

**Personal Factors and Access to Businesses: Perceptions of People with
Aphasia**

by

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Abstract

The current study investigated the relationship between participation at businesses (i.e., business access) and the personal factors (i.e., the identity, attitudes, and feelings) of people with aphasia (PWA). Five PWA were interviewed about their business experiences in Edmonton, Alberta, and how these experiences impacted and were impacted by their personal factors. Interviews were analyzed using qualitative content analysis and organized into six themes which represented this reciprocal relationship between business access experiences and personal factors. Three of the six themes were related to how personal factors impacted the business interaction: 1) participant expectations of businesses, 2) self-advocacy, and 3) participant perspectives on aphasia and disability. The other three themes represented the impact of business experiences on participant's personal factors: 4) impact on thoughts and beliefs, 5) future expectations and actions, and 6) lasting feelings. Participants described ways that personal factors were supports and hinderances to their access to businesses, and ways that positive and negative business experiences impacted their personal factors. Ultimately, this study highlighted the need to consider personal factors in the research, assessment, intervention, and advocacy efforts with PWA in order to maintain a holistic perspective of the person with aphasia and promote their quality of life.

Preface

This thesis is an original work by Leah Auch. The research project “Building Communication Ramps for People with Aphasia”, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Pro00096686, March 10, 2021. This thesis used data collected in the study accepted for publication as Kim, E.S., Mauriks, K., Auch, L., Wilson, C., Koo, H., Swensrude, D., Laccetti, J., Ruelling, A. (in press). Barriers and Facilitators to Communication Accessibility as Perceived by People with Aphasia. *Topics in Language Disorders*. This thesis extended the study from Kim and colleagues with additional data collection and different research questions, methodology, and data analysis, which resulted in codes, themes, and interpretations that were unique to this thesis. No part of this thesis has been previously published.

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Table of Contents

Abstract	ii
Preface	iii
Acknowledgements	iv
List of Tables	vii
List of Figures	viii
Introduction	1
Aphasia, Participation, and Quality of Life	1
Communication Access	7
Personal Factors and Communication Access	9
The Current Study	10
Case Study	10
Research Questions and Propositions	11
Research Question 1	11
Research Question 2	12
Method	12
Participants	12
Design	16
Procedures	17
Data Collection	17
Assessments	17
Semi-structured interviews	18
Analysis Procedures	19
Rigour.....	21
Analysis	21
Context for the Business Interaction.....	22
The Influence of Personal Factors on the Business Interaction	26
Participant Expectations of Businesses	26
Self-Advocacy	27
Participant Perspectives on Aphasia and Disability.....	31
The Influence of the Business Interaction on Personal Factors	32
Impact on Thoughts and Beliefs	32
Future Expectations and Actions	34
Lasting Feelings	35
General Discussion	36
Reciprocal Relationship between Personal Factors and the Business Interaction	37
Enhancing Participation	41
The Whole Person: Including Personal Factors	42

Limitations	44
Future Directions	46
Conclusion	47
References	49
Appendix A.....	58
Appendix B.....	60
Interview 1	60
Interview 2	62

List of Tables

Table 1: Personal and Environmental Factors in Previous Research.....	5
Table 2: Participant Characteristics	13
Table 3: Participant Communication Difficulties.....	14
Table 4: Example Analysis Process	20
Table 5: Summary of the Six Themes	22
Table 6: Summary of Participant Business Experiences	23
Table 7: Assessment Scores	25

List of Figures

Figure 1: Living with Aphasia – Framework for Outcome Measurement	3
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Introduction

Communication is central to many everyday activities, whether conversing with friends or ordering coffee. These everyday experiences can be challenging for people with impaired communication. Aphasia is a communication disorder characterized by difficulty speaking, understanding language, reading, and writing due to a brain injury, brain tumour, or dementia. The most common cause of aphasia is stroke and approximately 137,700 Canadians experience aphasia due to a stroke (Simmons-Mackie, 2018). People with aphasia (PWA) report having trouble fully participating in their life (Hilari, 2011; Parr, 2007). Enhancing participation is important to the quality of life of PWA, but participation is often impacted by environmental factors (e.g., ignorance of aphasia, social support) and personal factors (e.g., determination, emotional distress) in addition to aphasia severity (Brown et al., 2010; Brown et al., 2012; Hilari et al., 2012; Howe et al., 2008; Lanyon et al., 2018; Le Dorze et al., 2014; Worrall et al., 2011). Participating in business interactions can be particularly difficult for PWA because additional societal factors, such as a focus on efficiency and ignorance of aphasia, create a communication environment that is not supportive (Brown et al., 2006). The aim of this study is to describe the involvement of personal factors during business interactions from the perspective of PWA, which will be achieved using a qualitative case study.

Aphasia, Participation, and Quality of Life

The ability of PWA to fully participate in their life and community is influenced by the communication environment, their attitudes toward themselves and their

environment, and their reactions to this environment (Brown et al., 2010; Dalemans et al., 2010; Lanyon et al., 2019; Manning et al., 2019). Level of independence, aphasia severity, emotional distress, social support, activity limitations, and accessibility to the environment are some specific factors which influence participation and quality of life for PWA (Hilari et al., 2012; Ross & Wertz, 2003). Additionally, previous researchers have identified that living successfully with aphasia often requires a renegotiation of identity and self-concept (Hilari et al., 2012; Lanyon et al., 2019; Shadden, 2005; Simmons-Mackie & Elman, 2011). Active acknowledgement of the different factors at play in the lives of PWA is critical to truly enhancing their participation and, ultimately, quality of life.

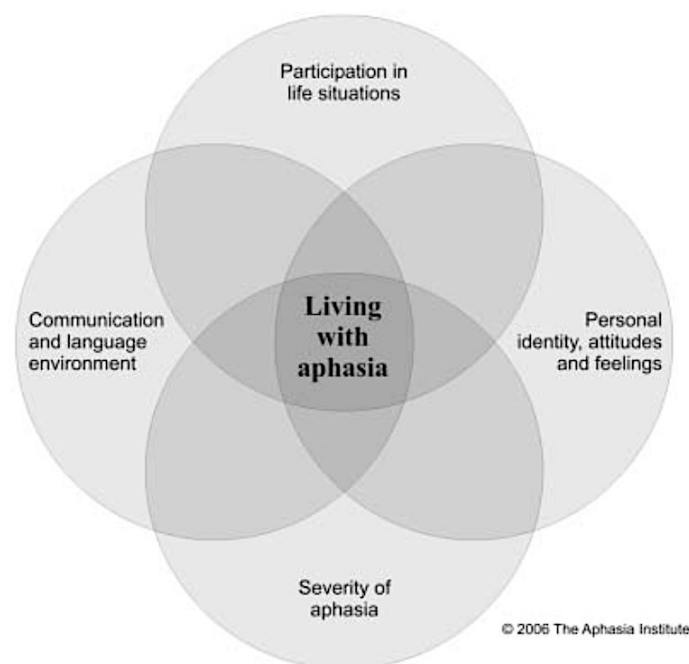
The *Life Participation Approach to Aphasia* (LPAA) is a therapeutic philosophy that focuses on enhancing the life participation of PWA and places the personal goals of the person with aphasia at the forefront of treatment (LPAA Project Group, 2000). The core principles of the LPAA are: 1) enhancement of life participation, 2) all those affected by aphasia are entitled to service, 3) the measures of success include documented life-enhancement changes, 4) both personal and environmental factors are targets of intervention, and 5) emphasis is on availability of services as needed in all stages of aphasia (LPAA Project Group, 2000). Clinicians and researchers ascribing to a LPAA framework recognize that intervention focused on communication impairments should ultimately aim to improve life participation (Principle #3), and that enhancing life participation requires more than only improving the communication abilities of the person with aphasia (Principle #4).

In alignment with the LPAA model, Kagan and colleagues (2008) designed and introduced a framework for approaching aphasia assessment, intervention, and

research called *Living with Aphasia - Framework for Outcome Measurement (A-FROM; Figure 1)*. The A-FROM was adapted largely from the *World Health Organization - International Classification of Functioning, Disability, and Health (WHO-ICF; World Health Organization, 2001)* and incorporated LPAA principles by integrating input from PWA, their families, and clinicians to directly represent the experiences of all those living with aphasia. The framework is not prescriptive, but rather considers living with aphasia and quality of life from four interconnected and overlapping domains: 1) *Participation in life situations*; 2) *Personal identity, attitudes, and feelings*; 3) *Communication and language environment*; and 4) *Severity of aphasia* (Kagan et al., 2008).

Figure 1.

Living with Aphasia – Framework for Outcome Measurement (A-FROM) from Kagan and colleagues (2008). Reprinted with permission from The Aphasia Institute.



