Building communication ramps: An examination of barriers and facilitators in making

businesses accessible for individuals with aphasia

by

Kira Alexandra Bryan Mauriks

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science

in

Speech-Language Pathology

Department of Communication Sciences and Disorders

University of Alberta

© Kira Alexandra Bryan Mauriks, 2022

Abstract

The present study investigated barriers and facilitators to making businesses accessible for people with aphasia – specifically, external factors that contribute to communication accessibility. Nine people with aphasia were interviewed about their experiences accessing businesses and services in the Edmonton community. Interviews were coded and thematically analyzed to identify key themes related to barriers and facilitators to communication during business interactions. Four main themes were found: communication strategy use, adaptation of communication, aphasia education, and respect for people with aphasia. The presence of these themes led to positive business experiences, and the absence of these themes contributed to negative business interactions. Future research should investigate how personal factors may affect businesses access, and how to best support businesses in incorporating these ideas to improve communication accessibility for people with aphasia.

Preface

This thesis is an original work by Kira Mauriks. The research of this project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, "Building Communication Ramps for People with Aphasia", Pro00096686, March 10, 2021. No part of this thesis has been previously published.

Acknowledgements

I would like to begin by expressing my sincere thanks to my thesis supervisor Dr. Esther Kim and Graduate Co-Supervisor Carlee Wilson for their guidance throughout this project, and for their confidence that I would do this important research justice. I would also like to thank my research colleague and friend Leah Auch for her constant support, thoughtful ideas, and for keeping me sane.

As well, I would like to express my sincere gratitude to the stakeholders involved in this project. Their contributions to the development and analysis of this research were invaluable. Their expertise, developed through the lived experience of aphasia, provided insight into findings that undoubtedly enriched the outcomes of this research. As well, thanks to my committee members Dr. Jessica Laccetti and Andrea Ruelling for their perspectives on and their enthusiasm for this project.

I am also incredibly grateful to the people with aphasia who agreed to participate in this project. I express my thanks to them for taking the time to speak with us about their personal experiences, and for being so candid and vulnerable.

Lastly, thanks to my friends and family for your loving support throughout this process. To Erin, Ben, Ali, Ciara, Maddy, Izzie, and Katie – your friendship has kept me grounded and off the edge of many a mental breakdown these last few months. Thank you for putting up with me. To Mom and Dad – your eternal encouragement is the reason I believed I could pursue this degree in the first place. Making you proud has and will always be my greatest accomplishment.

Table of Contents	v
List of tables	vii
List of figures	viii
Introduction	
Communication Access and Social Inclusion.	1
The LPAA and A-FROM.	4
Supported Conversation for Adults with Aphasia	6
Current Service Models of Communication Access	
Stakeholder Engaged Research	
Current Study	
Methods	
Participants	
Data Collection	
Analysis	
Trustworthiness	
Results	-
Theme 1: Communication Strategy Use Slowing Down Speech	
Repetition	
Giving Time	
Verifying Understanding	
Writing	
Use of Imagery	
Using Gestures	25
Theme 2: Adapting Communication	26
Theme 3: Aphasia Education	
Theme 4: Respect	29
Discussion	
Strategies for Communication Partners	
Self-Advocacy and Adapting Communication	
Respect	
Importance of Aphasia Education	
Limitations	
Future Directions	
Conclusion	

Table of Contents

References	41
Appendix A	41
Appendix B	

List of tables

Table 1 Parr's Markers of Social Inclusion	2
Table 2 Participant Characteristics	
Table 3 Interview Question Guide	13
Table 4 Codes and themes relevant to external communication barriers and facilitators	17

List of figures

Figure 1: Living with Aphasia: Framework for Outcome Measurement (A-FROM)	5
Figure 2: Visual supports depicting various business and services	15
Figure 3: Visual supports depicting supportive communication strategies	15

Introduction

Communication is essential to fully engaging in our lives. It allows us to participate in activities we enjoy, form meaningful relationships, and make positive contributions to our communities and society as a whole. Approximately 440,000 Canadians have communication disabilities, which may impact their life participation (Communication Disabilities Access Canada (CDAC), 2020). Specifically, it is estimated that 137,700 Canadians are living with aphasia, a communication impairment experienced due to cerebrovascular accidents (stroke), traumatic brain injury, or other neurological conditions (Simmons-Mackie, 2018). Although accommodations to ensure equal access to information, communication, and publicly available services are outlined in the United Nations Convention on the Rights of Persons with Disabilities, communities often fail to implement such accommodations, limiting social inclusion and life participation for individuals with communication impairments (United Nations, 2006; Collier, Blackstone, & Taylor, 2012; Solarsh & Johnson, 2017).

Communication Access and Social Inclusion

Communication access refers to policies that are in place to ensure people with communication impairments are able to understand and communicate when accessing businesses and services. This includes access to communication that may take place face-to-face, over the telephone, and online. This study will primarily address in-person business and service interactions (CDAC, 2020). Adherence to these policies contributes positively to the social inclusion of people with communication impairments (Collier, Blackstone, & Taylor, 2012; Solarsh & Johnson, 2017. In an ecological model of social inclusion, individual, interpersonal, organizational, community, and socio-political factors have both enabling and disabling properties (Simplican, Leader, Kosciulek, Leahy, 2014). Enabling conditions at these levels facilitate an increase in happiness, self-esteem, confidence, independence and mental health and well-being for people with disabilities, while also decreasing the stigma, negative attitudes, and discrimination towards individuals with disabilities. Thus, an increase in social inclusion benefits society as a whole by encouraging the participation of people with varying levels of abilities.

