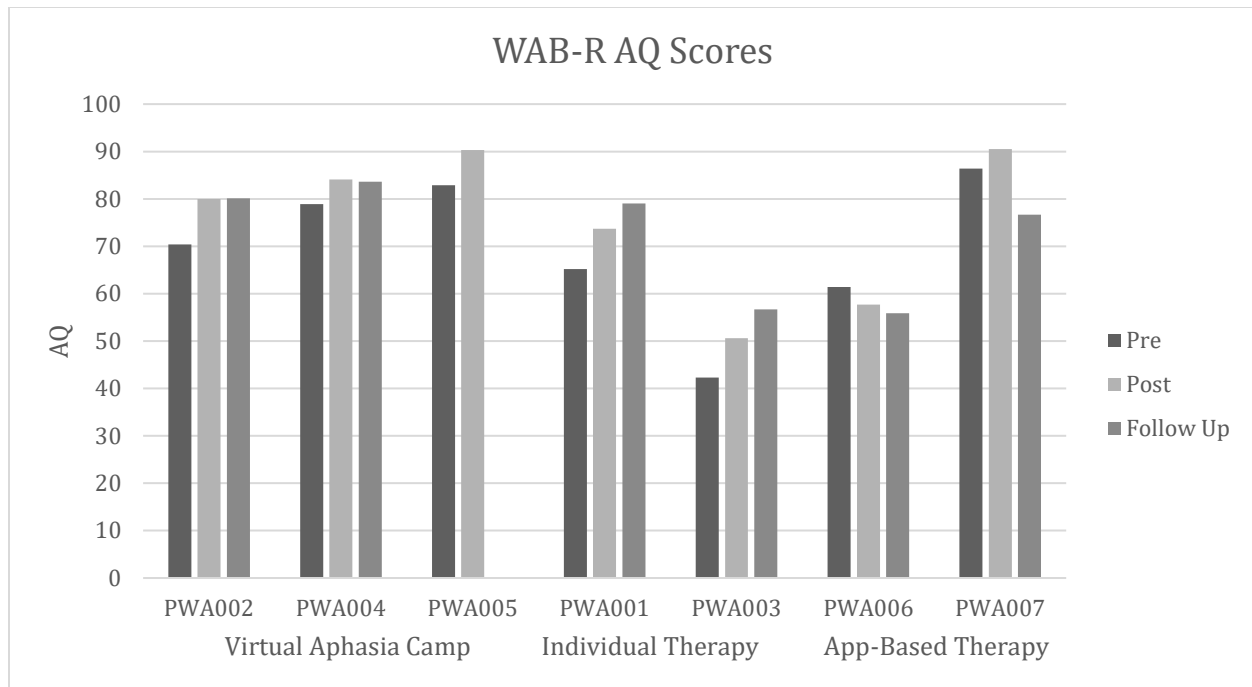
## **WAB-R Results.**

*Virtual Aphasia Camp.* The WAB-R AQ scores for all camp participants increased post therapy. The two participants who were able to complete follow up assessments, PWA002 (M, 30 years) and PWA004 (M, 80 years), maintained the post-intervention scores at the three month follow up (Figure 5).

*Individual Therapy.* PWA001 (M, 52) had a WAB-R AQ score of 65.2 at baseline, 73.7 post therapy, and 79 at three months follow up, demonstrating maintenance over time. PWA003 (M, 69) had a WAB-R AQ score of 42.3 at baseline, 50.6 post therapy, and 56.7 at three months follow up, also demonstrating maintenance (Figure 5).

*App-Based Therapy.* PWA006 (M, 47) decreased in their performance on the WAB-R from 61.4 at baseline to 55.9 at the follow-up assessment (Figure 5). PWA007 (F, 51) had an increased WAB-R between 86.4 at baseline and 90.5 at post therapy assessment, but this was not maintained at follow-up (76.7).

**Figure 5.**  
*WAB-R AQ Scores Over Time.*



### SAQOL-39 Results.

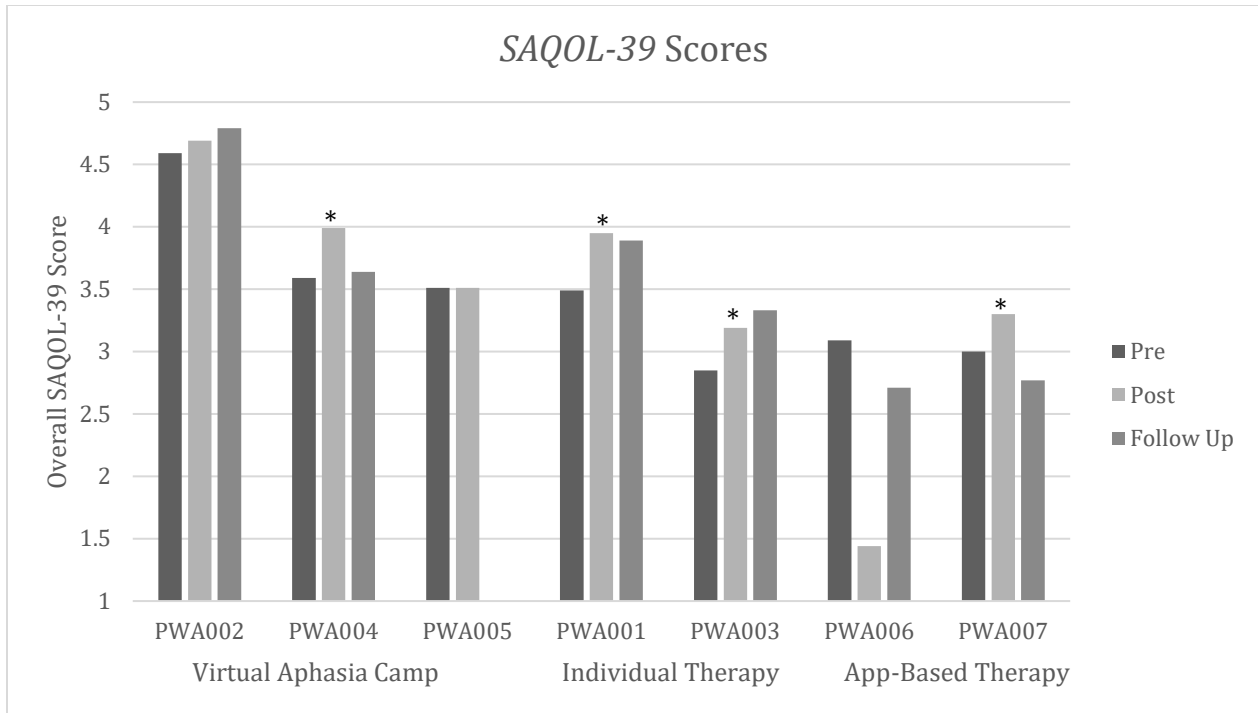
**Virtual Aphasia Camp.** For PWA002, the overall SAQOL-39 score of 4.59 at baseline increased to 4.69 at post therapy and to a MIC at 4.79 at follow up (Figure 6). The communication domain sub-score increased with a MIC between pre (4.43) and follow-up (4.71) assessments. Physical sub-domain scores also increased from 4.31 at the baseline to 4.63 at the post assessment, and this improvement was maintained at follow-up (4.75). For PWA004, the SAQOL-39 score at baseline (3.59) increased to 3.99 at post therapy, indicating a MIC (Figure 6). The psychosocial domain sub-score increased from pre (3.38) to post (3.5) assessments, again indicating MIC. The communication sub-domain score increased from pre (4) to follow-up (4.29) assessment, indicating MIC. For PWA005, the overall SAQOL-39 score did not reveal meaningful difference, however the communication domain improved with MIC between pre (2.71) and post (3.71) assessments (Figure 6).

**Individual Therapy.** PWA001 demonstrated MIC on the overall SAQOL-39 scores of 3.49 at baseline and 3.95 at post assessment, however there was some decrease in the score between post and follow-up (3.89) assessments (Figure 6). His psychosocial sub-domain score increased from 3.49 at baseline and 3.95 at post assessment, and this MIC was maintained at follow-up (3.89). His communication sub-domain score decreased throughout the assessments. PWA003 had the overall SAQOL-39 score of 2.85 at baseline, with a MIC as the score increased to 3.19 at post therapy assessment and this was maintained 3.33 at follow-up (Figure 6). His psychosocial sub-domain score increased from 2.63 at baseline and 2.88 at post assessment, and this MIC was maintained at follow-up. His communication sub-domain score decreased throughout the assessments. The physical sub-domain scores increased throughout the assessments (Figure 6).

**App-Based Therapy.** For PWA006, the overall SAQOL-39 scores between 3.09 at baseline and 1.44 at post assessment decreased, and then between post and follow-up (2.71) assessment increased to be a similar score to the pre-assessment (Figure 6). PWA007's overall SAQOL-39 scores of 3 at baseline had a MIC to 3.3 post therapy, which was not maintained at follow up (2.71). Her communication sub-domain score was 3.14 at baseline, and 3.29 at post-therapy assessment, but again this difference was not maintained at follow up (2.86). The psychosocial sub-domain was 1.88 at baseline, and 2.8 at post therapy assessment, but was not maintained at follow up (Figure 6).