The A-FROM draws from the WHO-ICF and exemplifies *personal factors* as those specific to the feelings, attitudes, and identities of PWA (Kagan et al., 2008). The stakeholders in the development of the A-FROM “felt strongly that these elements must be prominently represented” (p. 266). This framework aligns with the renegotiation of identity that is common to living with aphasia (Shadden, 2005) and suggests that the identity, attitudes, and feelings of PWA can influence *and be influenced by* factors in the other three domains. Under the A-FROM, accounting for personal factors in research and intervention requires an understanding of how personal factors influence the lived experience of PWA, and similarly how these personal factors may change or adapt to their lived experience.

Other researchers have proposed specific conceptualizations and codes to facilitate the study, understanding, and application of personal factors under the WHO-ICF framework. Threats (2007) emphasized the need to consider personal factors and drew a distinction between factors related to demographic information (e.g., age, race, gender), and those that represented personality traits (e.g., patterns of behaviour, coping styles). He discussed how some of these personality traits (e.g., determination) may influence access through an individual’s own self-advocacy. Geyh and colleagues (2019) studied individuals with spinal cord injuries and proposed a framework for coding personal factors. They proposed three groupings of personal factors: 1) individual facts (i.e., demographic information, position in social and physical contexts such as birth order or marriage, and personal history/biography), 2) subjective experience (i.e., feelings, thoughts, beliefs, and motives), and 3) recurrent patterns (i.e., general patterns of experience and behaviour). The personal factors within the latter two groups were

especially like those described in the A-FROM (Kagan et al., 2008). Like the stakeholders in the A-FROM project, Threats (2007) and Geyh and colleagues (2019) stressed the importance of understanding personal factors to improve quality of life through assessment and intervention. In this way, directly investigating personal factors will facilitate conceptions of disability and therapy that “respect and value the person” (Geyh et al., 2019; p. 1735).

Previous researchers investigated and identified environmental and personal factors that influenced experience of participation broadly for people with aphasia (e.g., Harmon, 2020; Howe et al., 2008; Le Dorze et al., 2014; Manning et al., 2019). Although these are often termed *barriers* and *facilitators* to participation, we use the terms *support* and *hinderance* because we are primarily focused on personal factors which are inherent to the person. Table 1 summarizes some personal and environmental factors identified by PWA as related to their participation. The factors listed here are broad (e.g., determination/perseverance, others tolerating their limitations) and may be applied to participation in many different life situations. At the same time, different situations have different expectations or requirements which can change the relative influence of a particular factor. Note that this table is not exhaustive.

Table 1

Examples from previous research identifying personal and environmental factors that can be supports or hinderances for the participation for PWA.

	Personal Factors	Environmental Factors
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<p>Support to Participation</p>	<p>Determination/perseverance^{2,3}</p> <p>Willingness to disclose aphasia/stroke^{2,3}</p> <p>Positive outlook and self-image²</p>	<p>Experiencing social support from family^{2,3}</p> <p>Others tolerating their limitations²</p> <p>Good/patient/supportive conversation partners¹⁻³</p>
<p>Hinderance to Participation</p>	<p>Fear of asking for help or being judged²</p> <p>Preferring to withdraw or to be alone²</p> <p>Putting themselves down or feeling like a burden^{2,3}</p>	<p>Treating PWA as less intelligent¹</p> <p>Ignorance of aphasia¹⁻³</p> <p>Lack of social support^{1,2}</p> <p>Expectations of efficiency^{1,2}</p>

Note. 1: Howe et al., 2008; 2: Le Dorze et al., 2014; 3: Manning et al., 2019

While certainly a useful concept, investigating hinderances and supports in the context of personal factors can be limiting. First, some personal factors are personality traits or characteristics that are relatively stable across adulthood (e.g., general outlook on life, extent of perseverance in adverse circumstances; general temperament; Kagan et al., 2008; Martin et al., 2020). Conceptualizing the inherent, stable, identity-related traits of a person as a hinderance or support to participation could be damaging (Simeonsson et al., 2014). In the current study, we avoid designating factors as invariably supportive or invariably hindering, and instead focus on describing how their beliefs, thoughts, and responses influenced the experience of access from the perspective of PWA. Second, this categorization does not address the notion that a person’s experience of participation, or lack thereof, may influence their personal factors. A positive experience at a business may be supported by disclosing aphasia or showing great determination, and this experience may also cause PWA to feel more confident in their communication

abilities in the future. Acknowledging the interplay between participation and personal factors may be especially important for business interactions, which often occur in an unsupportive environment with unfamiliar conversation partners who may not be aware of aphasia.

Communication Access

Communication access refers to the implementation of supports, generally within businesses or organizations, which allow people to understand and communicate information regardless of communication needs or communication method. The United Nations Convention on the Rights of Persons with Disabilities was passed in 2006 and affirmed accessibility to the environment as a human right (United Nations, 2006). Communication was listed among the environmental interventions to ensure equal access for people with disabilities. Despite this and other regulations, supports to ensure communication access are often lacking or nonexistent (Collier et al., 2012; Worrall et al., 2007). Some initiatives have created programs and networks to increase communication access around the globe (e.g., Borsatto, et al., 2021; Solarsh & Johnson, 2017); however, many areas and businesses still lack the skills and awareness to support communication for those with communication challenges, such as PWA. This means that currently, PWA are likely to experience reduced participation and reduced quality of life in business settings.

Before discussing communication access at businesses in more detail, we delineate between *interaction* and *transaction* as two goals of communication which occur in tandem (Kagan et al., 2001). *Interaction* encompasses communication meant to facilitate and develop social relationships, while *transaction* refers to the

actual exchange of information and resources. Business experiences are focused primarily on the exchange of information or resources, so it is tempting to consider these as exclusively transactional; however, doing so ignores the elements of interaction which occur between any two conversational partners, regardless of setting. The interactional elements of business experiences occur without the elements of social support and understanding that is present in friendships or familial relationships, which makes the overall transaction more complex. For example, we may put up with slow service at a busy restaurant because we do not want the wait staff to feel incompetent or feel ill-will toward us. Similarly, many business exchanges are formed on the basis of positive relationships and social capital. Here, we consider both the interactional and transactional components of business experiences and refer to them together as *business interactions*.

Due to the lack of awareness of aphasia and how to support PWA in communication, business interactions present a unique participatory challenge because of the shift in goals and expectations, emphasis on efficiency, and limited resources (Brown et al., 2006; Howe et al., 2008; Simmons-Mackie & Damico, 2007). While the challenges presented by businesses can certainly be mitigated by environmental changes (e.g., employee education and training), understanding the involvement of personal factors when these environmental supports are present or not present is critical for effective intervention and education. In one study with adult AAC users (largely people with cerebral palsy), Taylor and colleagues (2020) identified factors contributing to access in a retail setting, both from the perspective of the person with complex communication needs and the retail worker. The study identified several personal factors related to the persons with complex

communication needs, including *feeling strong [communicatively], identifying as a customer, and putting up with [poor communication]*; however, many of the facilitating factors identified were related to the individuals within the interaction, rather than organizational or societal supports (Taylor et al., 2020). Moreover, participants in the study felt that “when retailers made no accommodations for their disability their sense of independence and self-worth when shopping was challenged” (p. 8). Although not the primary focus of the study, this quote illustrated the importance of communication access for developing a positive self-concept, a sense of independence, and an identity as a communicator.

Personal Factors and Communication Access

Participation is a broad construct that comprises all possible life situations relevant to the person with aphasia. There is a reciprocal relationship between personal factors and participation, such that personal factors may be a support or hinderance to participation, and past or current experiences of participation can influence personal factors (Kagan et al., 2008; Manning et al., 2019; Simmons-Mackie & Damico, 2007). Business access for people with aphasia encompasses more than receiving information or resources. Not only can PWA be impeded from receiving necessary information and resources, but they may also incur a personal cost that affects their feelings, identity, and self-concept (Taylor et al., 2020). Conversely, successful business interactions provide a unique opportunity to positively influence the personal factors of PWA by affirming their competence and independence, thereby promoting participation at businesses in the future (Niemi & Johansson, 2013; Taylor et al., 2020). This complex relationship between business access and personal factors may similarly impact quality of life and affect their

experience of living with aphasia (Kagan et al., 2008). This interdependence between personal factors and participation for PWA has not yet been investigated in the context of business access.

The Current Study

This study aims to examine the relationship between personal factors and business access for PWA, which is clinically relevant and informative for clinicians, researchers, and businesses. In terms of the A-FROM (Figure 1; Kagan et al., 2008), the experience of living with aphasia will be investigated at the intersection between “Participation in life situations” and “Personal identity, attitudes, and feelings” in the context of business access. This understanding is important because experiences with business access extend beyond the immediate success or failure of the interaction which relies heavily on environmental supports; there is a reciprocal relationship that affects the identity, feelings, and attitudes of PWA and their experience of participation in the future. The results of this research will extend the evidence base regarding participation in business interactions for people with aphasia (e.g., Anglade et al., 2019; Borsatto et al., 2021). This knowledge may aid clinicians in creating and targeting participatory goals for their clients with aphasia. Further, it will provide an evidence basis for understanding how the personal factors of people with aphasia are related to business access. Results may also inform education programs designed to improve communication access and better integrate PWA and other complex communication needs (e.g., Borsatto et al., 2021), as well as bolster the appeals for the implementation of such programs.