In her ethnographic study on the day-to-day life of people living with severe aphasia, Parr (2007) identified markers of social inclusion and exclusion. These are summarized in Table 1, adapted from Parr (2007):

Table 1

Type of Marker	Included Elements
Infrastructural	Employment, finances, housing, services, information, training, information/communication technology, institutional geography
Interpersonal	Close personal relationships, relationships with service providers, relationship with peers
Personal	Identity, self-esteem, isolation, negative/positive feelings, motivation/aspiration

Parr's Markers of Social Inclusion

Parr suggests that social exclusion occurs at three levels: *infrastructural, interpersonal*, and *personal*. Infrastructural exclusion includes employment, finances, housing, services, information, training, information/communication technology, and institutional geography. Elements of infrastructural exclusion are largely outside the control of clinicians and people with aphasia (PWA), and are beyond the scope of this study. Interpersonal exclusion occurs for PWA in close personal relationships, relationships with service providers, and relationships with peers accessing similar services. Observation of PWA's interactions with service providers revealed some positive, respectful discussions, but additionally identified some problematic behaviours such as patronization and lack of respect for PWA (Parr, 2007). Responses to surveys given to service providers indicated that they found people with severe aphasia "hard to reach," and

mainly attributed communication difficulties to PWA, failing to acknowledge their competence and comfort in interacting with people with communication impairments (Parr, 2007). Ultimately Parr (2007) found that personal factors impact social inclusion, but inclusion relies predominantly on the manner in which people communicate with PWA, what communication strategies service providers have, their attitudes towards PWA, and how a space is laid out, organized, and maintained (i.e., institutional geography). Given the external nature of social inclusion, Parr emphasized the importance of providing education and support for people who interact with PWA in order to improve their life participation.

Parr (2007) primarily discusses the issue of communication accessibility in the context of accessing essential services such as medical appointments and rehabilitation programs, however accessibility extends beyond essential services. Taylor and colleagues (2020) note that in the retail sector, communication partners tend to control conversations, leaving people with communication impairments insufficient time to respond, or ignoring them completely. Additionally, although communication is a dyadic activity where both partners are responsible for the success of the interaction, it seems that people with communication disorders are expected to repair or prevent any communication breakdowns. In their analysis of social inclusion facilitators, Taylor and colleagues (2020) found facilitators to be largely attributable to the communication impaired individuals, such as self-advocacy skills and personal communication strategies (e.g., bringing a printed list to a grocery store or using personal signage to ask communication partners to be patient). Businesses participating in Taylor and colleagues' (2020) study exhibited little effort to improve communication access and therefore social inclusion. This may have perhaps been due to their limited understanding of communication impairments and the persistence of stereotypical ideas of people with

3

communication disabilities. The importance of developing viable strategies for increasing social inclusion is important, as research has indicated that staff and employees do not follow through with support strategies even when there are perceived positive outcomes (Simplican et al., 2014). Thus, the importance of social inclusion needs to be recognized and prioritized at a community, organizational, and political level.

The LPAA and A-FROM.

The life participation approach to aphasia (LPAA) is a service delivery philosophy that focuses on supporting the goals of people with aphasia (PWA), and emphasizes their competence and inclusion in society (Chapey et al., 2000). Whereas historically, research and clinical intervention has been focused on the impairments of PWA, the LPAA acknowledges how factors such as motivation and a supportive environment contribute to life re-engagement. There are five core values underscoring the LPAA pertaining to the goal of life participation: (1) the right to access service for all those affected by aphasia (e.g., PWA, family members, etc.); (2) measuring success through documenting improved life engagement; (3) targeting personal and environmental factors in intervention; and (4) making service available throughout the aphasia journey. Ultimately any research and treatment conducted with the LPAA in mind should be driven by the goals of PWA.

The Living with Aphasia: Framework for Outcome Measurement (A-FROM) is well aligned with the LPAA. The A-FROM structure organizes four interacting domains that contribute to living with aphasia: participation, communication environment, language impairments, and personal factors (Kagan et al., 2008). Figure 1 illustrates the interaction of these domains.



Figure 1. Living with Aphasia: Framework for Outcome Measurement (A-FROM). Taken from Kagan et al., 2008.

As demonstrated by this diagram, the four contributing domains are inextricable; outcomes in one domain will influence all the others, and they in turn will contribute to the lived experience of a PWA. For example, difficulty processing spoken language occurs in the "severity of aphasia" domain, which may impact a person's ability to participate in situations where spoken language is used and comprehension of spoken language is required. We could call this a *barrier* to communication. However, making modifications to the "communication and language environment" where spoken language is used, such as reducing background noise or using accompanying visual information, could be considered a *facilitator* to communication, leading to positive outcomes in the domains of life participation and personal identity (e.g., increased confidence in communicating). Barriers and facilitators can occur in each domain of the A-FROM. This multidimensional framework of living with aphasia demonstrates the importance of

addressing communication access at interpersonal and infrastructural levels, which are factors that are external to PWA. This research project will begin investigating these external considerations, driven by the desire to improve social inclusion for people with aphasia.