**Figure 6.**  
*SAQOL-39 Overall Scores Over Time. \* indicates MIC.*





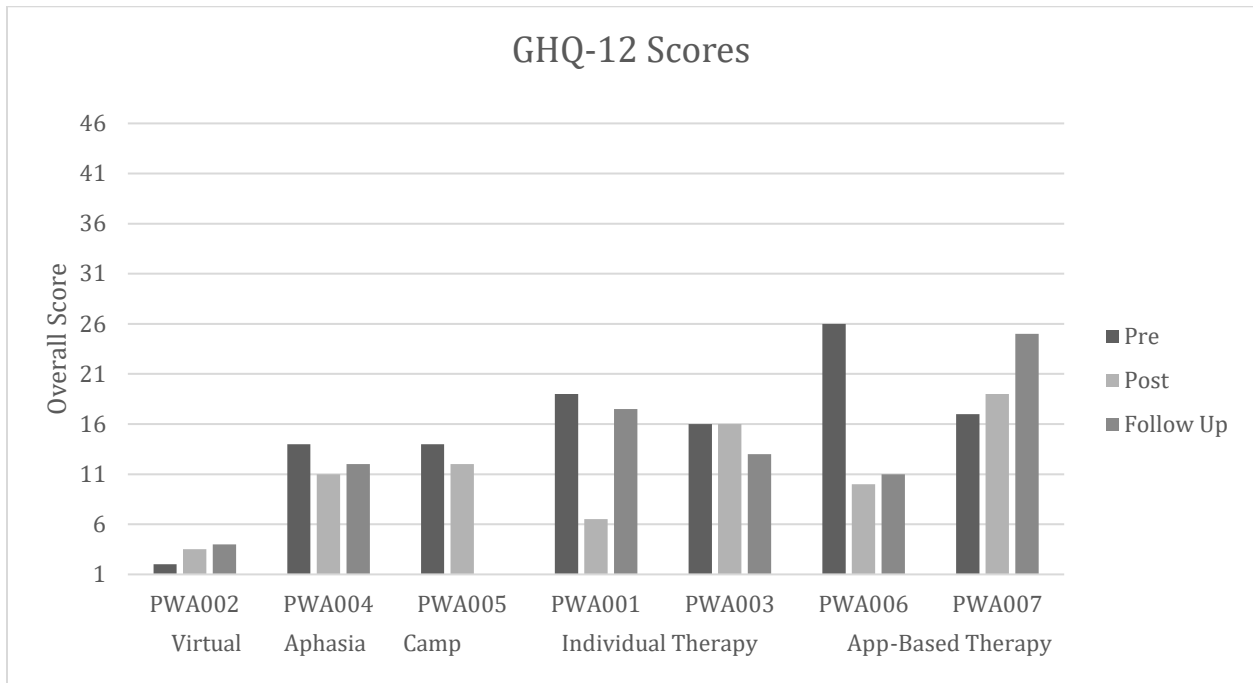
### **GHQ-12 Results.**

**Virtual Aphasia Camp.** The GHQ-12 scores remained relatively consistent for all aphasia camp participants with individual scores changing 2 points from pre-intervention and follow up (Figure 7).

**Individual Therapy.** PWA001's GHQ-12 score changed from 19 at baseline to 6.5 post therapy, and 17.5 at the three month follow up (Figure 7). PWA003's GHQ-12 score was maintained at 16 from baseline and post therapy, and then reduced to 13 at the three month follow up (Figure 7).

**App-Based Therapy.** PWA006's GHQ-12 score improved throughout the therapy, with a score of 26 at baseline to 11 at follow up (Figure 7). PWA007's GHQ-12 scores worsened over the course of the study, with a score of 17 at baseline and 25 at follow up (Figure 7).

**Figure 7.**  
*GHQ-12 Scores Over Time.*



Together across cases, these results answer research question four, *How are language and mood outcomes related to HRQL outcomes of therapy for PWA?* Although the HRQL measure (*SAQOL-39*; Hilari et al., 2003) considered aspects of communication and mood, the measures of language (*WAB-R*; Kertesz, 2006) and mood (*GHQ-12*; Goldberg, 1978) did not show similar patterns of improvement (or decline) when compared to the HRQL results for the participants. Therefore, based on current analyses, it is unclear how each outcome measure is related to the other.

### **Collective Case Results**

This section will bring together the qualitative and quantitative results. During the interviews PWA used words to discuss their experiences in therapy, which became a theme that described the **Meaning of Therapy** for PWA. Some of the words used (e.g., fun, happy, good

days, important, learning, helps) indicated that the participants overall enjoyed their time in therapy, and felt that it was important to them to be in therapy for their own growth and improvement. Other words (e.g., hard, work, practice, repetition, hope) demonstrate that therapy was not always easy or exciting but that the work they were doing provided hope. At the final interview, all participants were willing to try the same or a different therapy modality in the future. They felt that therapy was valuable regardless of modality, “I’ve learned so much more than I’ve ever did. Um... because that’s the, you know, I probably learned just as much before. ‘Cause I enjoy everything uh that I’ve learned because it’s uh-‘cause I-I-the-the-the only thing I don’t like is not doing anything... You know? Um so I’m always happy to do something” (PWA001).

Given that virtual aphasia camp is one weekend, it is unlikely to see a substantial improvement in language skills. Aphasia camp had the shortest duration but was arguably the most intense given that it took place in one weekend. Although it was anticipated PWA at camp would have the most chances for social interaction, the change to a virtual environment lessened the communication opportunities. Overall participants enjoyed their experiences at virtual aphasia camp and felt that they could take something away from camp, be it the crafts, baked goods, or something more personal such as a better understanding of their own aphasia severity. When observed at virtual aphasia camp, participants seemed to enjoy themselves and many smiles and laughs were shared.

Overall participants enjoyed their time in individual therapy. Individual therapy took place over the longest amount of time (12 weeks) and was less intense than both camp and the app, spending only about 2 hours per week in therapy. Although there is plenty of conversation in individual therapy, the social interactions may be limited because of the clinical relationship

between PWA and clinician. However, the student clinicians were observed to build rapport with the participants to understand their needs and set meaningful goals together. When observing therapy sessions, it was clear that the participants were focused on the activities, but there was always time for smiles and laughter.

The two participants who used the app both felt that they improved with its use but did not enjoy the technical challenges such as not being able to control the speed of the voice and the voice recognition software not functioning properly. When observing these technical challenges occurring, the participants appeared frustrated and upset. The participants confirmed these feelings and experiences in the interviews. Findings also demonstrate that quantitative outcome measures do not capture the entire experience of PWA, given that information participants shared in interviews was not always reflected in the outcome measures. For example, in the app-based therapy PWA006 loved using the app and felt good about his progress, but the WAB-R AQ scores did not demonstrate this. Researchers should continue to use both quantitative and qualitative methods of data collection to better understand this dissonance between outcome results and patient perspective. The app-based therapy took place over 5 weeks, and participants were to spend a minimum of one hour per day using the app. There was no social interaction for this modality, other than the weekly check-in emails. At this time, aphasia researchers are working to understand how to best capitalize on duration and intensity of treatment for PWA.

### **What A-FROM domain of functioning is most impacted by these different modalities of therapy?**

Given that Aphasia Camp (when in-person) provides a rich environment for communication opportunities, it was anticipated that the virtual version of aphasia camp would provide similar experiences. In the online environment it became quickly obvious to campers that the same communication opportunities are seen at in-person camp (e.g., chatting in the

hallway, sharing a meal) were not possible, and that the available activities did not offer the same number of chances for communication that was expected. It is understandable that participants in the virtual camp would have more to say about the Participation in Life Situations domain as virtual aphasia camp is a life situation that they are participating in. For example, in the coffee tutorial on Saturday of camp, participants were taught to make a special type of coffee. During this activity they were expected to engage in coffee chat and ask questions if they needed help. At virtual aphasia camp all volunteers have training in supported communication and so it is possible that the environmental barriers present in other situations are not present at camp, leaving participants able to focus on their participation. Even without the same communication opportunities, PWA still had a shared experience of camp, and the comradery observed in the Share Your Story activity was encouraging and demonstrated a positive impact on the participation in life situations domain of the A-FROM.

In virtual individual therapy, each PWA was able to indicate and work toward what was important for them in terms of goals for therapy. Individual therapy was impairment focused addressing the Language and Related Impairments domain, but also addressed the Personal Identity, Attitudes and Feelings domain of the A-FROM. If we consider that in individual therapy clinicians generally assess for strengths and weaknesses, and then focus on strengthening the weaknesses throughout therapy, it would be reasonable that participants and SLPs might focus on the environment outside of therapy to ensure generalizability of the skills and supports being taught.

If we consider that both PWA in the app-based therapy had change in their *GHQ-12* scores, and that in app-based therapy the PWA worked alone, it is plausible that inward reflection related to the Personal Identity, Attitudes and Feelings domain was more common in

app-based therapy. The app-based therapy in this study was impairment focused, with the goal of improving naming, without the same amount of social interaction offered by the other modalities of therapy. However, PWA006 really enjoyed the therapy and found it to be a valuable experience. This suggests that a feeling of agency within the PWA can impact how they perceive the therapy as well as the overall impact on their HRQL.

### **How do these modalities of therapy impact the HRQL of PWA?**

It appears, then, that it is not the modality of therapy *alone* that impacts HRQL, but rather a combination of the individual PWA and how they make sense of and experience the therapy modality. Each individual brings forward their past experiences, preferences and personality as they move through life. HRQL is a complex concept that in this study, is also demonstrated to be connected to the values, needs, and agency of each individual. Consideration of impairment, goals, and personal factors will be relevant moving forward when assessing the HRQL of PWA.

It is important to give PWA the ability to control their therapy and level of involvement, and to ensure that the therapy matches what they value. For example, PWA007 felt frustrated while using the app-based therapy and her SAQOL-39 score gains were not maintained, however PWA003 who really enjoyed individual therapy and felt like he improved a lot was able to maintain his SAQOL-39 gains. Therefore, if SLPs find the preferred modality of therapy for PWA, this might help to improve or maintain their HRQL.

When considering how measures of language and mood relate to HRQL outcome measures, this study did not provide a clear connection. When considering the quantitative outcome measure results, the different therapy modalities showed different patterns. Sometimes the participants within each modality did not exhibit the same patterns, demonstrating how individualized responses can be.

## **Discussion**

In this collective case study, seven PWA participated in one of three modalities of therapy (app-based, virtual individual, or virtual Alberta aphasia camp) and were interviewed concerning their thoughts and experiences in therapy. The purpose of this study was to understand how different modalities of therapy can impact the HRQL of PWA. Several concepts emerged relating to the Impact of Covid-19, that Aphasia is a Journey, Social Connections, Meaning of Therapy, and Comparisons made between types of therapy. Assessments and patient reported outcome measures also provided information regarding language, HRQL and mood outcomes for each therapy modality.

We found that in examining the lived experiences of PWA participating in various therapy modalities that PWA were happy to do any therapy modality, as it gives them hope that they will improve. Individual factors related to each PWA also impact their experience of the therapy and impact their HRQL. Previous therapy experiences were used as a comparison point, and PWA did not seem to prefer virtual or in-person, as long as communication with another person was part of the therapy. When considering the A-FROM, each modality of therapy had a different impact on each section.

### ***Virtual Aphasia Camp***

The *WAB-R* AQ improvements observed in participants at aphasia camp could have been due to a learning effect rather than a true improvement (Gilmore et al., 2019), particularly because participants discussed how they would have appreciated more opportunities to communicate with others over the weekend. The virtual version of aphasia camp did not provide the same level of socialization as previous in-person camps, but still provided important moments of a shared experience. Other studies of online group therapy designed to improve communication skills have reported improvements in communication, confidence, engagement

and aphasia severity (Cruice et al., 2021; Pitt et al., 2018). Together these results demonstrate that virtual group therapy can be impactful, however the more opportunities provided to engage and share an experience may result in more favourable outcomes.