Case Study

The objectives of this study will be achieved by conducting a qualitative case study, as described by Yin (2014; Baxter & Jack, 2008). Case studies consider a case in its natural context and involve the integration of multiple sources of data (Baxter & Jack, 2008; Yin, 2014). For this project, we have chosen to use qualitative interviews and quality of life assessments as two sources of data. Case study methodology has been chosen for the following reasons: 1) the research questions are “how” or “why” questions, 2) we cannot manipulate behaviour of study participants to better understand this relationship, 3) the focus is on current rather than historical phenomena and 4) the case (i.e., the individual) cannot be separated from its context (i.e., their life, experiences, and business interactions) (Baxter & Jack, 2008; Yin, 2014). Yin (2014) also states that case studies can either be exploratory, descriptive, or explanatory. This study will be descriptive because the aim of this project is to describe the case in its real-life context, rather than provide causal explanations for the observations or explore a novel situation without a set of clear outcomes (Baxter & Jack, 2008).

Research Questions and Propositions

Research Question 1

How do personal factors influence the experience of PWA when accessing businesses and services?

Proposition 1. Personal factors can impact business access for PWA; in some instances, their personal factors may be a support or hinderance to their business access. Factors more likely to be supportive may be those that make PWA more willing to continue through difficult communicative interactions, such as

determination, preparing beforehand, and having a positive self-image (Le Dorze et al., 2014; Taylor et al., 2020). Factors more likely to be hinderances may be those that lower the willingness of PWA to continue through difficult communicative interactions, such as fear of being judged, having a negative self-image, or feeling like a burden (Le Dorze et al., 2014; Manning et al., 2019).

Research Question 2

How are personal factors influenced by the experience of PWA when accessing businesses and services?

Proposition 2. Positive experiences at businesses (i.e., being respected, understanding and being understood by the employee/conversation partner) can help create a positive self-concept and identity as a communicator for PWA, and promote positive attitudes and feelings toward future experiences at businesses or other community participation opportunities (Manning et al., 2019; Niemi & Johansson, 2013; Shadden, 2005). Negative experiences at businesses (i.e., not being understood or not understanding, feeling patronized, being treated as less intelligent) can negatively affect the identity, attitudes, and feelings of PWA and lower their willingness or motivation to access businesses or even to participate in their community broadly (Manning et al., 2019; Parr, 2007; Simmons-Mackie & Damico, 2007).

Method

Participants

Five people with aphasia participated in this study. Table 2 summarizes the demographic characteristics of these participants (e.g., gender, age, race,

education, occupation, and years post-stroke). All participants experienced aphasia due to a stroke. Table 3 provides quotes from the participants describing their difficulties with communication. These participants were recruited from a larger sample of PWA participating in a study investigating experiences when accessing businesses (Kim et al., in press). Participants with aphasia were recruited locally in Edmonton through the Aphasia Research Lab, Alberta Aphasia Camp, and the Corbett Aphasia Rehabilitation and Education (CARE) program. The inclusion criteria were: 1) English as a primary language, 2) diagnosis of aphasia (any etiology), and 3) at least 2 years since aphasia onset.

One participant was deemed Non-Aphasic according to the Western Aphasia Battery – Revised (WAB-R; Kertesz, 2007); however, this participant had a diagnosis of aphasia and reported that her communication difficulties impacted her life and participation. Previous research has highlighted the significant impact of very mild aphasia (i.e., of individuals who score above the cut-off score on the WAB-R) on living successfully with aphasia (e.g., Campbell & Baker, 2020). Thus, this participant was included to represent a wider range of aphasia severities and perspectives.

Table 2.

Participant Characteristics.

Participant	P01	P02	P03	P04	P05
Gender	M	F	M	F	F
Age	62	51	52	62	43

Race	White	White	White	White	Black
Education	2 Years of a 4 Year Degree	2 Year Associative Degree	2 Year Diploma	2 Year Associative Degree	2.5 Years of a Bachelor's Degree
Previous Occupation	Producer/Director	Land Titles Examiner	Mechanical Operations	Nutrition and Foods Technologist	Client Care Assistant (Health)
Living Situation	With Spouse	Independent	Independent	With Spouse	With Family
Years Post-Stroke	7	10	7	14	2
WAB Aphasia Quotient and Type	87; Anomic	91; Anomic	79; Conduction	55; Broca's	95; Non-Aphasic
Primary Modality of Communication	Speech	Speech	Speech	Spoken single words, Writing Key Words	Speech

Table 3

Participant communication difficulties, described in their own words.

Participant	Description of communication difficulties since stroke
P01	My inside voice is fine and perfect. Outside it is "bluh bluh bluh," And it's trying to connect-connect those two and getting them back together. And it's amazing how much stuff is missing on the inside. Like, with your w-words and everything, they're missing. And you're-you're wondering, "Oh, wait, wha-what do I do? What did I

mean by that again?" ... You just have to ... learn it up, learn it, learn it, learn it, learn it. ... And now I'm slowly building every word and every sentence with my mouth.

P02	Talking ... Oh yes, but is hard but frusturding (frustrating) yes
P03	Talking. You know I am talking a lot better ... but ... really hard time to understand, to understand it. ... I'm feel better and better than most people, I guess? Um, uh you know I still have a hard time to read and write, but I do read a lot quicker now, and uh write I um read better, but I still have a hard time um because my-my right side is uh, I know it feels good, but it is slower. ... I do have a hard time, but it does uh, but it still do write good *laughs*.
P04	Wrote <i>sit</i> to express that she does not do as much now as she used to before her stroke. Since her stroke she shared that she enjoys <i>shopping, [visiting with] Oma, [travelling to the] lake.</i> Using supported communication (written questions, choice questions, verification questions) shared that talking is difficult, but that people tend to be receptive to her writing key words.
P05	I was able to communicate after – like, once I left the hospital. I would say it was mild aphasia, so people could understand me, but I had a really hard time with, like, three syllable words ... Before the stroke, I was quite, aca – like, I was writing a book. Like, speech and language was a strength for me, so I really struggled with that, and not being able to, like, read, or read something and then know what I was reading ... As far as my speech, it's come a very long way ... From the start, my cognitive ability – like understanding people – wasn't an issue. It was more trying to get the words out and not saying the wrong words, and people - being able to s-s-say what I wanted to say was more a struggle.

Purposive sampling was used to select participants from the original research sample in Kim and colleagues (in press) with differing experiences to be studied in-depth (Campbell et al., 2020). Considerations for capturing these different experiences included age, gender, aphasia type and severity, living situation (i.e., alone, or with spouse/family) and types of businesses being accessed. Specifically, purposive sampling ensured selection of participants from the original sample who

were sufficiently different from one another (e.g., not all men/women, range of ages represented in original sample, various business experiences). Informed consent was obtained prior to completing any data collection. Participants were provided a consent form detailing the background for the study, time commitment, risks, and confidentiality. This form was adapted to be aphasia-friendly (e.g., large font, more white space, picture supports, and bold titles). At the initial session, the primary researcher discussed this consent with the participant and ensured understanding using supported communication strategies where necessary (e.g., writing, rephrasing, slowing speech, using gestures).

Design

The current project employed a multiple descriptive case study design (Baxter & Jack, 2008; Yin, 2014). Baxter & Jack (2008) additionally recommended binding the case or determining what the case study would and would not include “to ensure the study remains reasonable in scope” (p. 547). The current case study was bound by one positive and one negative or neutral business interaction experienced and described by the participants with aphasia. In addition to integrating multiple sources and describing the context with each case, this multiple case study allowed comparison across diverse cases (Baxter & Jack, 2008). This design was chosen to answer the research questions because the intended outcome was an in-depth description of how the personal factors of PWA were influenced by previous experiences at businesses. Data interpretation for the cases (as described in Baxter & Jack, 2008; Yin, 2014) was guided by the A-FROM definition of personal factors (i.e., one domain relevant to living with aphasia, which is interconnected with their communication impairment, environmental factors, and participation in

life; Kagan et al., 2008) as well specific frameworks by Geyh and colleagues (2019) and Threats (2007) that provided insight into the study and conceptualization of personal factors.

Procedures

Data Collection

General case history information was obtained using an intake form at the initial session (Appendix A). Following this intake procedure, each participant completed three standardized assessments related to their aphasia profile and quality of life over one to two sessions. Participants were then asked to participate in two semi-structured interviews, over two sessions. Due to the COVID-19 pandemic, all data collection occurred online via Zoom. The intake form, standardized assessments, and interview guide were adapted to accommodate the online format. Each session was audio- and video-recorded and lasted approximately one hour.