Supported Conversation for Adults with Aphasia

The apparent absence of communication accessibility in the business and service sector may in part be due to widespread lack of understanding of aphasia and assisted communication; however, there are well-researched strategies that communication partners can use to assist in interactions with PWA. The Aphasia Institute's communication method, Supported Conversation for Adults with Aphasia (SCATM; Aphasia Institute, 2015), is a set of strategies for communication partners that is guided by the main goals of "acknowledg[ing] the competence of adult[s] with aphasia," as well as helping PWA to reveal this competence (Aphasia Institute, 2015, para. 3). The use of gestures while communicating, writing down key words, and allowing sufficient time to respond are just a few of the many strategies that are part of the SCA.

Kagan (1999; 2001) conducted research on the effectiveness of SCA training for communication partners. The training program included four modules aimed at educating conversation partners about aphasia, teaching them how to acknowledge and reveal the competence of PWA, and providing them with concrete strategies and materials to help support conversation. Kagan's research revealed PWA were judged more competent when speaking to conversation partners trained in SCA. These results speak to the efficacy of SCA training; PWA received no training as part of this study, but as the skill of their conversation partners improved, outside listeners were able to better understand PWA. This finding highlights that conversation is a partnership, PWA should not carry the full responsibility of communication success, and improving communication access should not be focused solely on the impairments of individuals with communication disorders.

Current Service Models of Communication Access

The Communication Access Network (CAN) is a service model developed in Australia to support the communication needs of individuals with communication impairments (Solarsh & Johnson, 2017). The CAN considers environmental support as a key part of social inclusion for people with communication impairments, acknowledging five main facilitators to communication access. These include: 1) the positive attitudes and actions of others; 2) communicative skills to improve interactions; 3) information presented in various formats; 4) optimized environmental conditions (e.g., well-lit spaces and reduced background noise); and 5) clear signage. With the help of community stakeholders (service providers and people with communication impairments), the CAN developed a framework including the key features of accessible environments, as well as an accessibility auditing process for community services and businesses.

This type of framework, specifically designed for improving the community participation of people with communication impairments, appears to be unique to Australia. While research on barriers to communication access has been done in other places, few projects have integrated the perspectives of both people with communication disabilities and business and service providers in order to develop concrete strategies for improving interactions between people with communication impairments and their communities.

In Canada, the implementation of models promoting communication access for communication impaired individuals is a relatively new phenomenon. Aphasia Friendly Canada, an initiative developed at the University of Windsor, recently introduced the Aphasia-Friendly

7

Business Campaign (AFBC) with the goal of helping businesses provide better access for PWA (Aphasia Friendly Canada, 2012; Borsatto, Buchanan, & Pineault, 2021). According to the LPAA, intervention approaches for PWA should focus on both internal and external factors (Chapey et al., 2000). The AFBC targets external environmental factors by providing education about aphasia to businesses, including supported communication strategies to enhance service delivery and social interactions. This program has demonstrated positive outcomes related to increasing public knowledge of aphasia and increasing confidence of employees interacting with PWA (Borsatto et al., 2021). The success of programs, such as the CAN and AFBC, which are aimed at improving external factors to communication, further demonstrates how social inclusion and life-participation for people with communication impairments are at least partially reliant on the societal adoption of communication strategies.

Stakeholder-Engaged Research

In order to develop meaningful and practical solutions to improving communication access for people with communication disorders, research should be guided by the priorities and perspectives of people who are impacted by research outcomes (i.e., stakeholders). For this project, stakeholders included people with communication impairments, business owners/service providers, and speech-language pathologists. Stakeholder-engaged research (SER) methodology acknowledges that including stakeholders in research design, implementation, and dissemination leads to better achievement of desired research outcomes (Mackie et al., 2016). There are three distinguishing levels of stakeholder engagement, each having different expectations of stakeholder involvement (Deverka et al., 2013). At the *communication* level, information is not exchanged but rather communicated from researchers to stakeholders. The *consultation* level involves information communication in the other direction, where stakeholders are providing

information to researchers. At the *participation* level, information is exchanged between stakeholders and researchers, which contributes to an environment of shared decision making (Deverka et al., 2013). SER is relevant to furthering communication access for people with aphasia, as it ensures that research outcomes are appropriate for enacting change. Making lasting changes to communication access requires outcomes to be useful for PWA, as well as for businesses, services, and policy makers.

Current Study

Research on communication access and social inclusion for individuals with communication disorders has identified that inclusion relies on internal and external factors, however businesses and service providers – such as those providing legal services, hairdressers, and house cleaning/yard maintenance services – generally do not demonstrate an effort to implement communication strategies that promote access. Communication access research has yet to identify why businesses have not adopted accessible communication strategies. Investigation needs to be done to address this question in order to provide realistic recommendations, strategies, and training programs for businesses and services. The current study delved into this essential query as part of a larger research project aimed to improve communication access for PWA by supporting Edmonton businesses in adopting supportive communication strategies. Taking notes from the CAN and the AFBC, the greater project aims to provide businesses in Edmonton with concrete strategies and supports to improve their accessibility to PWA, and to develop a resource for PWA that identifies aphasia-friendly businesses. The current study will focus on gaining insight into communication access in Edmonton from the perspectives of PWA. Within the A-FROM, this research will be exploring the domain of "communication and language environment," guided by the following research questions:

(1) What are *barriers* to improving communication accessibility as perceived by PWA

(2) What are *facilitators* to improving communication accessibility as perceived by PWA This study will add to the growing body of literature on communication accessibility, focusing on understanding perspectives of PWA so that it can be later integrated with the perspectives of retailers and service providers. Information gained from this research will be used to develop a survey for business owners and service providers on communication accessibility awareness and practices.