Each participant had unique virtual aphasia camp experiences as they each selected their own activities. The activities they participated in differed in the amount of conversation and interaction with other campers, and so it is possible that the different responses on the *SAQOL-39* are due to individual experiences and characteristics of each participant. Therefore, it is important to consider the personal factors of PWA when helping them to select the next stage of therapy in their journey with aphasia. Developing activities that are meaningful and relevant to the PWA in consideration of their personal identity, attitudes, and feelings is a central tenet of person-centered care and can lead to higher levels of motivation, improved capitalization of spared brain function, and increased recruitment of cognitive and contextual information to support activities (Thiessen & Brown, 2021). Aphasia camp allows PWA to select their own activities, but these are a pre-populated list and might not always match what activities PWA would hope to participate in.

### ***Individual Therapy***

The decrease in scores in the *SAQOL-39* communication domain could be due to these participants growing awareness of their communication challenges during therapy. Awareness of deficits could be more pronounced in individual therapy compared to aphasia camp or app-based therapy as the goals of individual therapy are meant to target weaknesses of one individual, rather than a group of individuals. It is of interest that the psychosocial domains of both participants improved during therapy, indicating that individual therapy can be an excellent way to build rapport and develop clinical relationships in a meaningful way that does not require



additional personnel. The fact that meaningful rapport can be developed between an SLP and PWA is of no surprise, but the importance of this rapport and the impact it has on the therapy outcomes should be acknowledged.

When considering the GHQ-12 scores of PWA001, the scores demonstrated that PWA001 was in an improved state of mental health at the post therapy assessment compared to the pre and follow-up assessments. It is important to note that this participant prefers individual therapy, and so it would be of interest to explore if this effect is observed in other PWA participating in therapy. However, overall, these results indicate that being in therapy has the potential to have a positive influence on the mental health of PWA. In a recent study by Cruice and Kate (2019), SLPs shared their views and methods for the assessment of HRQL. Discussion was focused on informal assessments and the scope of practice of SLPs in relation to mental health. Many SLPs felt unprepared to assess HRQL but felt that it was essential as part of their client's treatment.

### ***App-Based Therapy***

It is unclear why there was not at least maintenance of the WAB-R AQ scores for PWA006 and PWA007, indicating that there are factors beyond the therapy and language outcomes that must be considered when determining the effectiveness of therapy modalities. Other app-based therapies that have been studied (e.g., Alam et al., 2021 with the Jellow app) have had a focus on more functional communication and discovered that in addition to traditional therapy there were positive outcomes in terms of language and quality of life. The GHQ-12 score of PWA006 increased from baseline to post-intervention, suggesting improvement in his mental health and wellbeing. It is of note that PWA006 really enjoyed using the app and did not want to stop using it after the trial. Ensuring the enjoyment of therapy activities could be a meaningful

way to positively impact the mental health of PWA (Thiessen & Brown, 2021). PWA007 was known to be in treatment for depression during the study, and so this treatment along with changing medications may have had a negative impact on her scores. This participant demonstrates how knowledge of mental health conditions can improve our understanding of outcome measure results.

### ***Collective Case***

In considering the qualitative and quantitative results together, the completed analysis revealed that the modalities of therapy PWA participated in for this study was seen as a step on their journey with aphasia. However, the trends we saw warrant further exploration to determine if the same trends exist in a larger group. Given that this study is a Phase 1 proof of concept study, further exploration should begin by considering feasibility, usability and efficacy before moving to effectiveness and RCTs. At this time, one block of therapy was not enough to have *statistically* significant results, but qualitatively and with the concept of a *clinically meaningful difference*, we can see that therapy is a positive experience and can provide positive feelings concerning the communication of PWA in this study.

It is understood that language abilities and mood both contribute to HRQL (Bullier et al., 2020), but determining how much each of these factors impacts HRQL within different situations requires further exploration. Research on mental health of PWA has indicated that PWA struggle with depression and anxiety throughout their journey with aphasia (Baker et al., 2020; Hilari et al., 2003; Hilari et al., 2012). Therefore, it is essential that SLPs consider assessing or discussing the mental health of their clients to ensure that they are in the appropriate frame of mind to be able to achieve their goals in therapy. Previous studies have conceptualized the impact participating in interviews has on participants, with results demonstrating that even participating

in a qualitative interview can be therapeutic (Perry & Bigelow, 2020; Rossetto, 2014). When individuals are depressed, it can be difficult to complete familiar activities of daily living without the added effort required to participate and grow from speech-language therapy, and so it is essential that healthcare providers discuss these issues with their clients.

Sociodemographic factors can also play an important role in HRQL. For example, Ribeiro Lima and colleagues (2020) identified several characteristics of PWA who participated in a multicomponent group therapy program that were associated with higher gains in the communication domain of the *SAQOL-39*. These included identifying as female, younger age, and having a caregiver and multiple other people in the home. When providing healthcare without considering the whole individual, it can be difficult to understand why or how they came to feel particular ways about specific situations. Discussing past situations within the context of improving HRQL can help individuals to provide details about their experiences and preferences so that clinicians can help provide their clients with the best options available for treatment.

### ***Limitations***

Although PWA were only participating in one modality of therapy at the time of the study, all participants had participated in therapy previously. Thus, it can be difficult to understand their opinions on therapy without previous experiences colouring the new experiences. This study took place both virtually and within the context of COVID-19, therefore these findings are limited to this context and may not apply to experiences following in-person therapies. It is also relevant to consider that everyone was impacted by the pandemic differently, and many people experienced additional stress, anxiety, loneliness, and other feelings that would impact the results of this study. Each participant is an individual, with particular characteristics and personalities that would impact not only their preferences in what therapy modality they self-

selected to participate in (e.g., virtual aphasia camp vs app-based therapy) but also how they viewed their experiences in therapy. It is also of note that each modality had 2-3 participants, and so the lack of relationships found in this study may reflect the small sample of a heterogeneous population. Each modality of therapy also had different doses, meaning that many factors could have impacted the outcomes observed. As well, aphasia camp is only one example of how group therapy can take place. Given that purposeful selection was used to invite participants, we cannot rule out some bias that may have impacted the results. In addition, the first author (CW) conducted all assessments and interviews, and therefore was not blinded. Having a second person conduct the assessments would be recommended to reduce the potential of this bias in future work. Finally, given the design of this study, there were no intra subject or between subject controls. Therefore, it is difficult to assign observed changes on the outcome measures solely to the interventions PWA took part in.

### ***Future Directions & Clinical Implications***

To ensure optimal and meaningful delivery of therapy for PWA, it is essential to discuss their personality, preferences, and goals need to be considered when determining which modality best suits their needs. It is clear from this study that PWA want to have agency over their activities, including therapy. Therefore, it is relevant for SLPs to utilize motivational interviewing techniques to support clients to find the next step of treatment on their Journey with Aphasia (Adler & Pickering, 2019). PWA change over time, and so it is not appropriate to assume that their current preferences remained the same as their previous therapy preferences. Having a clinical discussion on what PWA are seeing as positive in their therapy and what they want to change can help SLPs know when it might be time to shift to new modalities or incorporate multiple modalities in the treatment plan.

Although this study followed recommendations of Wallace and colleagues (2019), other assessments can and have been used to explore HRQL, and should be considered in future studies.

The preliminary results from the analysis of the aphasia camp data were used to change how the 2021 camp was conducted online, which may have been a different experience entirely for participants. An example of a major change made was providing more opportunities for conversation within the camp activities, and ensuring breakout groups stayed small. Future studies should consider perspectives of larger samples of participants while continuing to incorporate both qualitative and quantitative methods.

These findings can help SLPs and researchers better understand the expectations and experiences of PWA participating in different modalities of therapy. Given that everyone had different experiences and opinions on the process, it is relevant to consider using interview techniques to help determine the best fit when providing a client with therapy options.

## **Conclusions**

The current study reports the perceptions of PWA attending various modalities of therapy, as well as the results from outcome measures of language, HRQL and mood. We now understand that considering personal factors of PWA is an important step in selection of therapy modality, and that each modality targets different sections of the A-FROM. A deeper understanding of outcome measures is required to understand how each is related to the other when discussing HRQL. Most studies of PWA receiving therapy from SLPs do not report HRQL outcome measures. Researchers should continue to use both quantitative and qualitative methods of data collection to better understand the reported dissonance between outcome results and

patient perspective. Future steps for healthcare professionals include using HRQL outcome measures in practice.

## **Chapter 7**

This doctoral dissertation concludes with a discussion of the implications of this work for speech pathology and speech-language pathologists.

### **Integrated Manuscripts: Constructing a Story**

This dissertation was completed using an integrated manuscript approach. The manuscripts, together, are meant to build a story of the foundations of this work, what it was able to grow into, and hints at future research endeavours. The first manuscript (Chapter 3) was inspired after conversations with my supervisor to better understand whether researchers were considering quality of life, and if so, what outcome measures they were using to capture potential change. This scoping review led to an examination of research on group therapy and an understanding that researchers were not exploring quality of life as often as they could, nor did they demonstrate consensus on what measures were being used.

The second manuscript (Chapter 5) arose from critical conversations about the state of qualitative research in the field of aphasiology. Discussions centred on the exclusion of PWA from studies, a lack of information on how to appropriately include PWA in studies, and a deep seeded interest in understanding the life experiences of PWA. This manuscript details how researchers can go about including PWA in qualitative interviews and research, and the considerations addressed in the manuscript helped to prepare me to complete interviews with PWA.

The third and final manuscript (Chapter 6) details the results of the collective case study examining how different modalities of therapy might impact the HRQL of PWA through the engagement of PWA as active participants. This manuscript provides empirical evidence in relation to language, HRQL, and mood outcome measures.

## **Summary of Findings**

The objective of this dissertation was to investigate how different modalities of therapy (i.e., app-based, aphasia camp, and traditional group therapy) for PWA impact their quality of life. To meet these objectives, a scoping review and collective case study were completed. The main findings and how they relate to the research questions are summarized below.