Assessments

The three assessments used in the current study included The *Western Aphasia Battery-Revised* (WAB-R; Kertesz, 2007), the *Assessment for Living with Aphasia-2* (ALA-2; Simmons-Mackie et al., 2014) and the *Stroke and Aphasia Quality of Life Scale-39* (SAQOL-39; Hilari et al., 2009). All assessments were adapted for online use. The WAB-R captured the aphasia profile for each participant. The ALA-2 and SAQOL-39 were included to provide another source of information regarding the lived experience and quality of life of each participant. These scores contributed to the context for the business experiences discussed

during interviews. In addition to obtaining the overall scores from these measures, the individual items (e.g., “Are you doing as much as you want?”, “During the week, where do you go?”, or “Do you feel confident?”) were considered in relation to the case history information to guide follow-up questions regarding the specific experiences of participants during the interviews. During data analysis, the specific items provided context to guide the interpretation of participant’s descriptions of their experiences.

Semi-structured interviews

Each participant engaged in two semi-structured interviews, lasting approximately one hour each. Initial assessments (WAB-R, ALA-2) and the first interviews were completed collaboratively by the primary researcher and another graduate student as part of a larger research project (Kim et al., in press). The second interviews and assessments (SAQOL-39) were completed by the primary researcher. The interviewer used an interview guide which detailed the topics and order of the major questions, specified topic areas to probe further, and included images to support communication and understanding for the participants with aphasia (Appendix B). The interviews were semi-structured in that the questions did not have a fixed wording and were revised to support understanding, and probing questions were generated based on participant answers and guiding topic areas of interest (e.g., “You mentioned your experience at [specific business]. Could you tell me about that?” or “How did you feel when you went to [specific business] the next time?”). The interviews followed many of the suggestions provided in Wilson and Kim (2019) regarding procedures for collecting data with people with aphasia. Examples of supported communication strategies used during

the interview include visual or written supports, rephrasing, gestures, verifications (e.g., yes/no questions, repetition of what has been understood), and slowing speech rate.

Immediately after each interview, the interviewer completed a set of field notes (Phillippi & Lauderdale, 2018) by answering the following questions: 1) what impressions and thoughts do I have immediately following the interview? 2) what relevant observations were made about the participant (reactions, engagement, etc.)? 3) how do I think that interview went for both myself and for the participant? 4) what could have been improved? 5) what do I want to know more about? These notes were used to support data collection, the analysis process, and reflexive practice (Korjsten & Moser, 2018; Wilson & Kim, 2019).

Analysis Procedures

Data analysis and data collection were conducted concurrently by the primary researcher and research team. The research team included the primary researcher, the thesis supervisors, another graduate student, an undergraduate research assistant, and two people with aphasia who were stakeholders in the project. Each interview was transcribed verbatim (i.e., including all hesitations, articulation errors, etc.) and used for subsequent analysis. Interview data was analyzed using qualitative content analysis (Mayan, 2009). The analysis for each participant was constrained to two of their business experiences: one positive, and one negative or neutral. Although the analysis process was iterative, it proceeded in the following general order (Mayan, 2009). First, codes were developed by the primary researcher to systematically highlight striking and relevant excerpts of the data. Once coding was complete, these codes were synthesized into categories. Then, a

second set of trained coders independently coded the interviews for relevant features. This second coding was used to refine the categories. After initial categories were made, the primary researcher reviewed each excerpt to ensure it fit within the category. When all categories were identified and summarized, they were evaluated for internal and external homogeneity by the primary researcher and other members of the research team. This included bringing excerpts of the interviews to the people with aphasia on the research team and asking them to contribute their perspective and interpretation based on their own experiences. Categories were also compared across cases. After the categories were finalized for all interviews, themes were developed by abstracting further from each category. Table 4 presents an example of the overall analysis process.

Table 4

Example of analysis process from interview excerpts to themes.

<p>Excerpt</p>	<p>P03: I usually tell them either at the beginning, or a little bit, but I say that "I've had a stroke with a-aphasia. So, could you please talk a little bit slower, and if you don't understand it's 'cause I have hard time to write, read, speaking, and understanding, and listening," you know? That's-that's what I- that's what I told 'em but um they understood and uh they slowed down, they-it was really very good with it. 'Cause I usually, I usually tell people at the very uh- I always tell everybody that I had a stroke with aphasia. I always say that.</p>	
<p>Example Codes</p>	<p>Willing to disclose difficulty</p>	<p>Educating others about his aphasia</p>
<p>Resulting Categories</p>	<p>Sharing difficulty</p>	<p>Aphasia education</p>
<p>Refined Category (after</p>	<p>Disclosing aphasia</p>	

discussion with research team)	
Theme Contributed To	Self-Advocacy

Rigour

Study quality was ensured using the criteria from Lincoln and Guba (1985) across the domains of *credibility, transferability, dependability, and confirmability*. Credibility was developed through investigator triangulation and peer debriefing where two or more researchers made coding decisions and interpretations (Korjsten & Moser, 2018). Transferability was developed through thick description of participant’s experiences, behaviour, and context (Korjsten & Moser, 2018). Dependability and confirmability were facilitated by keeping notes detailing the reasoning and logic behind the organization of categories and themes during the analysis process (Korjsten & Moser, 2018; Mayan, 2009). Reflexivity supported study confirmability through the continuous acknowledgement of biases of the research team members and the primary researcher (Korjsten & Moser, 2018).

Analysis

Six themes arose from the 10 interviews analyzed in this study: 1) Participant Expectations of Businesses, 2) Self-Advocacy, 3) Participant Perspectives on Aphasia and Disability, 4) Impact on Thoughts and Beliefs, 5) Future Expectations and Actions, and 6) Lasting Feelings. The first three themes addressed the first research question and represented the perspectives, beliefs, and traits which most impacted participant’s business interactions. The latter three themes addressed the second research question and comprised participants’

perceptions and experiences of the business interaction that impacted their lives even after the interaction had concluded. The themes and their relationship to the research questions are summarized in Table 5. These themes were based in a context for the business interaction, which represented the factors and features that were present in the business interaction but were not described as having a direct link to the impact placed on or by a participant’s personal factors. Codes relevant to the context are described first, followed by a description of themes related to each research question.

Table 5

Summary of the six themes, by research question.

Research Questions	Themes		
How do personal factors influence the experience of PWA when accessing businesses and services?	Participant Expectations of Businesses	Self-Advocacy	Participant Perspectives on Aphasia and Disability
How are personal factors influenced by the experience of PWA when accessing businesses and services?	Impact on Thoughts and Beliefs	Future Expectations and Actions	Lasting Feelings

Context for the Business Interaction

The context of the business interactions set the groundwork for the described impact exerted on and by their personal factors. Although context may have influenced the impact described by participants, it did not define this impact. That is, these factors were present in the interaction, but were not described as having a lasting impact on their personal factors or on their experiences of access. For

example, when participants felt they were perceived as less intelligent, they did not share that this impacted their beliefs regarding their own intelligence; however, this perception, in combination with other aspects of context (e.g., minimal communication supports provided), could contribute to the true impact described by participants, such as decreased confidence. Some aspects of the context were external to the person with aphasia (e.g., supports received from others, presence of friend or family), while others were internal (e.g., perception that others believe they are unintelligent; overall quality of life).

Regarding the external context, each participant identified specific business experiences which were used to “bind the case”. Except for P01, who could only identify one specific positive business experience, each participant identified one positive and one negative or neutral experience. Table 6 summarizes these experiences and aspects of their external context (i.e., presence of friends/family, communication support provided by employees)

Table 6

Summary of the participant business experiences that were included in analysis. These are the experiences which ‘bound the case’. P01 could only describe one specific experience and spoke generally about his experiences otherwise.

Participant	Positive Experience			Negative/Neutral Experience		
	Business	Friend or Family present?	Supports provided by employee	Business	Friend or Family present?	Supports provided by employee
P01	Restaurant	Yes; wife	None	--	--	--

P02	Fast food coffee shop	No	Give time	Mortgage renewal at bank (neutral)	Yes; brother	None
P03	Purchasing new vehicle at dealership	Yes; daughter's partner	Speak slowly	Telephone conversation with financial service company (negative)	Not initially; daughter arrived partway through	Speak slowly
P04	Houseware and clothing retail store	No	Acknowledge alternative communication	Sporting goods retail store (negative)	No	None
P05	Telephone conversation with insurance representative	No	Speak slowly, give time, use simple sentences	Drive thrus (neutral)	No	None

Participants also described internal feelings and beliefs that did not have a direct or lasting impact on their experience of access or their personal factors in the future; thus, these were considered aspects of the internal context for the interaction. For example, P05 described gratitude as one contributor (along with her overall success, support provided by employee, etc) to the lasting feeling of hope after a positive interaction but did not describe this gratitude itself as lasting (e.g., it did not improve her level of access, make her a more "grateful" person, or make her more conscious of gratitude in the future).