Methods

This study employed the methodological approach of qualitative, stakeholder-engaged research at the participation level (Deverka et al., 2013). Two PWA, a marketing/communications expert, and speech-language pathologists were included in the study as collaborative members of the research team. Both PWA had suffered brain injuries and had been living with aphasia for 3 and 7 years, respectively, at the time of the study. One individual was recruited as a stakeholder after he expressed interest in contributing to aphasia and communication access research. The other individual had been involved in presenting to and training health care workers on communication access, based on her experiences working in and accessing services in the health care system. Additionally, both PWA lived alone and had many personal experiences accessing businesses and services in their communities. Having stakeholders as part of the research team, especially those with aphasia, promoted reflection on research procedures, materials, and data in order to mobilize action for improvement in

10

communication access and social inclusion. Hereafter, mention of stakeholder involvement specifically refers to the stakeholders with aphasia.

This methodology was informed and selected based on the primary researcher's constructivist philosophical perspective. Constructivism is a theoretical position that assumes reality depends on perspective, and it is created through context-specific interactions (Denzin & Lincoln, 2005). Specifically, the primary researcher chose stakeholder-engaged research to not only construct findings based on the perspectives of participants, but also the perspectives of other individuals with aphasia. The intention is that including multiple perspectives of PWA makes the outcome of this research actionable, as it is a more accurate portrayal of the realities of those with communication disorders.

Participants

Nine PWA were recruited to participate in this study through programs that serve adults with aphasia in the Edmonton area (e.g., Corbett Aphasia Rehabilitation and Education program, CHAT Society, Alberta Aphasia Camp). Participants had a diagnosis of any type of fluent or non-fluent aphasia with mild to severe severity and were at least 2 years post onset of aphasia. This was to ensure participants had experiences accessing businesses and services in their communities prior to the start of the ongoing Covid-19 pandemic. Participants in this study were between the ages of 31 and 67. All participants completed the *Western Aphasia Battery Revised* (WAB-R) over Zoom to characterize their aphasia symptoms (Kertesz, 2007). As well, participants completed an intake questionnaire to collect information about their demographic characteristics (see Appendix A). Participants were selected to include a diversity of characteristics related to age, aphasia type, severity, and primary method of communication (e.g., speaking, writing, use of an augmentative communication device). A varied participant group

11

was essential to capture a picture of communication accessibility that represents the experiences of many PWA. Six out of nine participants in this study used speech as their primary communication modality, one participant paired short utterances with frequent and descriptive gestures for support, one participant paired limited single-word utterances with writing for support, and the other used a text-to-speech application on an iPad to support their communication. Table 2 summarizes the demographic characteristics of participants in this study as collected through the intake questionnaire and administration of the WAB. See Appendix B for a flowchart depicting the different types of aphasia.

Table 2

Participant Characteristics

Participant	Gender	Age (at time of study)	Race	Highest Level of Education	Years post- stroke (at time of study)	Aphasia Quotient (WAB)	Aphasia Type (WAB)	Primary Modality of Communication
01	М	62	White	2 years of a 4 Year Degree	7	87	Anomic	Speech
02	F	51	White	2 Year Associative Degree	10	91	Anomic	Speech
03	М	52	White	2 Year Diploma	7	79	Conduction	Speech
04	Μ	31	White	4 Year Bachelors Degree completed over 10 years	11	80	Anomic	Speech
05	М	67	White	GED	9	79	Transcortical Motor	Short Utterances + Descriptive Gestures
06	F	62	White	2 Year Associative Degree	14	55	Broca's	Single Words + Writing
07	Μ	47	White	2 Year Associative Degree	6	56	Broca's	Single Words/Short Phrases + text-to- speech iPad application
08	F	61	White	4 Year Bachelors Degree plus additional 2 years	7	61	Conduction Aphasia	Speech
09	F	43	Black	2 ½ years of post secondary education	2	95	None	Speech

Data Collection

Data was collected throughout two to three sessions with each participant – one to two sessions were dedicated to intake assessments and the final session consisted of a semi-structured interview. Interviews lasted between approximately 30 minutes to 1 hour and 15 minutes, with the average interview lasting approximately 50 minutes. Interviewing was chosen as the method of data collection to form an in-depth understanding of PWA's experiences accessing businesses in their communities, including what factors restrict and facilitate their access. Interview questions primarily focused on gaining insight into external factors related to communication access, such as environmental supports and communicative behaviours of conversation partners. All interviews were guided by the same series of questions, shown in Table 3:

Table 3

Interview Ouestion Guide

	Guiding Questions	Optional Probes	
1.	Tell us about your aphasia.		
2.	What places do you go to in Edmonton?	a. Are these places that you go to by yourselfb. Where do you go by yourself?	?
3.	What businesses do you go to often?	a. Are these places that you go to by yourselfb. Where do you go by yourself?	?
4.	What businesses make you feel safe/competent/comfortable?	a. Can you describe that experience?	
5.	^a Are there any service providers that come to your home?		
6.	Are there any businesses that you use an online website for instead of going in person?	a. Why do you use these online instead of in person?	

- 7. Are there any businesses that you contact over the phone?
- 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?
- 9. If a business wanted some advice on how they could be more aphasia friendly, what would you tell them?
- 10. Are there any specific businesses you would like us to contact during this project?
- 11. Is there anything else you want to share?