### ***What is the lived experience of PWA during participation in different modalities of therapy?***

Each PWA who participated in this study had their own unique set of circumstances and personal characteristics before starting the study. Each participant had previously had speech-language therapy, however the modality of therapy they engaged in for this study was new to each participant. In addition, each modality was provided virtually, which provided another element of novelty. Therefore, it is difficult (if not impossible) to narrow down the lived experiences to a concrete set of words, when each individual, each modality of therapy, and each experience of the therapy was unique. However, it seemed that overall PWA found therapy to be an important part of their personal journey with aphasia. All participants wanted to continue to participate in therapy (whether the same modality or a different one) and even when therapy was not enjoyable, the experience of doing the therapy and learning from it was seen as valuable by PWA. What the PWA communicated suggests that they are willing to work to improve their language skills, no matter the circumstances, because they wanted to regain language abilities that aphasia has taken from them. Some of the PWA even mentioned that when they are in therapy, 'every day is a good day', therefore participation in therapy is meaningful and important for PWA.



***What A-FROM domain of functioning is most impacted by these different modalities of therapy?***

All therapy modalities touched on the Language and Related Impairments domain as this domain is at the core of all speech-language therapy. However, it seems that no one domain of the A-FROM (Kagan, 2008) is most impacted by participation in therapy, as each therapy had differing elements that involved particular domains.

The PWA who participated in virtual aphasia camp discussed themes related to the Participation in Life Situations domain. It is understandable that participants in the virtual camp would have more to say about this domain as virtual aphasia camp is a life situation that they are participating in. Participants discussed wanting more opportunities to engage in conversation, and felt that although the activities were enjoyable, they would have been more enjoyable had there been more communication opportunities. At virtual aphasia camp, all volunteers have training in supported communication and so it is possible that the environmental barriers present in other situations were not present at camp, leaving participants able to focus on their participation.

In individual therapy, participants discussed themes related to the Communication and Language Environment domain. If we consider that in individual therapy clinicians generally assess communication strengths and weaknesses, and then focus on strengthening the weaknesses throughout therapy, it would be reasonable that participants and SLPs might address the environment outside of therapy to ensure generalizability of the skills and supports being taught. Participants discussed their interactions with family, friends and strangers explaining what went well and what did not. The Language and Related Impairments domain was also frequently discussed as participants enjoyed speaking of their achievements in therapy, often

feeling proud of what they accomplished, and what they hoped to continue to strengthen in future therapy.

In app-based therapy, focus was more on the Personal Identity, Attitudes and Feelings domain. Considering that both PWA in the app-based therapy had the most change or movement in their *GHQ-12* scores, and that in app-based therapy the PWA works alone, it is plausible that inward reflection related to the Personal Identity, Attitudes and Feelings domain was more common in app-based therapy. The participants in the app-based therapy modality also talked about the burden of their communication challenges more than other participants, which suggests that the involvement and support that an SLP can provide when clients are having challenges in their environment cannot be replaced by an app. The Language and Related Impairment domain was also frequently discussed as participants wanted to share what the app changed for them and what they hoped therapy could provide them in the future.

### ***How do these modalities of therapy impact the HRQL of PWA?***

It appears that it is not the modality of therapy *alone* that impacts HRQL, but rather a combination of the experiences of participating in therapy and the interactions that occur as a result of being in therapy, as well as personal factors that PWA bring with them. For example, PWA007 felt frustrated while using the app-based therapy and her overall *SAQOL-39* score gains from pre to post therapy were not maintained at follow-up. Whereas PWA003, who really enjoyed the individual therapy and felt like he improved a lot was able to maintain his *SAQOL-39* gains at follow-up. However, it is of interest to consider which specific aspects of each modality contributed to HRQL changes.

Those PWA who participated in virtual aphasia camp discussed their opportunities to meet other PWA. Although they were not able to build a long-lasting friendship over the virtual

camp weekend, participants mentioned that meeting others with aphasia was impactful. PWA002 and PWA005 both discussed that it was encouraging and eye-opening to them to find that some PWA were more severe than themselves. This observation provided participants with hope and made them feel less alone seeing how many other people live with aphasia. After a stroke, PWA often experience loss of relationships, or if relationships are maintained they often are left out of conversations (Northcott et al., 2016). At virtual aphasia camp, everyone was included in the activities, and these feelings of belonging and hope suggest a positive impact on how PWA view themselves. When we view ourselves in a positive way, the rest of the world tends to appear more positive as well and living in a world of positivity can improve HRQL (Kato et al., 2016).

When discussing individual therapy, participants mentioned how the student clinicians worked with them to find personalized, meaningful treatment goals. PWA001 was pleased that he received resources and support to help him make phone calls, as this is what was useful for his daily life. PWA003 demonstrated his improved communication abilities when using his AAC device and mentioned that it gave him more to talk about. Personalization of treatment is one way that SLPs can ensure engagement and motivation increase (Marshall & Freed, 2006; Thiessen & Brown, 2021). When clients are engaged in goal setting, it gives them a sense of agency and responsibility over their progress and work in therapy. Collaborative goal-setting has been demonstrated to result in positive outcomes, including higher motivation and improved communication (Haley et al., 2019). Being encouraged by the students at each session and seeing the final treatment report with clear explanations and examples of the gains they made throughout treatment was also a meaningful part of therapy for the participants. When PWA are involved in meaningful activities, they are able to live successfully with aphasia long-term,

resulting in an improved HRQL (Brown et al., 2012; Manning et al., 2019; Wray & Clarke, 2017).

In examination of the app-based therapy, the two participants felt differently. PWA006 really enjoyed the app, whereas PWA007 was frustrated by it. However, both participants elected to continue to use the app. They both wanted to improve their naming and verbal output, both of which are specific skills that the app allowed them to practice. Given that they were both determined to improve and were working towards a specific skill, it is possible that a sense of agency over working on the app could contribute to increased confidence, which could in turn improve HRQL (Braley et al., 2021). In the case of app-based therapy, working independently towards gains in relation to a specific skill may mean more to PWA than those without aphasia can understand.

When PWA feel agency and are specifically involved in their treatment, we are able to see improvements in HRQL. Therefore, if SLPs find the preferred modality of therapy for PWA who provides them with a sense of agency and involvement, this might help to improve or maintain their HRQL. It is also possible that personal factors are a meaningful basis to consider when attempting to understand the best modality of therapy.

### ***How are language and mood outcomes related to HRQL outcomes of therapy for PWA?***

When considering how measures of language and mood relate to HRQL outcome measures, this dissertation did not provide a clear connection. Although the HRQL measure (*SAQOL-39*; Hilari et al., 2003) considered aspects of communication and mood, the measures of language (*WAB-R*; Kertesz, 2006) and mood (*GHQ-12*; Goldberg, 1978) did not show similar patterns of improvement (or decline) when compared to the HRQL results for the participants. When considering the quantitative outcome measure results, the different therapy modalities

showed different patterns. Sometimes the participants within each modality did not demonstrate the same patterns, demonstrating how individualized responses can be. It is posited that language abilities and mood both contribute to HRQL but determining how much each of these factors impact HRQL within different therapy modalities requires further exploration.

## **Implications**

The current dissertation contributes to the current understanding of HRQL in PWA and the current knowledge of how PWA experience different modalities of therapy.

### ***Implications for Researchers***

From the scoping review (see Chapter 3; Wilson et al., 2021) considering outcome measures used in group therapy, we discovered that few researchers are using explicit measures of HRQL, suggesting that the exploration into HRQL is new for SLP. It will be necessary to include measures of HRQL in future treatment studies to better understand the concept of HRQL as well as how therapy can improve it. Measures of HRQL and other outcomes, such as language and mood, should be carefully selected to follow the Research Outcome Measurement in Aphasia (ROMA) consensus statement when possible (Wallace et al., 2019). In the review, the selected outcome measures provided different information compared to interviews with participants, suggesting that using quantitative outcome measures alone is not sufficient to capture change, especially when considering changes in personal feelings.

The findings included in this dissertation contributes to the evidence that utilizes the ROMA core outcome set of outcome assessments (Wallace et al., 2019). To be able to produce meta-analysis level synthesis in our field we need to have studies that utilize the same outcome measures. Having used the recommended outcome measures in this study, it is possible that our data could be used in future knowledge synthesis.

Using qualitative methods with PWA allowed us to explore the complex experience of living with aphasia. Much of the current research on aphasia has a quantitative focus, however we know from the scoping review that quantitative research methods do not allow us to learn the entire story. Given that quantitative methods do not allow researchers to answer all questions, qualitative research is necessary to gain a more fulsome understanding of experiences of PWA. However, qualitative research traditionally requires verbal discussion, which is difficult for PWA without the proper support. Chapter 5 (Wilson & Kim, 2021) provides a tutorial concerning how to make qualitative research aphasia-friendly. These strategies were then utilized in this dissertation to successfully interview PWA with varying severity about their therapy experiences, demonstrating that it is possible and important to get input from PWA who have different abilities and experiences. It is essential that researchers continue to use qualitative methods with PWA, so that we can learn more about aphasia, how people experience it, and hopefully interpret how SLPs can best serve PWA (Damico et al., 1999; Luck & Rose, 2007).

### ***Implications for Clinicians***

Within Chapter 6, it was noted that it is possible for therapy to improve HRQL as assessed by the SAQOL-39. We propose that all SLPs should assess HRQL as part of their usual plan for assessments. The SAQOL-39 assessment has been recommended for use in the ROMA consensus statement (Wallace et al., 2019), however there are also alternative options available for clinicians to use in their assessment of HRQL, such as the *ALA* (Simmons-Mackie et al., 2014). Although SLPs are not mental health care providers, considering topics such as HRQL and mood can help PWA build deeper connections. There is also evidence that talking to someone about their HRQL has the potential to improve HRQL (Perry & Bigelow, 2020; Rossetto, 2014). In fact, at the end of the final interview with PWA002, he mentioned that being

able to talk in the interview and tell his story was like therapy for him, “it’s good to talk and this is why like it’s like yeah, it’s very good like you are listening to me, and it’s it’s my um... my uh therapy”. Given that SLPs have specialized training in communication and are often the member of the healthcare team patients will confide in due to the use of supported communication, it is relevant for SLPs to assess and discuss HRQL with PWA.

Although many PWA struggle with depression and anxiety (Bays, 2001; Northcott et al., 2016), it can be difficult for them to receive appropriate mental health services. Many psychologists/counsellors are not trained to support communication (Morrow-Odom & Barnes, 2019), and most therapy relies heavily on verbal communication. For PWA this means that mental health therapy sessions can be challenging due to not only emotional response, but also the communication challenges experienced by PWA who are not always supported by the psychologists/counsellors. Therefore, SLPs have a role in helping to educate counsellors that work with PWA on how to support communication to get the most out of the sessions.