All five participants shared that they felt as though others perceive them as less intelligent during negative or neutral experiences. Three participants, P01, P03, and P05, also shared that they felt their aphasia was confusing to others during their business experiences, regardless of whether the experience was positive or negative. P03 and P05 felt that their aphasia was confusing because people expected them to have less difficulty with communication based on their lack of (or

not overt) physical disabilities, while P01 felt that his aphasia was confusing because people expected him to have more difficulty with communication based on his overt physical disabilities. P04 and P05 shared that they felt gratitude during positive experiences where employees made a special effort to support them. P04 further described feeling respected by the employees during this experience. Three participants, P02, P03, and P05, shared that they felt nervous or anxious during their business experiences; for P03, this was related to talking on the phone rather than in-person, while P02 and P05 were predominantly anxious about speaking to a new person.

Table 7 summarizes the ALA-2 and SAQOL-39 scores for each participant. For three of five participants, their lowest domain scores were "Personal" and "Psycho-social". These domains most closely correspond to the WHO-ICF's definition of personal factors. One participant had both "Personal" and "Psycho-social" as their highest domain scores. The final participant had "Personal" as their highest domain score on the ALA-2 while "Psycho-social" was their second highest score (by a difference of .3) on the SAQOL-39. This showed that for approximately half of participants, personal factors were their most affected area of quality of life, while the other two participants felt that this area was less affected.

Table 7

Assessment scores for each participant from the Assessment for Living with Aphasia – 2nd Edition (ALA-2; Simmons-Mackie et al., 2014) and Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39; Hilari et al., 2009).

Participant	ALA-2 Total Score (out of 4)	ALA-2 Domain Scores (out of 4)		SAQOL-39 Mean Score (out of 5)	SAQOL 39 Domain Scores (out of 5)	
P01	3	Aphasia	2.6	4.3	Physical	4.3
		Participation	3.0		Communication	3.7
		Environment	2.8		Psycho-social	4.5
		Personal Wall Question	2.8			
P02	2.5	Aphasia	2.8	3	Physical	3.8
		Participation	3.1		Communication	3.9
		Environment	2.5		Psycho-social	1.9
		Personal Wall Question	2.0			
P03	2.9	Aphasia	2.9	3.5	Physical	4.7
		Participation	2.8		Communication	3.3
		Environment	2.9		Psycho-social	2.4
		Personal Wall Question	2.5			
P04	2.7	Aphasia	2.4	3.6	Physical	4.1
		Participation	2.7		Communication	2.1
		Environment	2.4		Psycho-social	3.8
		Personal Wall Question	2.5			
P05	2.8	Aphasia	3.3	3.7	Physical	4.4
		Participation	2.9		Communication	4.6
		Environment	3.8		Psycho-social	2.7
		Personal Wall Question	3.0			

The Influence of Personal Factors on the Business Interaction

Participant Expectations of Businesses

The first theme summarized participant's expectations for the business experiences discussed in the current study. All five participants had their own expectations for businesses. P01 felt that the business did not care because it was a

quick transaction where “we move in, you eat your food, and we move out again.” P02 approached businesses by focusing on and preparing herself rather than thinking about who she might talk to. P03 worried about potential communication issues:

P03: It was easy. Very easy. Um I had no problems. I was expecting a little bit p- little bit of problems, but I had no problems at all so yeah.

I: Okay, what problems did you expect?

P03: Well, I didn't expect having a problem, I just uh, I was just uh thinking “Is there going to be any problems?”

P04 felt that her experiences at both retail stores would be positive as she had not previously been shown otherwise. P05 expected to be rushed:

Many places they um. ... They just want to rush you and uh like just next, next, next. Like uh and that's what I expected. That someone- I didn't expect someone to take the time that he did to, like he went above and beyond, to help me. And then he even followed up with a phone call.

Self-Advocacy

The second theme represented aspects of participant’s self-advocacy relevant to the business interaction. Specifically, participants discussed their willingness to disclose their aphasia to employees, their willingness to ask for help with their communication, and their feelings of personal responsibility during the interaction.

Disclosing Aphasia. All participants discussed disclosing aphasia to their communication partner. P02, P03, and P04 often disclosed that they had a stroke and have aphasia, and, in general, found this helpful for facilitating communication

at businesses. P04 shared that she brings her aphasia card even if she is with a friend or family member, so that employees know they need to talk with her. P03 repeatedly stated that he almost always tells people that he “has a stroke with aphasia.” He found that most people would help him after being told this, even if they didn’t understand what aphasia was at first.

The other two participants, P01 and P05, shared that they often do not disclose their aphasia to employees for various reasons. For instance, they felt that there was reduced public awareness which impacted their willingness to disclose. P05 stated, “I avoid [disclosing my aphasia] because they just don’t know, so then I just don’t do the things that I want because I avoid it.”

Both P01 and P05 made statements about wanting to improve their abilities such that it would not be necessary to disclose their aphasia and explain why they had difficulty speaking or understanding. P01 additionally pointed out that other people are not required to explain their problems to new communication partners. When asked if he uses an aphasia card, he shared:

I never pull it out. I never beca-. Because why? Why should I have to you as a pe-per-person have to express? “Oh, you will have that, and you have that and you have-” Sorry that you are you and I am I and that's it. ... I- I- I’m figuring to come back up to everybody else.

Asking for Help. While all participants shared that they may ask for help from family or friends when accessing businesses, not all were likely to ask employees for help with their communication at a business. P03 and P04 stated they were likely to ask for communication help from employees, while P01, P02, and P05 stated they would not.

Both P03 and P04 found that asking for help at businesses made them more accessible. Typically, asking for help from employees involved some level of education on what aphasia is, how they best communicate with their aphasia (P04, for example, predominantly writes key words for communication), and how others could change their communication to support them. P03 shared that most people were accommodating when he asked them to slow down, while P04 shared that occasionally people ignored or misunderstood her writing.

P01, P02, and P05 were less likely to ask for help with their communication at businesses but stated differing reasons for this. P02 and P05 both appreciated help when it was provided but were not likely to ask. P05 shared that she would rather “fake it” than explain that she doesn’t understand, especially when she is by herself. For P02, she recognized that she wanted to think for herself, and would get frustrated: “I just nope, nope *hands up in ‘surrender’* and go home.”

P05 disclosed a personal sense of guilt as a reason to avoid asking for help. She shared that she feels guilty that she experiences day-to-day difficulty even though her aphasia is mild relative to other people with aphasia. She stated:

I happen to have damage in areas that I used to be the most uh the strongest in. ... I pass for someone like who's fine. ...I see people who have been so impacted and I uh sometimes I just don't want to ask for help, because I feel like uh I’m feeling sorry for myself.

In contrast to P02 and P05, P01 did not ask for help because he felt that one cannot expect businesses to use communication strategies. He may have asked for help in other ways, but for communication, he was “expected to get them.” When

asked if he would like more people to use communication strategies, he stated, "No, because they won't. Th-they won't."

Personal Responsibility. Two participants discussed beliefs and opinions that pointed to their feeling of responsibility during the interaction. P01 framed this as personal responsibility for success of the interaction; that is, if there is a communication breakdown, he should be able to repair it. In this way, he was responsible for making communication successful. In his words:

I: So, you get a little bit flustered, if people aren't understanding in those situations?

P01: A little bit [flustered] in those scenes. Yeah, yeah. But why should they not be? You know, they should be, but I should be ready for it. ... Everything that happens out there, I should be ready for it not talking around the other way ... And I'll have to come up with ways of making `em do it, and how to talk to me and how to care for me and everything else.

P03, on the other hand, appeared to take on personal responsibility for any difficulty during business interactions. Specifically, if there was a communication breakdown even after his communication partner had attempted to adapt their communication (e.g., by slowing down), P03 felt responsible for the confusion:

Well, like I said he did slow down, and he sound perfect, but he said other stuff I uh just uh was too fast for me. And I got too embarrass maybe to say pardon me, pardon me, pardon me, so um I don't know I might have screwed it up, or I had a hard time to understand it anyways, yeah ... I was getting a little bit excited about him and uh I felt bad about it after.

Participant Perspectives on Aphasia and Disability

The third theme comprised participant's views on how aphasia and other disabilities are perceived in society, and their own personal identity. Specifically, participants discussed aphasia awareness, stigma related to disability, and their desire to maintain their identity.

Participant Perceptions of Awareness and Stigma. Two participants, P01 and P05, widened their discussions of aphasia to include awareness in society broadly. Both participants recognized that aphasia awareness is low, and P05 additionally felt that people did not care about aphasia and that they had misconceptions about what aphasia is and when it occurs. P01 felt that stroke awareness was improving, but still felt that "they've got to see you and hear you, and you've got to talk for yourself first."

While discussing disability in general, P05 said, "I feel like we've been trained to like "don't mention it, don't mention." She further pointed out the perceived stigma associated with disability in general and how this contributes to lowered awareness overall.