^aQuestion 5 was added to the interview guide following P2's interview

Due to the flexible nature of qualitative research, interviews were not bound by this set of questions. Participants' responses to the Assessment for Living with Aphasia (ALA-2; Simmons-Mackie et al., 2014) self-report measure were used to tailor the interview question outline for their interview, and questions were sometimes followed by a series of related questions aimed to gain a deeper understanding of a participant's response; however, potential probing questions were not developed in advance for all questions. Interviews were conducted over the Zoom video conferencing platform, and were audio and video recorded for data collection and transcription purposes. Video recording was required to capture the non-verbal aspects of communication often used by PWA to support verbal expression (e.g., gestures, facial expressions, writing).

To support communication, pictures and pictographs were used in addition to verbal and written information to illustrate important concepts. These images displayed different business types to support questions 2 through 6, as well as different communication strategies to support questions 7 and 8. Figures 2 and 3 below demonstrate examples of the pictures and pictographs that were included.

a. Is there anything that makes talking on the phone easier?



Figure 2. Visual supports depicting various business and services



Figure 3. Visual supports depicting supportive communication strategies

Analysis

Interview transcripts were thematically analyzed to identify key themes related to the research question. Thematic analysis was conducted using a constructivist approach, where themes were investigated within and related back to the social contexts in which they emerged (Braun & Clarke, 2006). That is, important concepts such as communication access and social inclusion were front of mind when interpreting interviews. Each transcript was independently co-coded by two researchers involved in the project (Padgett, 2014): the author (primary investigator) and an additional researcher or research assistant. Prior to organizing codes into themes, quotes representing key ideas from 6 interviews were presented to the project's stakeholders with aphasia. Stakeholders shared their interpretations of the passages, and provided guidance for thematic analysis going forward - mainly offering perspective into motivations of participants, and highlighting situations where there may have been misunderstandings between interviewers and participants. Advice from stakeholders was carefully considered in further analysis. Codes were then compiled into key themes based on their relevance to communication

facilitators and barriers. Themes were identified at the semantic level and explained at the latent level. A semantic approach uses explicit information given by participants to organize and summarize patterns in the data, and a latent approach endeavors to theorize the broader implications of the data (Braun & Clarke, 2006). Therefore, after identifying themes semantically, data was analyzed using a latent approach to help relate the information provided to the concepts of social inclusion and life-participation for PWA.

Trustworthiness

Establishing quality varies greatly between qualitative and quantitative research, and varies greatly within qualitative research itself. The traditional validity, generalizability, and reliability used in quantitative research does not necessarily fit into qualitative frameworks. To ensure quality of the present study, process validity, outcome validity, and dialogical validity were considered during data collection and analysis (Ozanne & Saatcioglu, 2008). *Process validity*, which encourages continued reflection and improvement on data collection and analysis, was established in this study by having stakeholders involved in multiple stages of the research. Considering multiple perspectives throughout analysis results in the production of higher quality data.

Including stakeholders in the research process also speaks to considerations of *outcome validity*, whereby research should contribute to the resolution of the problem in question and stakeholder perspectives should advise these solutions (Ozanne & Saatcioglu, 2008).

Dialogical validity requires researchers to challenge any assumptions and biases affecting research findings. Given that qualitative research is significantly guided by the theoretical positioning of those conducting it, it is critical to welcome discussion and reflection into the process of analyzing and interpreting research findings. To establish this in the present research,

16

codes and themes gleaned from the interviews were discussed with stakeholders and researchers who are part of the Aphasia Research Lab in the Department of Communication Sciences and Disorders at the University of Alberta. Each interview was coded by two researchers. Differing codes were then discussed, and researchers came to a common resolution of how each passage in question should be coded. Themes identified by the primary investigator were discussed with both researchers and stakeholders to clarify if the interpretations made could be corroborated. The participation of people with aphasia in these discussions was invaluable, as their perspectives helped to identify if incorrect assumptions were made based on researcher ignorance, biases, or leading questions. The perspectives they provided on a subset of the data analyzed was applied to analysis of all the data to ensure researchers were capturing the experiences of PWA as accurately as possible.

Results

From the nine interviews analyzed in this study, four primary themes emerged as barriers and facilitators to communication accessibility: 1) utilizing communication strategies, 2) adapting communication, 3) aphasia-specific education, and 4) respect for PWA. Table 4 below summarizes the codes extracted from the interviews relevant to the emerging themes, in the context of barriers and facilitators surrounding communication access. N refers to the number of codes associated with a particular theme, and n denotes the number of times a specific code was used.

Table 4

Codes and themes relevant to external communication barriers and facilitators

Theme	Barrier Codes	Facilitator Codes
Communication Strategy Use	Only auditory info (<i>n</i> = 1)	Slowing down helps ($n = 21$) Repetition is helpful ($n = 17$)