SLPs also have a responsibility to refer their clients to the next step in care. Having an open and honest conversation about the therapy modalities available to PWA might help SLPs provide recommendations for future treatment that align best with the priorities, wants and needs of the PWA. The quotes and experiences in the interviews presented in this dissertation could act as guidelines for what different PWA might be looking for and how to deliver that to them.

### **Methodological Insights**

When detailing the results of a study, the consideration of context is important to contemplate when thinking about implications of the results and directions for future research. This work involved participants situated in both a virtual context, and a broader Canadian context. Each individual interview completed for the collective case study provides a deep

contextualization of the data. Within the cross-case analysis, some of the depth of contextualization is lost when looking for patterns across cases. However, this additional contextual information available for each individual case is valuable and has contributed to the work overall.

The reasoning behind the selection of different therapy modalities had to do with differing levels of social interactions involved in each modality. Both individual and group therapies offer some social interaction, with group therapy offering more opportunities for interacting with more people, while app-based therapy offers little to no interaction. Due to the understanding that PWA tend to have small social circles, the interviews addressed socialization. The participants had a lot to share in terms of both their past and current relationships, and their understanding of the social changes that occurred after their strokes. This information on relationships emerged into multiple themes providing abundant and rich data that will be further explored in a future manuscript.

Given that the study was conducted online, a potential concern was that building rapport with participants would be difficult. I was pleasantly surprised that this was not the case. I found I was quickly able to build rapport with the participants - it is amazing what happens when you ask someone who doesn't have many opportunities to communicate to share their story. In particular, I was concerned about the participant with Wernicke's aphasia (PWA003), as his verbal expression is severely impaired, which makes it difficult for him to participate in conversation. PWA003 also had some doubts about the value of his participation at one point asking, "Do my-do you understand timy vicing [my talking]?". I responded by saying, "Yeah" and he said, "You do?" with a tone of shock. Of course, I didn't understand everything he said, but between his use of gestures, an AAC device, a few interactions with his spouse to clarify



items of discussion, and my use of supported communication skills, such as confirming what was said and asking follow-up questions, we were able to complete the interview. I feel that although there are not many ‘quotable quotes’ that came from this interview, I was still able to get all of the information I wanted and more. When participants told me about their interests or hobbies, I also made sure to follow up with them about these activities at subsequent interviews, which showed that I was listening and that I cared about what they had to say. I think that this small consideration is what helped me to understand and build rapport with the participants.

### **Quality Criteria for Rigor**

There are few guidelines specific to qualitative case study research available to help authors and reviewers consider the quality of the work. However, qualitative research in general has many quality guidelines available that can be applied to case study research. To evaluate this research, I took a collection of criteria from various scholars that best fit the nature of the study. I have combined elements from the criteria provided by Charmaz (2006), Morrow (2005) and Finlay (2002) to address the data, and reflexivity.

*Adequacy of data* as a means of addressing quality in research is a concept presented by Morrow (2005). This concept goes beyond the number of participants or number of interviews and delves into the richness of information provided. Purposeful sampling (Creswell, 2007) was used to ensure participants would be able to provide rich data. It was also determined that multiple interviews would take place (one before, one after, and one at three-month follow-up), which allowed for development of rapport as well as deep and rich data (Polkinghorne, 2005). To develop the interview guide, literature on quality of life, therapy modalities, and life experiences of PWA was explored. Observations and being an active listener in interviews led to spontaneous questions beyond the interview guide to develop a deeper understanding of the topic

from the perspective of PWA. Multiple data sources are encouraged by Morrow (2005) and Stake (1995); in this study the following sources were used in triangulation: three semi-structured interviews, language assessment, HRQL assessment, mood assessment, observation of therapy sessions, review of therapy materials, and reflexive journaling. It is also relevant to examine the data for disconfirming evidence to avoid confirmation bias. Both confirming and disconfirming instances were explored by first attending to the details of each case during the analysis of each case, and then commonalities and unique aspects were identified with cross case analysis.

*Reflexivity* helps researchers to understand how their experiences and the world around them shape their research (Finlay, 2002). In chapter 4, I situate myself as a researcher and am upfront about my beliefs that research is a construction built by the participants, researcher, and reader. I have embraced reflexivity throughout this dissertation by taking time before and after each data collection and data analysis session to reflect on what happened, what I learned, and how I impacted what happened. Through this process I have kept reflexive notes and had reflexive discussions with my doctoral supervisor. Questions that I asked myself at the beginning of this dissertation journey included: What biases am I bringing? Why am I asking the questions that I am? What information am I willing to share about myself with participants? Questions that came up for myself as the research continued included: How did this data collection session make me feel? This set of questions was something I reflected on frequently and wrote about in depth in my reflexive journal.

### **Future Directions**

Several possibilities for future research emerged from the current dissertation. One of these possibilities is to explore the perspectives of SLPs delivering treatment to PWA to

understand what considerations they make in terms of health-related quality of life when planning therapy. This will help us to learn whether or to what extent SLPs have the concept of HRQL “on their radar”, and what they are doing to assess and treat concerns related to HRQL.

Considering that this study was completed with virtual therapy modalities during a global pandemic, it would be of interest to replicate this study at a time when SLPs and PWA can do therapy in person to gain a better understanding of therapy preferences and experiences.

In conclusion, there are many possibilities for research to examine how speech-language therapy modalities impact the HRQL of PWA. For me, the next step in this journey will involve the use of advocacy for PWA and PWA as research partners in hopes of learning more about aphasia that is meaningful and important to the people that live with it every day. There is potential in this work to influence researchers to use HRQL outcome measures and qualitative methods, as well as influence for clinicians to explore meaningful conversations about HRQL and mental health with their clients.

## **Conclusions**

This dissertation provides evidence that different modalities of therapy provide different supports for PWA, and that when selecting the modality of therapy there are many things to consider, such as mental health, personal factors, and motivation. All participants discussed how they would like to do more therapy in the future to continue to address their communication concerns, and were willing to participate in any modality of therapy in hope of improving their aphasia. Further, I highlight the importance of using not only language outcomes, but also outcome measures related to HRQL in research. I also encourage readers to consider using an interview as part of the assessment, given that in this study the interviews provided more in-depth information than could be learned from assessments or patient-reported outcome measures.

Finally, I demonstrate that it is possible to complete qualitative interviews with PWA, regardless of their aphasia type or severity.

Further research is required to confirm and expand on the findings of this study to ensure that we are providing appropriate therapy opportunities that are well-suited to each individual.

PWA lost a large part of their life when they acquired aphasia, and it is our responsibility to help them maintain and regain their communication abilities to ensure that they are able to participate in life.

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Zumbansen, A., Peretz, I., Anglade, C., Bilodeau, J., G n reux, S., Hubert, M., & H bert, S.

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## **Appendix 1: Search terms as input into each database.**

### **Ovid MEDLINE(R) ALL 1946 to July 30, 2020**

1. exp "Quality of Life"/
2. ("Quality of Life" or QoL or HRQOL).mp.
3. ("life satisfaction" or wellbeing or well-being).mp.
4. 1 or 2 or 3
5. exp Aphasia, Conduction/ or exp Aphasia/ or exp Aphasia, Broca/ or exp Aphasia, Wernicke/
6. aphasi\*.mp.
7. 5 or 6
8. (aphasia group\* or group session\* or group-based or group encounter\* or group format or group setting\*).mp.
9. ((group or groups) adj3 individual).mp.
10. exp Community Networks/
11. "community group\*".mp.
12. "group therapy".mp.
13. "group treatment".mp.
14. "group intervention".mp.
15. exp Stroke Rehabilitation/ or exp Rehabilitation Centers/
16. "aphasia centre\*".mp.
17. "aphasia center\*".mp.
18. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. 4 and 7 and 18

### **SCOPUS**

(( TITLE-ABS-KEY ( "Quality of Life" OR "Health related quality of life" OR qol OR hrqol )) OR ( TITLE-ABS-KEY ( "life satisfaction" OR wellbeing OR well-being ))) AND ( TITLE-ABS-KEY ( aphasia )) AND ( ( TITLE-ABS-KEY ( aphasia AND group\* OR group AND session\* OR group-based OR group AND encounter\* OR group AND format OR group AND setting\* )) OR ( TITLE-ABS-KEY ( "group therapy" OR "group treatment" OR "group intervention" OR "aphasia centre\*" OR "aphasia center\*" ) ) ) )

### **Embase 1974 to 2020 July 30**

1. exp "quality of life"/
2. ("Quality of Life" or QoL or HRQOL).mp.
3. ("life satisfaction" or wellbeing or well-being).mp.
4. 1 or 2 or 3
5. exp conduction aphasia/ or exp Western aphasia battery/ or exp aphasia test/ or exp aphasia/ or exp Boston diagnostic aphasia examination/ or exp cortical sensory aphasia/
6. aphasi\*.mp.
7. 5 or 6
8. (aphasia group\* or group session\* or group-based or group encounter\* or group format or group setting\*).mp.
9. ((group or groups) adj3 individual).mp.
10. exp community care/



11. ("community group\*" or "group therapy" or "group treatment" or "group intervention" or "aphasia centre\*" or "aphasia center\*").mp.
12. exp community based rehabilitation/ or exp "speech and language rehabilitation"/ or exp stroke rehabilitation/ or exp rehabilitation center/
13. 8 or 9 or 10 or 11 or 12
14. 4 and 7 and 13

**APA PsycInfo 1806 to July Week 3 2020**

1. exp "Quality of Life"/
2. ("Quality of Life" or QoL or HRQOL).mp.
3. ("life satisfaction" or wellbeing or well-being).mp.
4. 1 or 2 or 3
5. exp Aphasia/
6. aphasi\*.mp.
7. 5 or 6
8. (aphasia group\* or group session\* or group-based or group encounter\* or group format or group setting\*).mp.
9. ((group or groups) adj3 individual).mp.
10. ("community group\*" or "group therapy" or "group treatment" or "group intervention" or "aphasia centre\*" or "aphasia center\*").mp.
11. exp Rehabilitation Centers/
12. exp Social Networks/
13. 8 or 9 or 10 or 11 or 12
14. 4 and 7 and 13

**CINAHL plus with full text**

- S1 (MH "Quality of Life+")  
 S2 "Quality of Life" or QoL or HRQOL  
 S3 "life satisfaction" or wellbeing or well-being  
 S4 S1 OR S2 OR S3  
 S5 (MH "Aphasia+")  
 S6 aphasi\*  
 S7 S5 OR S6  
 S8 "aphasia group\*" or "group session\*" or "group-based" or "group encounter\*" or "group format" or "group setting\*" or "community group\*" or "group therapy" or "group treatment" or "group intervention" or "aphasia centre\*" or "aphasia center\*" ) OR ( ((group or groups) N3 individual )  
 )  
 S9 (MH "Community Networks") OR (MH "Health Information Networks")  
 S10 (MH "Rehabilitation Centers+") OR (MH "Rehabilitation, Speech and Language+")  
 S11 S8 OR S9 OR S10  
 S12 S4 AND S7 AND S11