Maintaining Identity. Three participants, P01, P02, and P03, shared their desire to maintain their identity and be treated, in the words of P02, like a "regular person." P01 desired that people treat him as himself rather than as a person with aphasia or someone who has had a stroke. P03 specifically addressed how others felt sorry for him when he told them that he has aphasia. Although he said that he thanked them for their concern, he responded in this way:

I just keep forgetting that I had s- had a stroke, you know. Kind of. I do know that I had it but I ... have to say that ... don't have to feel so bad for me. Cause I'm- that is what I'm feeling.

The Influence of the Business Interaction on Personal Factors

Impact on Thoughts and Beliefs

The fourth theme represented the impact of business experiences on certain thoughts and beliefs held by the participants. Business experiences showed participants how their abilities had changed – both because of their injury and because of their recovery – and impacted participant's confidence in participating in future business experiences.

Changes in Abilities. All participants discussed how business experiences pointed to changes in their abilities because of and since their injury. This included changes which represented lost abilities and changes which represented improvement toward their pre-injury skills.

All participants appeared accepting of these changes in life but described frustration with their difficulties. P05 said, "when I have a hard time and stuff too, it just uh- it's not bad, but just a reminder that my life has changed."

In general, there were fewer instances where participants noted a positive change in their abilities since their injury during a business experience, but two participants (P01, P03) discussed instances of these positive changes. P01 expressed that he and his spouse were, at times, surprised by his communication abilities and independence. P03 also shared that when his communication partners affirmed his communication abilities, he knew he was "doing some right."

Two participants, P02 and P05, described feeling “normal” after positive experiences. When discussing a phone interaction, P05 said, “I don't want to say normal, 'cause normal's overrated anyway. um. ... might look- I don't know, just like myself. Like it didn't matter that I had a stroke, or sometimes, like it didn't matter.” This was echoed by P02, who said, “They're um joking and stuff. And you know, it's nice that um people like me. Yeah, I was just like, 'I feel normal.'”

Changes in Confidence. We defined confidence as feeling sure of yourself and your abilities. All participants discussed changes in their confidence during and following business experiences. One participant, P02, talked about feeling more confident after a negative experience where she was still successful. She also shared the importance of family support during her business interactions and how this helped her feel like “I can do this.”

Three of five participants, P01, P04, and P05, described feeling more confident in their abilities and independence after a positive experience where they accomplished their goal. A quote from P05 summarized this:

I think any positive experience, especially with the business, and we're talking in this context, is that it gives me the confidence um and that I'm capable of doing these things myself. And uh that's a big deal when you- You feel independent, I guess. It increases independence for people. And well like anything that's inclusive, right? Like, I could get my insurance myself.

laughs

Two participants, P03 and P04, found that their confidence was either unchanged or lowered following their business experiences. P04 felt that her confidence didn't change after a negative experience; she would not feel more

confident next time, but she would not feel less confident either. P03, on the other hand, shared that he frequently wonders whether he will have problems understanding with any new experience (i.e., he is unsure of his abilities). He shared that after a negative experience, he assumed that he'd have problems understanding next time.

Future Expectations and Actions

This theme encompassed codes where participants shared how their experiences impacted their future actions and expectations for future interactions. Four of the five participants discussed ideas that were coded under this theme.

When P03, P04, and P05 had a positive experience, they shared that they expected a similar experience at that business to be positive again in the future. If they had a negative experience, they expected any future experiences at that business to be negative. This was true even if they had positive experiences there in the past or began the interaction with positive expectations. Their negative experiences made them avoid similar experiences in the future.

P03 and P05 additionally reflected on how they would change their actions to improve their experiences in the future. For P03, this reflection involved addressing the difficulties that arose, such as requesting an email instead of continuing with the phone conversation. P05 reflected that her approach depended on her "current headspace"; sometimes she would try to solve the problems that arose (e.g., by bringing a family member with her next time) and other times she may "avoid it altogether".

Three participants, P01, P03, and P05, discussed feeling embarrassed during business interactions because of their communication difficulties. P01 shared that in

public spaces he generally “keeps quiet” and further stated, “I don't let them see it much but that's because I don't go out much.” P03 and P05 shared that they might pretend to understand or stop asking for the communication partner to repeat themselves because of their embarrassment. P05 phrased this as trying to “make it easier on the other person.”

Lasting Feelings

The final theme described feelings which remained with participants beyond the immediate interaction. Although participants described experiencing other feelings (e.g., gratitude, anxiety), the feelings which remained with them after the interaction were *frustration* and *hope*.

Continued Frustration. P03 and P04 discussed the frustration they experienced during and after their business experiences. For P03, this frustration was rooted in his own difficulty understanding while on the phone with a business, rather than being related to what his communication partner was doing. P04, on the other hand, was frustrated by her experience with an employee at a clothing retailer, who she described as “unhelpful” and “rude”. She shared that she wrote “stroke” on her note pad but was brushed off by the employee. She found this very frustrating, and it contributed to her decision to avoid this business in the future (see *Future Expectations and Actions*).

Both P03 and P04 were frustrated by their experiences long after they were concluded. They also felt that they were likely to feel frustrated when frequenting that business again or when they remembered this experience. When asked how he managed his frustration, P03 shared, “Well ... it like it still bothers me thinking about it. Whenever I- Whenever I think about it, it's always bothered me.”

Hope. P03 and P05 talked about feeling hopeful after business experiences. P05 shared that her positive experience gave her hope about life in general, that there was “more good than not” in the world. After a negative experience, P03 had hope that he would improve his ability to understand in the future. When discussing a negative experience while on the phone with a business, he said:

I would still try them again next time I talk to them or hopefully. 'Cause it's been a-a while *pause* a while longer. You know, I hope that I would understand better now. But I'm not expecting myself to be better, but I-I'm hoping I would be better.

General Discussion

This qualitative multiple case study aimed to understand how the personal factors of PWA impact their business access and vice versa. Through qualitative content analysis of the participant interviews, six themes emerged. The first three themes encompassed the impact of personal factors on business interactions: 1) Participant Expectations of Businesses, 2) Self-Advocacy, and 3) Participant Perspectives on Aphasia and Disability. The final three themes summarized the impact of the business interactions on their personal factors: 4) Impact on Thoughts and Beliefs, 5) Future Expectations and Actions, and 6) Lasting Feelings. The themes presented here suggested a reciprocal relationship such that personal factors of PWA formed the foundation of the business interaction and interacted with the business and its context to form the experience of the PWA. This experience then impacted the personal factors of people with aphasia which would be brought into future interactions.

Reciprocal Relationship between Personal Factors and the Business

Interaction

The first research question addressed the impact of participant's personal factors on their access to businesses. Those that were willing to disclose their aphasia and to ask for help shared that this supported their access to businesses, in general. These actions typically involved some level of aphasia education regarding what aphasia is or caused by, and helpful communication strategies. This aligned with previous research in the context of businesses which showed that people with aphasia are required to be strong self-advocates to facilitate access and are responsible for educating others on aphasia and raising aphasia awareness (Brown et al., 2006).

Some participants who generally did not disclose their aphasia or ask for help found that this limited their access to businesses at least some of the time. Lack of aphasia awareness was cited as one reason for this decision. Their perception of low awareness aligned with previous studies that showed limited public knowledge and awareness of aphasia (Code et al., 2016; Flynn et al., 2009; Simmons-Mackie et al., 2002). As described by one participant, this lack of awareness contributed to a perceived stigma, which studies have shown impacts the presence and degree of disclosure (Taubner et al., 2017; Goffman, 1963). Additionally, although not described in this study, PWA who disclose their aphasia may encounter people who perpetuate this stigma which could result in reduced, rather than enhanced, access. Participants also shared that they wanted to reach a point in their recovery where it would be unnecessary to explain to employees that they have aphasia. Worrall and colleagues (2011) highlighted the desire of PWA to return to their pre-stroke life

and improve their communication in real-life contexts. This and other studies have also described the desire of people with aphasia to be treated with respect and to have their communication partners understand that they are competent (Dalemans et al., 2010; Simmons-Mackie & Damico, 2007; Worrall et al., 2011). The experience of participants in this study was congruent with these results described in the literature.

Finally, one participant shared that she did not ask for help because of a sense of guilt stemming from the fact that there are others who, she felt, experienced a greater impact on their life because of severe aphasia. Because this participant had very mild aphasia, she felt that asking for help was a way of “feeling sorry for herself.” Cavanaugh and Haley (2020) interviewed people with aphasia who, like this participant, scored above the cut-off score on the WAB-R (Kertesz, 2007). Their study showed that participants with very mild aphasia still experience significant difficulties that impact their ability to live successfully with aphasia. Previously identified feelings of guilt in PWA have tended to be related to PWA feeling that they are unable to contribute to personal relationships or that they are a burden to their loved ones (e.g., Baker et al., 2020). This participant’s sense of guilt from experiencing difficulty, despite having a mild aphasia, was a novel finding. This pointed to the complex influence of aphasia on self-efficacy and quality of life, even for very mild aphasia. Decisions to engage in or not engage in self-advocacy behaviours, such as disclosing aphasia or asking for help, are similarly complex.