(N = 67)		Writing helps understanding $(n = 12)$ Giving time is helpful $(n = 9)$ Being able to point helps $(n = 2)$ Simpler language is helpful $(n = 2)$ Gestures help understanding $(n = 1)$ Pictures and drawing $(n = 1)$ Quiet spaces to reduce pressure $(n = 1)$ Verifying understanding $(n = 1)$
Adapting Communication (N = 22)	Communication is a two-way street $(n = 1)$ Communication partner not responding to request $(n = 1)$ Ignoring bid for communication $(n = 1)$	Ability to adapt communication $(n = 9)$ Flexible communication $(n = 6)$ Adapting communication $(n = 3)$ Communication is supported $(n = 1)$
Respect for PWA (N = 31)	Lack of communication partner effort $(n = 3)$ Negative attitudes $(n = 3)$ Ignoring PWA $(n = 2)$ Impatience makes communication difficult (n = 2) Lack of communication partner patience (n = 2) Assuming incompetence $(n = 1)$ Condescending communication partners (n = 1) Defaulting to care partners $(n = 1)$ Lack of respect $(n = 1)$ Negative attitudes make communication harder $(n = 1)$ Younger people don't care $(n = 1)$	Treating me like normal $(n = 4)$ Attitudes impacts interactions $(n = 2)$ Being treated with respect $(n = 1)$ Encourage to communicate $(n = 1)$ Older people more considerate $(n = 1)$ Patience helps communication $(n = 1)$ People want to understand $(n = 1)$ Positive attitudes help communication (n = 1) Taking the time $(n = 1)$
Aphasia Education (N = 27)	Lack of understanding of aphasia $(n = 3)$ Don't know about aphasia $(n = 2)$ Businesses are not educated $(n = 1)$ Lack of education leads to reduced participation $(n = 1)$	Aphasia education is important $(n = 11)$ Everyone with aphasia is different $(n = 3)$ People read aphasia card $(n = 2)$ Aphasia pin is helpful $(n = 1)$ Asking what accommodations are necessary (n = 1) Comfort with supporting communication (n = 1) Reducing stigma $(n = 1)$

Theme 1: Communication Strategy Use

Across the nine participants in this study, PWA identified eight communication partner

strategies such as speaking slowly, repeating oneself, giving PWA more time to respond,

verifying understanding, simplifying language, and supporting speech with additional

communication strategies including writing, drawing, sharing pictures, and using gestures. These

strategies were mentioned by participants 67 distinct times throughout the interviews. Additional suggested approaches included pre-prepared supports for those with communication challenges. These included menus with images of each item available, a quiet space to complete paperwork, as well as adjustments an employee/provider could make to their communication during a conversation while interacting with PWA. Many of the strategies discussed applied to both in-person and telephone-based business interactions.

Slowing Down Speech

Seven participants offered that slowing down speech was a strategy to support their business and service interactions (n = 21). In response to the question "if a business wanted some advice on how they could be more aphasia friendly, what would you tell them?," P5 responded "uh slow down…uh the-but-the slow down, sip it – give it time." P6 also offered slowing down as a helpful strategy:

I: If you could think of a time that a business had made you feel safe and competent and comfortable?

- P: Oh, yeah!
- I: Why do you think that is?
- P: Yeah! [written note slow down]
- I: So they slow down?
- P: Yeah.

Participants mentioned conversation partners slowing down their speaking in a variety of different business contexts. These included both in-person business interactions and business conducted over the phone, such as conducting banking transactions and contacting internet providers. Many participants explicitly mentioned that they would ask a communication partner

to slow down if they were having difficulty understanding them. P3 described this when he shared "I said – I told him that uh 'can you slow down?,' and he did. He sound perfect," in regards to a phone conversation. Additionally, it was facilitative when a communication partner realized that the PWA was not understanding and would slow down spontaneously. A quote from P2's interview demonstrates this:

I: The times that you have gone to the bank in-person and you might be a little frustrated with not being able to remember some of the numbers, what have the employees' responses been to that?

P: Um slows down, and just speak. That's it. That was it.

Repetition

Three participants (n=17) discussed that having communication partners repeat their message can support business interactions. In response to a question on how businesses could be more aphasia friendly, P4 shared "I always say you 'can you repeat,' yeah so maybe it's to repeat a lot." For P3, repetition of specific words was helpful; he emphasized that if he requested repetition and someone rephrased their message in response to that request, this was a detriment to the interaction:

I have a hard time to understand what you have to say and um I'd say, 'can you just say one word?,' you know. And they - they always tell me an entire new word about it, and I thought 'oh god at all I'm wanting, all I need to hear is one word, because I have a hard time with it' ...that um screws that up when they - they tell me another - another type of word to tell me.

Participants highlighted that repetition is especially facilitative when paired with the conversation partner slowing down. P3 shared he often tells people "I had a stroke with aphasia,

and you have to slow down for me to repeat." Similarly, P3 shared that "sometimes I have to repeat – repeat – repeat – repeat – and sometimes you have go slow."

Giving Time

Four participants shared that allowing adequate time for understanding and responding is a strategy communication partners can use to improve access to businesses and services (n=9). Participants presented the allowance of more time in two different ways. First, a communication partner could leave more time between utterances for a PWA to respond during a conversation. In response to a question about what an employee could have done to help in a stressful interaction, P2 said "just take time right. Just let me think right." An alternative take on this strategy was leaving more time for an interaction overall. For example, this could be seen in a longer appointment time being offered with a doctor or at a bank. This idea is represented in a quote from P6:

I: And would you agree with that, [name], that it's more of a time issue rather than a skills issue?

P: Yeah.

•••

P: Yes. [note – 20 mins, yes]

I: So, ten minutes, not enough time; twenty minutes is enough time.

P: Right.

A quote from P9 also supports this idea:

Yeah, so it's just like they had all these forms and stuff, and I was just having a hard time filling them out. I was just going blank, and then I feel pressure 'cause there's people behind me...the more pressure you feel, the harder it is for me to get it out, so just

wishing that businesses, especially when there's lots of forms to sign, even just saying, like, 'Would you like a little bit of extra time?'.