## Appendix 2: Data Extraction Table

Article Reference	Country	Type of article	Participants	Race/Ethnicity	Gender	Time post stroke	Participant Age (Range in Years)	Participant Education (Range in Years)	Type of Group	Size of group	Facilitator	Focus/Topic of Group	Frequency of Group Meetings	Length of Meetings	Duration of Meetings	Outcome Measures Used	Results
Atard, M. C., Lopus, Y., Tothet, L., & Rose, M. L. (2018). The efficacy of an inter-disciplinary community aphasia group for living well with aphasia. <i>Aphasiology, 32</i> (2), 105-138. doi:10.1080/02687038.2017.1381877	Australia	quantitative pre/post Pilot Case Series	4 PWA		M 3; F 1	31 - 81 months	53-73		Inter-D-Community Aphasia Group (living successfully with aphasia)	8	SLP, social worker, peer aide, community aide	Structured: stroke/aphasia education, communication therapy, conversation, psychological support, social support, participation.	once weekly	2 hours (with a 20 minute break)	12 weeks	ALA, WAB, CETI, MPC, CCRSA, MOS SSS, SNCI, C-SADQ-10	2-4 clinical significant increase of QOL. In language and communication gains; participation/activity gains
Brunfin, S. M., & Sheeran, P. (1997). An evaluation of short-term group therapy for people with aphasia. <i>Disability &amp; Rehabilitation, 19</i> (6), 221-230.	UK	quantitative pre/post Pilot Case Series	6 PWA		M 3; F 3	13 - 120 months	21-52		Enhance existing skills & help PWA manage successfully in everyday life	6	SLP	sharing stories, role playing, homework practice	one morning a week	1.5 hours	10 sessions	FCP, S24, RSE, HADS, satisfaction scale, situational communication scale, RLOC, WAB, Stutterer's Self-rating scale	improvement in communicative behavior, satisfied with intervention
DeDe G, Hoover E, Mass E. (2019). Two to Tango or the Merrier? A Randomized Controlled Trial of the Effects of Group Size in Aphasia Conversation Treatment on Standardized Tests. <i>Journal of Speech Language &amp; Hearing Research, 62</i> (5), 1437-1451	USA	quantitative RCT	15 PWA		M 11; F 4	at least 5 months	mean of 61.4	mean of 13.8	Conversation Treatment (Life Participation Approach)	13-20	SLP student clinicians	Conversation topics: personal history, dining, travel, news/events and entertainment.	2 x per week	1 hour	10 weeks	CAT, NAVS, PNT, ACOM, LINS	Participants in the large group showed a significant improvement from pre- to post-testing on the CAT picture description total score; Participants in the large group showed a significant improvement from pre- to post-testing on the ACOM, - but effects did not last to post test
Fogg-Rogers, L., Butters, S., Talanga, A., McCann, C. M., Liao, S. H. S., Tippet, L., ... Parry, S. C. (2016). Choral singing therapy following stroke or Parkinson's disease: An exploration of participants' experiences. <i>Disability &amp; Rehabilitation, 38</i> (10), 952-962. doi:10.1080/09638288.2015.1068875	New Zealand	qualitative descriptive research	8 PWA	NZ European - 5; European - 1; NZ European & Pacific Peoples -1; Asian Filipino -1	M 4; F 4	6 - 144 months	32-77		Choral Singing Therapy (CST)	25 regular members	music therapist and volunteers	Physical warm-up, breathing exercises, vocal exercises & singing (songs selected by members or are old favourites)	Once weekly	1.5 hours	12 weeks	WAB-R, WHOQOL-BREF or WHOQOL-BREF, SIPSO, MDS-UPDRS	improve social isolation, mood, breathing, swallowing, language and voice - therapeutic benefit - shared fun interest, help each other, women - mood boost, fluency, improve word finding fluency and confidence for some Good QoL scores compared to other studies with similar population.
Heon, B., Thulander, M., & Worsley, J. (1997). Improvement in psychological well-being of people with aphasia and their families: Evaluation of a community-based programme. <i>Aphasiology, 11</i> (7), 681-691. doi:10.1080/02687039708249415	Canada	quantitative pre/post Case Series	35 PWA		M 2/3 of participants; F 1/3 of participants	12 - 240 or more months	31-90		Communication Group	5 per group, with 5 or 6 groups	SLP, volunteers, CDAs	exchange ideas, make friends, improve communication	twice a week	half day	6 months	psychological well being scale (short)	positive change in well being (self acceptance, purpose, personal growth, autonomy, independence)
Lanyon L., Worrall L., & Rose, M. (2013). Combating social isolation for people with severe chronic aphasia through community aphasia groups: Consumer views on getting it right and wrong. <i>Aphasiology, 32</i> (3), 493-517. doi:10.1080/02687038.2018.1431430	Australia	qualitative - constructivism - interpretative phenomenology	7 PWA		M 6; F 1	12 - 120 months	49-79		Unknown/Variou s	4-15	SLP, Peers, Peer & Partner, SLP & Partner	Unknown/Variou s	weekly or monthly	Unknown/Variou s	2 months or more	WAB, AusTOMs,	"happy", "laugh", and "good" to describe their overall group experience, "safe" or "friendly" at the prospect of not attending their group, isolation in group context, ambivalence, SLP reasons for leaving Need to feel connected to others in safe environment (ear at first) - when comfortable group is exciting and fun - helpful to meet others with aphasia - motivation: meet others, make friends, education, improve communication - might be only social interaction - needs to be meaningful - relaxed social environment with structure to support engagement (nurs - isolation and disabled if not provided, prepared topics, materials) - want to share and be acknowledged - drink/smuck, laughter, formal facilitator - need to be genuine and open - if no passion group doesn't work, pass may feel unsupported - didn't expect to improve communication, did improve confidence - listening to learn about group members and being it up in future was important, something they can contribute is being a good listener Most participants improved in comprehension and speaking as measured by the CAT, and on the total score of the ALA.
Pitt, R., Theodoros, D., Hill, A. J., & Russell, T. (2017). The development and feasibility of an online aphasia group intervention and networking program - TeleGAIN. <i>International Journal of Speech-Language Pathology, 1-14</i> doi:10.1080/17546597.2017.1369567	Australia	quantitative Pilot Case Series	4		M 2; F 2	23 - 158 months	41-78		Telehabilitation Group Aphasia Intervention and Networking (TeleGAIN)	4	SLP	(1) create opportunities for communicative success, (2) share personal life history and (3) provide support for living successfully with aphasia through networking with others. New topics each week.	weekly	1.5 hours	12 weeks	ALA, CAT	

PH, R., Theodores, D., Hill, A. J., & Rouse, T. (2018). The impact of the tele-rehabilitation group aphasia intervention and networking programmes on communication, participation, and quality of life in people with aphasia. <i>International Journal of Speech-Language Pathology</i> , DOI: 10.1080/17549507.2018.1489990	Australia	quantitative Case Series	19 PWA		M 9; F 10	13 - 223 months	21-79	Tele-rehabilitation Group Aphasia Intervention and Networking (TeleGAIN)	2-4 per group, with 6 groups	SLP	(1) create opportunities for communicative success, (2) share personal life history, and (3) provide support for living successfully with aphasia through networking with others. New topic of conversation and learning each week (e.g. "Travel", "Living with Aphasia" and "Hobbies and Interests").	weekly	1.5 hours	12 weeks	ALA, OCL, COMACT, CAT,	increased communication related quality of life, decrease aphasia severity
Plouffe, Julie M. H., Parry, Suzanne C., Moore, Celia, Friary, Philippa, Brown, Roger, McCann, Clare M. (2019) Gavel Club for people with aphasia: communication confidence and quality of communication life. <i>Aphasiology</i> , 33(1), 73-93.	New Zealand	quantitative Case Series	8 PWA		M 5; F 3	24-216 months	44-71	Gavel Club (GC; using Tomlinson's International approach)	8	1-2 SLP, SLP students, instructor mentor, volunteers	Give and listen to presentations on specific topics.	weekly	2 hours	4 years (3-4 month blocks, with some months taken off as breaks (e.g. New-Jan for holidays)	WAB-R, ASHA QCL, CCRSA	improved QCL as measured by the ASHA QCL and improved communication confidence as measured by the CCRSA.
Purves B.A., Petersen J., & Pauwson, G. (2013). An aphasia mentoring program: Perspectives of speech-language pathology students and of mentees with aphasia. <i>American Journal of Speech-Language Pathology</i> , 22(2), S370-S379. doi: 10.1044/1058-0360.28201312-00711529	Canada	qualitative description	14 PWA		M 11; F 3	36-264 months	47-67	Mentor Program	12 - 14	SLP, SLP students	PWA mentors did presentations about Living with Aphasia, shared stroke stories, website development, book club, field tips	weekly	2 hours	14 weeks in term 1; 19 weeks in term 2	WAB-R	value in helping students learn, see others with aphasia, become a team, helping others to help self, new experiences, - PWA as mentors for students - recovery long process but would like to improve - lack of resources, want to build an aphasia community - helping others helps me, work on impairments, try new things, work together, shared experiences, - value of teaching others about aphasia so they can share that knowledge, students would help them too
Ross, A., Winslow, L., Marchant, P., & Brunell, S. (2006). Evaluation of communication, life participation and psychological well-being in chronic aphasia: The influence of group intervention. <i>Aphasiology</i> , 20 (5), 427-448.	UK	quantitative pre/post Case Series	7 PWA		M 5; F 2	4 - 29 months	53 - 85	communication group	8	2 SLP, 4 students, disability equality trainer, 2 care workers	communication and conversation skills, enlist an understanding of disability and rights, and engage in social participation.	weekly	2 hours	11 weeks	CAPPA, HADS, VASES,	change in conversation not statistically significant, no significant changes to anxiety/depression, no significant change to self-esteem
van der Gaag, A., Smith, L., Davis, S., Moss, B., Cornilias, V., Laing, S., & Mowles, C. (2005). Therapy and support services for people with long-term stroke and aphasia and their relatives: A six-month follow-up study. <i>Clinical Rehabilitation</i> , 19 (4), 372-380.	UK	quantitative pre/post Case Series	38 PWA	Asian - 2; Black African - 4; Black Caribbean - 1; Chinese - 1; White British - 25; White other - 5	M 26; F 12	6 to 48 or more months	31-81	communication group		SLP	communication, lifestyle, identity	once or twice weekly	2 hours	7 - 20 weeks	EQ-5D, SAQOL-29, CETI, CADI	no significant difference for QOL, increased confidence, communication, independence, not everyone enjoyed group-thing with PWA, significant score increase on CETI,
Zumbansen, A., Pretz, L., Anglade, C., Bilodeau, J., Gintreau, S., Hubert, M. & Hébert, S. (2017) Effect of choir activity in the rehabilitation of aphasia: a blind, randomized, controlled pilot study. <i>Aphasiology</i> , 31: 8, 879-900. DOI: 10.1080/0264938.2016.1227424	Canada	quantitative RCT	15 PWA		M 7; F 8	12 - 179 months	28-82	Choir or Drama Group	7 choir; 8 drama	choir leader, drama teachers (2)	Social stimulation and support, production of familiar and novel songs in speech facilitating choral singing, and drama activities.	once weekly	2 hours	24 weeks	TLC, ABAT, MT-36, CHU, VAMS, SIPS5	no significant differences in outcomes, correlation between attendance of social activities and functional communication changes, small sample size

### Appendix 3: Recruitment Emails

Dear Alberta Aphasia Camp Virtual attendees/Corbett Clinic clients/VoiceAdapt trialists,

Greetings from the Aphasia Research Lab at the University of Alberta!