Some factors discussed by participants were not consistently described as a support or a hinderance and depended largely on the experience, its context, and

the participant. Regarding participants' expectations of businesses, their experience of access was influenced by whether their initial expectation was positive or negative, and whether those expectations were met. However, this relationship was not clear or consistent across participants: positive expectations did not necessarily support participation (i.e., participants may still have difficulty accessing the business even if they did not expect these difficulties) and negative expectations did not necessarily hinder participation (i.e., negative expectations did not preclude participants from having positive experiences at businesses). In terms of personal responsibility, this factor appeared to cause negative feelings during and after the interaction for one participant and additionally influenced their willingness of participants to ask for help; however, it appeared to give another participant a sense of agency in their interactions and motivation for their recovery. Finally, participants shared a desire to maintain their identity at businesses regardless of their aphasia and be treated as "normal" by others. Similarly, Taylor and colleagues (2020) found that PWA desired and took steps to maintain their identity as a customer within the retail space, as this related to their "independence and strength" (p. 5). In the current study, this desire to maintain identity was difficult to appropriately categorize as a support or a hinderance. Considering previous identity research, this desire may be better summarized as one manifestation of the complex renegotiation and recognition of identity in the context of aphasia (Shadden, 2005; Strong & Shadden, 2020; Simmons-Mackie & Elman, 2011).

The second research question investigated the impact of business access (or lack thereof) on the personal factors of participants. This impact generally fit into three domains: 1) thoughts and beliefs, 2) expectations and actions, and 3)

feelings. These domains were similar to the categories and subcategories described in the framework by Geyh and colleagues (2019). Positive business interactions showed people with aphasia how they had improved since their injury, made them feel “normal” or as though their injury did not matter, and allowed them to expect future experiences to be similarly positive. Negative or neutral business interactions reminded people with aphasia of their lost abilities, caused them to expect future experiences to be similarly negative or embarrassing, made them avoid future interactions, and provided a long-standing feeling of frustration.

Interestingly, participants’ confidence and hope for the future were not always negatively affected by negative experiences or positively affected by positive experiences. Participants experienced increased confidence when they achieved their goals, even if their overall experience was negative. Their confidence was either unchanged or lowered if they did not achieve their goals. Achieving their goals was more likely when the experience was positive, but participants could still be successful during negative experiences depending on other features of the context (e.g., family support). The concept of ‘hope’ was similar; positive experiences were more likely to provide general hope for the future, but one participant noted that even after a negative experience, he had hope that his communication and overall experience would be improved the next time. Previous research has referenced ways that access or social participation can impact personal factors (e.g., Dalemans et al., 2010, Simmons-Mackie & Damico, 2007; Taylor et al., 2020). For example, Simmons-Mackie and Damico (2007) referenced the interplay between “saving face” and “losing face” and the impact that both can have on motivation to participate (p.91). The current study added to this line of

research by describing the impact of business interactions on personal factors in the context of participation.

Enhancing Participation

Promoting the participation of people with aphasia involves enhancing supports and diminishing hinderances to participation. Assessments and interventions which fall under the LPAA model place real-life enhancements in participation across settings, including access to businesses, at the forefront of aphasia rehabilitation (LPAA Project Group, 2000). A variety of approaches could accomplish this goal. For example, Howe (2017) described several opportunities for SLPs to facilitate the social participation of an individual with aphasia, such as connecting to peer-groups or providing ways for PWA to contribute to society (e.g., volunteer opportunities or advocacy groups). Many other studies have summarized how the participation of PWA could be enhanced through specific treatment approaches, such as community aphasia groups (e.g., Attard et al., 2018), or by enhancing communication accessibility in everyday activities, such as in retail or service environments (e.g., Taylor et al., 2020; Brown et al., 2006; Anglade et al., 2019) or yoga classes (e.g., Ross et al., 2018; Ross et al., 2022).

The results of this study pointed to a few recommendations to improve the participation and overall quality of life of PWA through the consideration of personal factors. First, SLPs should consider addressing the mental health concerns of PWA. In this study, participants discussed many factors which fall under the scope of mental health professionals and interventions, such as changes in confidence or coping with loss of ability (Santo Pietro et al., 2019). Recent studies have highlighted the high prevalence of mental health disorders among people with

aphasia and the importance of mental health supports for enhancing the quality of life of people with aphasia (Baker et al., 2020; Cruice et al., 2003; Manning et al., 2022; Sandberg et al., 2021). Addressing these concerns could involve increased training in counseling for SLPs or routine mental health screenings in treatment, and increased communication training for mental health professionals (Sandberg et al., 2021; Santo Pietro et al., 2019). Clinicians and researchers should consistently consider mental health supports and interventions in the context of aphasia therapy and treatment.

Second, the lives of people with aphasia would be supported across domains of functioning (e.g., personal factors, participation) with continued focus on increasing awareness and public knowledge of aphasia. Low awareness and understanding of aphasia were cited as and contributed to significant hinderances to participation for people with aphasia in this study, which was in line with previous findings related to participation and access (e.g., Brown et al., 2006; Howe et al., 2008; Niemi & Johansson, 2013; Taylor et al., 2020; Worrall et al., 2011). This study again highlighted the importance of considering the impact of the communication environment on the participation and personal factors of PWA. Increasing overall aphasia awareness and education through targeted programs (e.g., the Aphasia Friendly Business Campaign; Borsatto et al., 2021) could enhance the business access, participation, and overall quality of life of people with aphasia in their communities.

The Whole Person: Including Personal Factors

The A-FROM (Kagan et al., 2008) encourages clinicians and researchers to consider one's life with aphasia as the intersection between four domains: 1)

Participation in life situations; 2) *Personal identity, attitudes, and feelings*; 3) *Communication and language environment*; and 4) *Severity of aphasia*. In this framework, personal factors are an equal contributor to the lived experience of a person with aphasia. This study emphasized the need for research focusing on personal factors in people with aphasia and in disability broadly. For three of five participants, their quality-of-life scores were lowest for domains related to personal factors, highlighting the need to address personal factors in PWA specifically. Even at businesses, which are typically thought to be transactional settings that are heavily dependent on environmental factors, personal factors impacted *and were impacted by* participants' business interactions. As previous researchers have noted (Geyh et al., 2019; Threats, 2007), considering personal factors in research is crucial to creating assessments and interventions which ensure consideration and dignity for the whole person. Although demographic information is typically included in research, factors related to the personal identity, thoughts and beliefs, attitudes, feelings, and patterns of behaviour of PWA are less often investigated directly. Current frameworks purport personal factors as a critical contributor to a person's overall level of functioning and impairment, yet our systematic understanding of these factors is more limited than other proposed domains of functioning.

Currently, the WHO-ICF does not contain a specific classification system for personal factors due to the wide variability between individuals and cultures (World Health Organization, 2001). The study of personal factors would benefit from a comprehensive system of coding and categorization that can simultaneously allow for this variability. Previous studies investigating this potential categorization delineated between factors addressing objective characteristics, such as gender,

occupation, or level of education, and subjective factors which address the lived experience or perceived identity. Geyh and colleagues (2019) referred to the former category as 'individual facts' and the latter as 'subjective experience' and 'recurrent patterns of experience or behaviour'. Threats (2007) delineated between 'demographic information' and 'personality traits'. Currently, demographic characteristics are more easily incorporated into research or assessment than subjective factors like past experiences, personality traits, or patterns of behaviour. Although many personal factors are, by necessity, subjective to the lived experience and life of the person, this does not preclude a systematic method of categorizing and organizing their study. Ultimately, research, assessment, and interventions which simultaneously incorporate these subjective factors are those that will more readily represent, assess, and treat the whole person. In this way, health researchers and practitioners can support a holistic approach (e.g., through mental health supports and training) to enhancing quality of life and life participation.

Limitations

This study represented the personal factors of five people with aphasia in a small sample of their business experiences in Edmonton, Alberta, Canada. The constellation of personal factors which are involved in the business experiences of one PWA will inherently differ from another PWA, even if similarities might be discovered. Similarly, although these personal factors comprised the results of this study, they may have indirectly impacted the way in which the participants viewed and shared about their experiences with the interviewers. This latter impact is difficult to measure, represent, or mitigate based solely on participant interviews

and would be better represented by conducting observations with interviews of both PWA and the employees to follow. Due to the time constraints of a Master's thesis, this study represents a single snapshot in time where participants described their prior experiences, thoughts, feelings, and beliefs at two businesses.

Data collection for this study was conducted in 2021 during the COVID-19 pandemic, which affected the mode of data collection and quantity of participants' recent business experiences. To support future applicability of the conclusions of this research despite the vast difference in public experience during the height of the pandemic, participants were asked to discuss business experiences occurring prior to the pandemic in addition to those occurring recently. The inclusion criteria for this study required that participants be at least 2 years post-onset of aphasia to ensure that they had some business experiences with their aphasia prior to the onset of the COVID-19 pandemic.