Verifying Understanding

One participant, P9, described how verifying understanding is a strategy used by employees at a pharmacy she frequents (n = 1). This followed a negative experience she shared about interacting with employees at a previous pharmacy. The interviewer asked if there were specific communication strategies used by employees at the participant's new pharmacy that made the interactions more positive. Her perspective is represented below:

Not– no, not specific strategies. I think it's more just they'll ask the question first – like 'Do you want me to go over this with you? Do you under – so, have you take' – you know, how they go through that spiel? But I feel like sometimes if they – they just – I get flustered like I am now – like I can't find my words, and it's – they just – they just guide me through it.

Simplifying Language

Two participants discussed that the use of simplified language would improve their communicative access to businesses and services (n = 2). Simplifying messages includes the use of common vocabulary and reducing the complexity and length of sentences. Deconstructing a message into smaller parts and rephrasing complex vocabulary can be facilitative for business access. P1 describes how "they-they-they-they use lots of words…and you may want people to work at, you better get some words that people can use." P9 also shared that "even using laymans – I don't know if I'm saying that right – ter – lay-man's terms" would support communication.

Writing

Six participants shared that writing improved their understanding in business interactions (n = 12). Multimodal communication can be supportive for people with aphasia, for both understanding (getting the message *in*) and expressing (getting the message *out*). Producing a message both verbally and in writing facilitates understanding. As well, PWA can use writing as a strategy to get their message out or they can use written materials to make choices by pointing. Written support takes different forms. Menus and signage are a commonplace example of written supports in a business setting. Participants described how menus provide an alternative to spoken communication. If speaking is difficult, PWA who are able to read can simply point to what they want on a menu. From the interviews, it was clear that participants were commonly comfortable at restaurants, as P1 shared:

I: Were there things at the restaurant that made it easier or harder for you to order your food yourself?

P: Nothing harder. Everything was good. Eh that I- because I-I could look and see the words and I-I read the words perfectly and everything else. And everything. I just can't say it out loud.

Although, communication breakdowns in restaurants did occur. This was due to a lack of written support, such as a server listing the daily specials that were not written on the menu, as was the case for P3:

P: Um well, last night, what I did I uh just uh I know she was- she did talk s- the same place she didn't slow down at all, she's very nice though she did repeat herself and you know a couple of times, but I just uh think well okay I -I know what I want on the uh menu um so I can't I have no idea what she said, like you know she usually says uh you know there's. A few things that she says it's on...

I: Like on special?

P: Yeah on yeah, that's right yeah exactly, and uh so I just kinda ignored it because she did tell me a couple times, but I had a hard time to understand.

Another form of writing that can also be used by businesses and services to support understanding includes summarizing key information in writing or providing documents for PWA to review without time constraints are facilitators to access. This is highlighted in the following quote from P3:

Uh for the money stuff, um I do have a harder and harder to understand, but uh there's alsomebody always either me or somebody's written it down uh cause I'm making sure I didn't say like uh '10,000' instead of '1000' or something.

P9 had a similar experience, where writing helped to eliminate any miscommunications:

We had a guy who was coming to do a quote...and he said, 'You know what, why don't – do you want me to just write this all off for you – like this is what I want to do; this is what I'm doing, and have it all on paper?'... it was so helpful 'cause then he did the information, it was there, and then I don't have that pressure of trying to like – be like – or screwing – or making a mistake, I really appreciated that.

Use of Imagery

Three participants shared that using pictures or drawings is helpful to support communication (n = 3). Like writing, pictures can be supportive for understanding and expression. As P9 highlights, this is especially true for PWA who have difficulty reading:

P: ... a basic little menu or, like, something that they can even just show, and be like,'This – would you like this? Is it a beverage?...

•••

I: So something like a menu card where people could just point. Would it be helpful to have that in pictures, in writing? ... what do you kinda picture?

P: ... I think picture would be better because a big part of aphasia can be reading... In P3's case, he has "always tried using everything to make somebody understand" him, and drawing pictures is no exception.

Using Gestures

One participant, P2, shared that she finds gestures supportive during business interactions (n = 1):

I: So there's like slowing down which you've mentioned quite a bit, um things like writing or gestures –

P: Gestures, yeah.

I: Are these helpful? Would you tell someone that using these when you're talking to them would be helpful?

P: Yes... oh yes.

Gestures are often naturally integrated into our conversation style, and they can help provide clarification, context, and emphasis to what we are saying. The gestures that are facilitative for people with aphasia are generally *iconic* gestures, such as holding up fingers for numbers or throwing your hand behind your shoulder when referring to things in the past. These types of gestures carry more language content to aid in comprehension.

Theme 2: Adapting Communication

Seven participants discussed the need for communication partners to adapt their communication (n = 18). Passages were coded into this theme if the PWA advocated to have an employee at a business adapt their communication in some way (e.g., asking them to slow down) or if the employee sensed the person with aphasia needed additional support during the conversation. The quote from P7 demonstrates an instance where his alternative form of communication (use of an iPad text-to-talk app) was ignored by employees at a hardware store:

I: Um hmm. How do people react to you using your iPad?

P: Yeah – no. [shake head, no]

I: Not so well? Do they just not pay attention to it, or do they ignore you?

P: Yeah - no - ignore me - yeah. Ugh. [shakes head, no, gestures as if brush off]

I: Right, so they kinda just brush you off sort of?

P: Yeah.

In contrast, P8 describes how employees at a recreation center that she frequents respond well to her request for adapting communication (i.e., slowing down and repeating themselves):

I: Okay. When you used to go to the gym or the rec centre, did you speak with people, often, when you went?