We are conducting a study to learn about how speech-language **therapy** impacts **quality of life**.

If you want to participate, you would do **interviews** and **assessments** with me before, after and three (3) months after virtual aphasia camp.

If you are interested, I would be happy to tell you more about the study. You can write back to this email ([carlee1@ualberta.ca](mailto:carlee1@ualberta.ca)) for more information.

I have also attached a poster and information letter to this email for you to look at.

Thank you,  
Carlee Wilson, PhD Candidate  
[carlee1@ualberta.ca](mailto:carlee1@ualberta.ca)

## Appendix 4: Recruitment Poster

DEPARTMENT OF COMMUNICATION SCIENCES & DISORDERS

2-70 Corbett Hall  
Edmonton, Alberta, Canada T6G 2G4  
Tel: 780.492.5990  
Fax: 780.492.9333  
Corbett Clinic: 780.492.5314  
MSc-SLP Inquiries: 780.492.0840  
csd@rehabmed.ualberta.ca  
www.csd.ualberta.ca

### RESEARCH STUDY

Understanding the impact of therapy on the quality of  
life of people with aphasia

#### Currently recruiting adults with aphasia

We are trying to learn about how speech-  
language therapy might improve quality of  
life.



If you:

- Have aphasia as a result of left hemisphere stroke
- Are at least 6 months post onset
- Speak English as your primary language
- Are currently doing app-based, individual virtual, or group virtual speech-language therapy
- Want to participate in research

Please contact:

Carlee Wilson, PhD Candidate  
Aphasia Research Lab  
(780) 248-1542  
Carlee1@ualberta.ca

Pro00097283 Understanding the impact of therapy on the quality of life of people with aphasia

**Appendix 5: PWA Letter of Information & Consent**  
**PWA PARTICIPANT CONSENT FORM**

Title of Research Study:

**Understanding the impact of therapy on the quality of life of people with aphasia**

Principal Investigator: Dr. Esther Kim Phone: (780) 248-1542  
Student Investigator: Ms. Carlee Wilson Phone: (780) 492-3419

Why am I being asked to take part in this research study?

You are being asked to be in this study because you have aphasia as a result of a left hemisphere stroke. Aphasia is a language problem that affects speaking, understanding, reading, writing. You are also participating in therapy for your aphasia. We want to learn about your experience participating in therapy.

Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What will I be asked to do?

This study will take place in 4 parts. If you agree to participate in this study you will:

1. Before Therapy : We will ask you to complete a language assessment and 2 questionnaires. We will interview you and video record it, and ask you about therapy and your opinions. These sessions will take place via Zoom in your home. The assessments will take about an hour, and the interview will take about an hour.
2. During Therapy : We will organize a time to observe you during therapy. We will look at activities you have done during therapy and talk to your SLP about the therapy. When we talk to the SLP we will not talk about you specifically, the SLP will not know who is enrolled in the study unless you tell them.
3. After Therapy : We will ask you to complete a language assessment and 2 questionnaires. We will interview you and video record it, and ask you about how therapy went and your opinions. These sessions will take place or via Zoom in your home. The assessments will take about an hour, and the interview will take about an hour.
4. Follow-up 3 months after therapy : We will ask you to complete a language assessment and 2 questionnaires. We will interview you and video record it, and ask you about therapy and your opinions. These sessions will take place via Zoom in your home. The assessments will take about an hour, and the interview will take about an hour.

What are the risks and discomforts?

There are no known risks associated with this study. You may or may not feel fatigued after the interview or assessment sessions. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant. If we find out anything new during the course of this research which may change your willingness to be in the study, we will tell you about these findings.

What are the benefits to me?

By taking part in this study, you may help researchers and others with aphasia learn about what sorts of treatments are helpful. However, you may not get any benefit from being in this research study.

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, for any reason. There will be no penalty for withdrawing from this study. If you withdraw from the study before you complete everything, we will not use your data. If you withdraw after you complete everything, we will not be able to withdraw your data.

Will I be paid to be in the research?

You will be compensated with a \$10 gift card for participating in this study.

Will my information be kept private?

During the study we will be collecting data about you. We will record your participation and store the recording on a computer that only the researchers are able to access. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher’s office or published by the researchers. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your health information is kept private. We may use the data we get from this study in future research, but if we do this it will have to be approved by a Research Ethics Board.

What if I have questions?

If you have any questions about the research now or later, please contact Esther Kim at (780) 248-1542. If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

**CONSENT FORM**

**Title of Study:** Understanding the impact of therapy on the quality of life of people with aphasia

**Principal Investigator:** Esther Kim, PhD, R.SLP      **Phone Number:** (780) 248-1542

**Student Investigator:** Carlee Wilson, MSc      **Phone Number:** (780) 492-3419

	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>

Do you understand that you are free to leave the study at any time,    
without having to give a reason and without penalty?

Has the issue of confidentiality been explained to you?

Do you understand who will have access to your study records?

Do you know that video and audio recordings will be collected during the data collection  
phase?

Do you consent to be video and audio taped for research purposes?



## Appendix 6: Aphasia-Friendly PWA Letter of Information & Consent

DEPARTMENT OF COMMUNICATION SCIENCES & DISORDERS

2-70 Corbett Hall  
Edmonton, Alberta, Canada T6G 2G4  
Tel: 780.492.5990  
Fax: 780.492.9333  
Corbett Clinic: 780.492.5314  
MSc-SLP Inquiries: 780.492.0840  
csd@rehabmed.ualberta.ca  
www.csd.ualberta.ca

### RESEARCH STUDY

Understanding the impact of therapy on the quality of life of people with aphasia

**Principal Investigator:** Esther Kim, PhD, R.SLP (780) 248-1542

**Student Investigator:** Carlee Wilson, MSc (780) 492-3419

### BACKGROUND

- After a stroke, nearly 1/3 of people will have **aphasia**.

**APHASIA** = difficulties with communication  
(e.g., producing and/or understanding language)



## **WHY ME?**

You are invited to participate because you have a diagnosis of aphasia after having a stroke.

You are also participating in aphasia therapy.



## **WHO IS ELIGIBLE?**

### **Inclusion**

- ✓ Men & Women
- ✓ At least 6 months post onset of left hemisphere stroke
- ✓ English used as primary language
- ✓ Be willing to commit to entire study
- ✓ Already participating in therapy

### **Exclusion**

- ✗ No pre-existing speech, language or cognitive disorders (such as dementia, mild cognitive impairment)

## **WHAT IS THE REASON FOR THIS STUDY?**

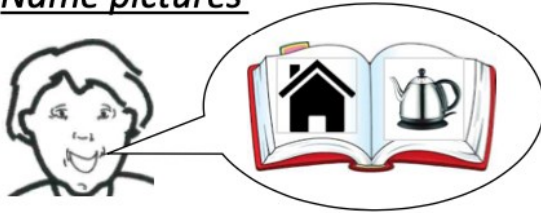
- ✓ We want to know about your experience with therapy

# WHAT WILL I DO IN THE STUDY?

## Assessment

Examples of Language Assessment & Questionnaires:

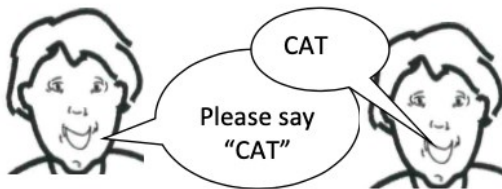
### Name pictures



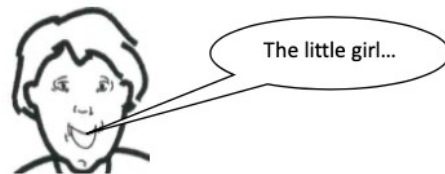
### Point to pictures



### Repeat words & sentences



### Produce sentences & stories sentences



### Read



### Answer Questionnaires



## Interviews



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*We will send you questions ahead of time.*

*Then we will ask you some questions about therapy and your opinions and you will answer them.*

*We can use writing and pictures to help you.*

## Observations

*We will watch you do therapy.*

## **WHEN?**



These language tests, questionnaires and interviews will be completed at three (3) different time points. Before therapy, after therapy, and 3 months later.

## HOW LONG?

Each assessment session will be no longer than 2 hours. We will take breaks if you get tired.



## WHERE?

- Language tests, interviews, and questionnaires will be done at:



Your home via Zoom

## Digital Audio/Video Recording

- Many of the language tests will be audio recorded.
- The interview will be video recorded.



# PARTICIPATION IN THE STUDY

## Possible Risks



*No danger*

- NO medical procedures and NO known risks
- You may or may not be tired during the interview and assessment. We can stop and take a break.



## Potential benefits

- ✓ This *may* help researchers
- ✓ This *may* help others with aphasia
- ✗ This is **not regular therapy**
- ✗ There may not be any direct personal benefit



## Right to withdraw

- ✓ It is your choice
- ✓ You can stop at any time
- ✓ It is okay to quit
- ✓ Withdrawal will not affect your usual care



## WILL I BE PAID TO BE IN THE RESEARCH?

- You will be given a \$10 gift card as a thank you.