Related to both points above, there were limitations in study transferability. Transferability was addressed through the thick description of participant's experiences, behaviour, and context; however, the ability to achieve this thick, in-depth, description was somewhat limited given the format for data collection (interviews only) and the delay between the time of participant's experiences and the time of interview. In this way, although the most salient and relevant aspects of their experiences were likely to be well-represented, descriptions of relevant aspects of the context or participant's experiences may have been forgotten, limited, or omitted. This limitation may have been mitigated with careful questioning about possibly relevant aspects of the context, although consideration for study scope and limited interview time would be necessary. Given this limitation

and the subjective nature of both personal factors and participant's perceptions of their previous experiences, readers may require careful thought to determine how the findings of this study apply to their specific client, practice, circumstance, or setting.

Future Directions

The results of this study were applied to consider ways to enhance personal factors that were supports to business access and reduce those that the participants described as hinderances. Future researchers may consider investigating how participation-focused intervention programs, mental health supports, and aphasia awareness and education interacts with the personal factors of PWA. For example, Baker and colleagues (2020) highlighted the need for intentional psychological care for people with aphasia. They specifically emphasized the need for a "stepped" approach that begins with screening for mood disorders and 'sub-threshold' mood symptoms and increases in intensity of intervention depending on severity of symptoms and progress (Baker et al., 2017; Kneebone et al., 2016). How might personal factors impact the reception of and progress within these interventions or programs? How would they be impacted by these programs? Learning to live with aphasia almost invariably involves a renegotiation of identity and self (Shadden, 2005) and this, by definition, would involve change to either the characteristics or manifestation of a person's personal factors. Previous research has further found that this renegotiation of identity may be navigated through the development of personal narratives and life stories (Strong & Shadden, 2020; Taubner et al., 2020) or through confirmation of personal and shared identity in

aphasia groups (Shadden & Agan, 2004; Simmons-Mackie & Elman, 2011; Lanyon et al., 2018)

Researchers may additionally consider studying how the personal factors of PWA manifest in different settings, such as in social community settings, in therapy programs, or at home with caregivers. In this way, researchers can continue to work toward a comprehensive and systematic coding system for personal factors that would be valid for any setting or scenario. Geyh and colleagues (2019) provided a comprehensive framework in the context of spinal cord injury which may be tested and evaluated across different disability types or settings. This replication and application would refine this line of research and ensure the validity of any coding systems used to represent personal factors. Personal factors are as important as other domains of the WHO-ICF, and clinicians and researchers alike would benefit from a valid and reliable framework to guide their incorporation into practice.

Conclusion

Communication accessibility is a human right. Business interactions present a unique challenge to PWA because of expectations of efficiency, limited resources or employee time, and business-specific goals or expectations that extend beyond social connection or inclusion. Business access for people with aphasia is heavily dependent on communication accessibility. As illustrated by the A-FROM (Kagan et al., 2008), participation at businesses (i.e., business access) influences and is influenced by the communication environment, overall aphasia severity, and personal factors (i.e., the personal identity, attitudes, and feelings) of PWA. Using a qualitative case study method, this study found that personal factors impact and

are impacted by the business experiences of people with aphasia. Factors representing PWA's self-advocacy behaviours, expectations of businesses, and their beliefs about aphasia or disability influenced the business interaction. In turn, business interactions influenced personal factors related to the thoughts, beliefs, expectations, actions, and feelings of PWA. Ultimately, the results of this study highlighted the importance of studying personal factors systematically and in a variety of individuals or settings. By doing so, advocacy, research, assessment, and intervention may address and respect the whole person with aphasia, and more readily improve their quality of life.

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Appendix A

Participant Intake Questionnaire

Name of Participant: _____		Date you are filling this form out: _____
Address: _____ Telephone Number: _____ Email Address: _____		Contact Name: _____ (if different than participant) Contact Relationship: _____ Contact Email Address: _____
Date of Birth: _____ (dd/mm/yyyy)	Age: _____	Gender: Male Female Transgender Male Transgender Female Other Not reported
What racial and/or ethnic origins do you identify with (choose all that apply)?: Indigenous Black Latin/Hispanic Middle Eastern White Asian Other Not reported		
Primary Language: _____ Other languages spoken (if any): _____	Highest Education Level: GED High School Diploma 2 Year Associative Degree 4 Year Bachelors Degree 5 Year Bachelors Degree Masters Degree PhD/Doctorate Degree	
Occupation (pre-aphasia): _____	Do you wear glasses to correct your vision? Yes No	
Handedness (current): _____ Handedness (pre-aphasia): _____	Do you have hearing loss: Yes – and I wear hearing aids Yes – but I do NOT wear hearing aids No	
Diagnosis: Stroke Brain Injury	If you wear hearing aids – they are worn (in the):	

Other Date of event: _____ (dd/mm/yyyy)	Left Ear Right Ear Bilaterally
Other than a stroke/brain injury, do you have any other neurological conditions? (e.g., Parkinson's, MS, Alzheimer's): No Yes If yes, please elaborate: _____	
This form was completed by: _____	

Appendix B

Interview 1

1. Tell us about your aphasia.
 - a. If finding it difficult to answer: What caused your aphasia? When did that happen?
 - i. What's that like for you?
 - ii. What's difficult for you now since you've had your stroke?
2. What places do you go to in Edmonton?
 - a. Are these places that you go to by yourself? Where do you go by yourself?
 - i. Probe for:
 1. Why they bring someone along
 2. Why they go by themselves
3. What businesses do you go to often?
 - a. Are these places that you go to by yourself? Where do you go by yourself?
 - i. Probe for:
 1. Why they bring someone along
 2. Why they go by themselves
 3. Which places are easy/hard to go to (when specific places mentioned) and why
 4. Do you speak with people when you go to these places?
 - a. Yes? How do these conversations go for you?

- b. No? Why don't you speak with people here?
- 4. What businesses make you feel safe/competent/comfortable? Can you describe that experience?
 - a. Probe for:
 - i. Difference between the first time they went (pre-covid) & now
 - ii. Why do they feel that way within those businesses
 - iii. How do you feel about the staff at these businesses?
- 5. Are there any service providers that come to your home? (e.g., plumber, yard worker, maintenance person, house cleaner?)
 - a. Do you often talk to these people when they come?
 - b. How do you feel about these interactions?
 - c. Is there anything that makes these conversations easier or harder?
- 6. Are there any businesses that you use an online website for instead of going in person? (e.g., online banking, online groceries, online shopping, internet/phone service - Amazon, GAP, Chapters).
 - a. Why do you use these online instead of in person?
- 7. Are there any businesses that you contact over the phone? (e.g. banking, internet service providers, buying groceries). Why?
 - a. Is there anything that makes talking on the phone easier?
- 8. Think about a good experience you had talking with an employee at a business by yourself. What do you think made it easy to speak with them or understand them?
 - a. Supports used for this question:

- i. communication strategies and tools (e.g., “slow down”, writing, etc.) so participants can describe what works and what doesn’t
 - b. Probe for:
 - i. First time at business vs multiple times (or first time they encountered this employee)
- 9. If a business wanted some advice on how they could be more aphasia friendly, what would you tell them?
 - a. Supports used for this question:
 - i. communication strategies and tools (e.g., “slow down”, writing, etc.)
- 10. Are there any specific businesses you would like us to contact during this project?
- 11. Is there anything else you want to share?

Interview 2

The second interview included questions developed for each participant, based on the content of the first interview. They were specific to a businesses discussed prominently in the first interview. These questions highlight the primary topic areas of interest.

Last time, you talked to me about your experience at _____.

1. Tell me a little bit more about your experience at _____. What happened?
2. Why did you go to this business? What were you trying to get/do?
3. What did you expect to happen when you got there?

- a. Did this experience meet your expectations? Why or why not?
- b. Consider probing:
 - i. Preferences for conversations with new people (avoid them? Like to chat with new people?) -- can bring back ALA data if relevant

Now we're going to talk about your thoughts, feelings, and reactions before, during, and after this experience. If you ever need a break, just let me know.

- 4. How did you feel before this experience/before you went to ____?
 - a. Consider probing (where relevant):
 - i. Their thoughts and opinions of the other person/business
 - ii. How they perceived themselves
- 5. How did you feel while this was happening?
 - a. Consider probing (where relevant):
 - i. How they managed these feelings in the moment
 - ii. How they reacted throughout this experience
 - iii. Their thoughts and opinions of the other person/business
 - iv. How they believe the other person perceived them
 - v. How they perceived themselves
- 6. How did you feel immediately after? What about a few days after?
 - a. Consider probing (where relevant):
 - i. How they processed these feelings afterward (e.g., talking to others? Individually? Not really processed?)
 - ii. Their thoughts and opinions of the other person/business
 - iii. How they believe the other person perceived them

iv. How they perceived themselves

7. Did this change how you acted and felt the next time you went to this business/service/person? Tell me more about that.

a. Did it change how you acted at other businesses/services?

Repeat interview 2 questions for the other experience which binds the case.