## WILL MY INFORMATION BE KEPT PRIVATE?



Everything is confidential ✓ 

Personal information, data and digital audio/video recordings are all kept confidential and are only seen by the researchers working on the study.



This information is kept in locked cabinets behind locked doors.



No personal information will be mentioned in any resulting publication or presentation.



## QUESTIONS or CONCERNS



### 1) About this project?

Please contact:



Dr. Kim, 780-248-1542, [esther.kim@ualberta.ca](mailto:esther.kim@ualberta.ca)

Carlee Wilson, 780-492-3419, [carlee1@ualberta.ca](mailto:carlee1@ualberta.ca)



### 2) About your rights as a research participant?



University of Alberta Health Research Ethics Board

780-492-2615



We would like to acknowledge and thank the Aphasia Institute for some of the pictographs used in this information consent form



## Appendix 7: Session 1 Interview Guide

### Session 1: Semi-structured Interview Guide

#### Interview Guide:

1. How would you describe yourself?
2. Tell me about yourself and what you do on a normal day.
3. Tell me about your experience with aphasia.
  - a. Talk about some challenges and accomplishments you have experienced.
    - i. Use A-FROM for domains of functioning
  - b. What does having aphasia mean to you?
4. Have you participated in therapy before?
  - a. If yes, what was it like?
    - i. How do you feel about therapy?
    - ii. Barriers/facilitators
  - b. If no, why not?
5. What do you think will happen in \_\_\_ therapy you are participating in? What do you want to happen?
  - a. GROUP Therapy
    - i. How often would you like a turn speaking?
    - ii. Do you think you would make friends?
6. What is your mood like? How do you expect to feel after therapy?
7. Tell me about your social network. How would you describe your relationships?
  - a. Family
  - b. Friends
  - c. Others
8. Tell me what you think about your quality of life?
  - a. What does quality of life mean to you?
  - b. What would improve your quality of life?
9. Is there anything else we did not talk about today that you would like to tell me?

Thank you very much for your participation and for helping me out today!

## Appendix 8: Session 2 Interview Guide

### Session 2: Semi-structured Interview Guide

#### Interview Guide:

1. Tell me about your experience with aphasia.
  - a. Talk about some challenges and accomplishments you have experienced.
    - i. Use A-FROM for domains of functioning
    - ii. What was most impacted by therapy?
  - b. What does having aphasia mean to you?
2. What was participating in therapy like?
  - a. What activities did you do?
    - i. What did you think of them?
  - b. What did you think about the SLP/leader of therapy?
  - c. Did you feel comfortable in the room?
  - d. What helped?
  - e. What did not help?
  - f. What would you change?
  - g. What would you keep the same?
  - h. GROUP THERAPY
    - i. Did you enjoy therapy?
    - ii. Did you make friends?
    - iii. Did you enjoy spending time with the other members?
3. What is your mood like? How do you feel after therapy?
4. Tell me about your social network. How would you describe your relationships?
  - a. Family
  - b. Friends
  - c. Others
  - d. How often talk - in person vs phone vs email?
5. Tell me what you think about your quality of life?
  - a. What does quality of life mean to you?
  - b. What would improve your quality of life?
  - c. Do you think therapy improved your quality of life? Why or why not?
6. Is there anything else we did not talk about today that you would like to tell me?

Thank you very much for your participation and for helping me out today!

## Appendix 9: Session 3 Interview Guide

### Session 3: Semi-structured Interview Guide

#### Interview Guide:

1. What have you been doing since therapy ended?
2. Tell me about your experience with aphasia.
  - a. Talk about some challenges and accomplishments you have experienced.
    - i. Use A-FROM for domains of functioning
    - ii. What was most impacted by therapy?
      1. Do you still feel the impact now?
  - b. What does having aphasia mean to you?
3. What is your mood like? How do you feel after therapy?
4. Tell me about your social network. How would you describe your relationships?
  - a. Family
  - b. Friends
  - c. Others
5. Tell me what you think about your quality of life?
  - a. What does quality of life mean to you?
  - b. What would improve your quality of life?
  - c. Do you think therapy improved your quality of life? Why or why not?
6. Is there anything else we did not talk about today that you would like to tell me?

Thank you very much for your participation and for helping me out today!

### Appendix 10: Virtual Aphasia Camp Schedule

Time	Activity	Location
<b>Friday September 18<sup>th</sup></b>		
7:00 – 8:30 PM	Welcome Introductions Sing-along	Zoom Main Room
<b>Saturday September 19<sup>th</sup></b>		
9:00 – 9:15 AM	Morning yoga and Camp cheer!	Zoom Main Room
9:15 – 10:00 AM	A. Communication Games	Zoom Breakout Rooms
	B. Movie and Discussion	
	C. Coffee Tutorial and Games	
	D. Travel Odyssey	
10:00 – 10:15 AM	Show & Share	Zoom Main Room
10:15 – 10:45 AM	<b>BREAK</b> <i>(work on finding items from BINGO card)</i>	
10:45 – 11:00 AM	BINGO Scavenger Hunt	Zoom Main Room
11:00 – 11:45 AM	Share your story (PWA)	Zoom Breakout Rooms
	Share your story (PWA)	
	Share your story (PWA)	
	Share your story (PWA)	
	Share your story (Family)	
11:45 – 12:00 PM	Wrap Up	Zoom Main Room
<b>Sunday September 20<sup>th</sup></b>		
9:00 – 9:15 AM	Freeze Dance!	Zoom Main Room
9:15 – 10:00 AM	E. Talent Showcase	Zoom Breakout Rooms
	F. Painting	
	G. Stretching	
	H. Singing	
10:00 – 10:15 AM	Show & Share	Zoom Main Room
10:15 – 10:45 AM	<b>Break</b> <i>(work on creating flag for final activity)</i>	
10:45 – 11:45 AM	Final Activities: Aphasia Camp Flag S'mores and Hot Chocolate Slideshow Sing-Along Wrap Up	Zoom Main Room

### Appendix 11: PWA001 Sample Virtual Individual Therapy Treatment Plan

Time	Short Term goal	Task Complexity/Support Level	Cueing hierarchy	Materials/Approach
<b>1:00-1:10</b> - share online agenda and SCA page	Welcome - How was your week? How was homework? Comment on reading homework Go over writing homework with him Ask if he used any of our suggestions presented, what worked for him  Agenda - overview of day	SCA (slow rate, witten words, pictures, gestures, choices, rephrasing/repeating)		Google doc for Agenda and SCA (camera with paper and pen as well)  - Give him choices on the order of tasks
<b>15 min</b> - share SFA slides	Verbal Expression LTG  PWA001 will be able to describe a picture with 70% CIU with Mod support	Task complexity: Type of task - picture description  Support level: MOD: Word map (visual prompt)	Cueing hierarchy: <ul style="list-style-type: none"> <li>• Verbal prompt</li> <li>• Cloze sentence</li> <li>• Multiple choice</li> <li>• Skip that feature and come back</li> <li>• Provide answer</li> </ul> SCA (slow rate, written key words, pictures, choices, rephrasing/repeating)  No visual prompt: Ask him to describe, write down what he says, ask him to read it out loud and see if we can say it differently so it makes more sense.	Semantic Feature Analysis: <ul style="list-style-type: none"> <li>• Calculator</li> <li>• Fork</li> <li>• Phone</li> <li>• Sink</li> <li>• Calendar</li> <li>• Pumpkin</li> </ul> SFA google slides  **Model the use of the strategy after filling out the boxes  **Use visual prompt for at least 3, move to no visual prompt if client successful - can try it if running out of time too

<p><b>15-20 mins</b> - share video and Session 7 materials with questions</p>	<p>Aud Comp: LTG PWA001 will answer 2 concrete questions about 15 second clips with Mod Support.</p>	<p>Task complexity: Concrete questions 15 second video clip  Support level: MOD: Written questions, prime for questions, slowing down video to 0.75x</p>	<p>Cueing Hierarchy:</p> <ul style="list-style-type: none"> <li>• Repeat question</li> <li>• Give choices for answers</li> <li>• Rewatch clip with closed captions</li> <li>• Provide the answer to the question</li> </ul>	<p>Google doc for questions Dog park for small and shy dogs <a href="https://www.youtube.com/watch?v=eTutv2Xpe9g">https://www.youtube.com/watch?v=eTutv2Xpe9g</a>  How to - we are going to watch some short video clips on a news clip. We'll give you hints about what to listen for in the clips, and then answer questions about them like we did two weeks ago.  Depending on the strategies he found helpful during the homework discussion, encourage him to try them during the video clips.</p>
<p><b>15-20 mins</b> <i>A - Share page with reading passages and question tab</i></p>	<p>Writing LTG PWA001 will be able to write 2 sentences about a topic generated by PWA001 and clinicians without an email template</p>	<p>Task complexity: Length of email: 2 sentences  Support MIN: Generating topics together, no template</p>	<p>Spelling Cues (least to most)</p> <ul style="list-style-type: none"> <li>• Have client re-read phrase / word</li> <li>• Prompt to use dictionary on his phone</li> <li>• Clinician verbally spells the word for him</li> <li>• Clinician writes word for him to copy</li> </ul> <p>Composition and Grammar Cues (least to most):</p> <ul style="list-style-type: none"> <li>• Remind client to verbally self-cue</li> <li>• Clinician re-read any phrase/sentence in error and see if client can self-correct</li> <li>• Clinician verbally tell client the correct grammar</li> <li>• Clinician write phrase/sentence for him to copy</li> </ul>	<p>Writing Document to share</p>

			<p>Word Retrieval Cues (least to most)</p> <ul style="list-style-type: none"> <li>• Verbal self-cue</li> <li>• Description of word</li> <li>• Choices</li> <li>• Clinician gives word</li> </ul>	
<p><b>1:55 - 2pm</b> <i>Screen - Share Agenda</i></p>	<p>Wrap-up/summary of today, overview of next week. Homework prep: Ask how he feels about reading: Ask: do you like these types of articles? Do you want to read what you're currently reading? Etc.) Ask if he has any questions. Comments about how he did</p>			<p>Google doc with agenda</p>

## Appendix 12: Field Notes Guide

Pro00097283 Understanding the impact of therapy on the quality of life of people with aphasia  
June 29, 2020

### Field Notes Guide

Location	
Weather	
Others Present + Reason	
Interactions with others	
Overall appearance of participant	
Demeanour	



Non-Verbal behaviours	
Demographic Info	
Environment	
Sketch of room	
Tentative thoughts/codes	
Personal Reflections	