P: (laughs) Um – okay, I think – yes [nods], but no – not – not words, and people know me – I'm problem with my speech, so – so they – but I know [participant's name], 'Oh, hi, hi', but – and sometimes, if I question, I have to just say – I have to, 'Please, slow', so every – not everybody – but some people slow – yeah – slow what [participant's name] about.

I: Um hmm. So, did you find that the people who worked there were pretty good at speaking with you?

P: You know, they're okay. People, if know – I told them – 'Sorry, I have a speech – speech – or aphasia.' Some people – not every – know what aphasia. Some people know what aphasia – and some people, I dunno, I guess, but, and sometimes they said, 'Yeah, stroke, oh, you had stroke, okay', too, yeah.

I: Um hmm, but they usually responded quite well when you would ask them to, like, slow down or to repeat themselves or something like that?

P: Yeah, if – if you told them who – that you have a problem, they – they try, yes [nods].This quote from P9's interview highlights how it is facilitative when employees recognize if aPWA is struggling and adjusts their communication to provide additional support:

I: Have you been to a specific business that has made you feel, like, especially safe or competent or comfortable?

P: ...I was trying to help my nephew 'cause he's eighteen and doesn't know how to insure a car, and he's moving out, and just those sort of things, and we were – I was trying to understand how it worked when you get a car...there was an employee who – like, 'cause I'll cover things up with humour or wit or being sarcastic – and he sensed that – that I was having a hard time...and he didn't make me feel stupid, and he – he changed it – tailored it for – for me..and he did it in such a way that I didn't feel embarrassed that I didn't understand, and he kinda – he went a little bit above to help me, so I could still do it and understand.

P1 expressed that he did not believe that employees would adapt their communication, even when asked:

27

I: ...is there anything like that, that you have found businesses to do that's really helpful?P: Uh ... Not really. Because, um no, no-not for me. Unless, unless you got somebodyfrom who knows you and knows what you have will they sh-slow down and will they sp-spread out the lines...that only works in people like that. But uh most people they don't.I: Would you like for more people to use those strategies?

P: No, because they won't, th-they won't.

Theme 3: Aphasia Education

The notion of aphasia education and awareness was discussed by eight participants, who identified lack of knowledge of aphasia as a predominant barrier to communication accessibility in their communities (n = 27). P9 shared "a basic thing that businesses don't seem to even know what aphasia is. There's no signs; there's no - even if I told them, I don't think they'd even know what that means."

Participants reflected on their knowledge of aphasia prior to having a stroke. P7 admitted that prior to his stroke, he was also not familiar with aphasia:

- I: When you tell people that you have aphasia, do they know what you're talking about?
- P: Yes and no. [shakes head, no]
- I: Not so much?
- P: Not so much.
- I: ...so do you think it would be helpful if more
- people knew about aphasia?
- P: Stroke before no me no.

I: Mhmm, you didn't know before your stroke. Right, so that education piece would be a good thing?
P: Yes.

An important aspect of education that was identified by several participants was that every person with aphasia is different. Different people have different strengths and challenges, and require different supports for communication. P1 highlighted this:

Some people...people that have brain, and people that don't have a brain...we have some people who have no words, cannot serve a word, but I can tell, just tell, by their head that they're smart...but you - you go oh okay she just doesn't have a voice. So it - it - it's different but everybody thinks it's the same and it's not. Everybody is a little bit different.

Theme 4: Respect

Seven participants (n = 31) discussed interactions where the amount of respect shown to them facilitated or established a barrier to their business and service access. This theme was established to include codes that were in reference to the attitudes or behaviours of communication partners, such as a communication partner rolling their eyes, speaking in a condescending tone, or treating PWA differently than they would someone without a communication impairment. This theme is captured in this quote from P1's interview:

P: Yeah, I got I got one with that with the proper d-d-this guy has got blah, blah, blah, and such and such. And um I never pull it [aphasia card] 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. And 'he is she me? I-I- I'm figuring to come back up to everybody else.

I: Right. Are you saying that you prefer to be treated as just an individual rather than a person with aphasia?

P: Yes, I would.

P2 discussed issues and experiences related to the theme of respect at 11 occasions. It was discussed in a variety of different contexts, such as being ignored during business interactions and interacting with a condescending doctor. This participant's perspectives are quite unique, as they were not only informed by her personal experiences living with aphasia, but also by her role as a care partner for a family member with aphasia. Therefore, she has both the lived experience of a person with communication challenges and the experience of supporting someone with aphasia. An example of this experience is captured below:

I: How do you feel that people interact with him?...

P: Ooo [with emphasis] I remember one time he was - um - some - um - someone was speaking to him but it's - especially because of me- because my [family member] is just sitting there and I said...there's my [family member] talk to him [gesturing forward]

P: Yeah just like really guys? Come on.

Here, the P2 is discussing her personal experience renewing her mortgage:

P: She treated me like um garbage um she's not um explaining to me uh uh explaining to my um...mother or wh-whoever who was with me, um just uh I was there.

I: Right, she treated you like you didn't exist.

P: Yep yep. Oh yes I hated that, oh my god!

P6 participant shared that the age of her communication partner seemed to impact the respect she was shown, with older communication partners facilitating more positive interactions:

I: ... is there anything that you wish that maybe some younger employees would do when you're trying to talk to them?

P: Hmm, ahh (LP), ahh, wee, ahh, yeah, yeah. [rolls eyes]

I: You mean, like, don't roll your eyes?

P: Yeah. [nods]

•••

I: So, it comes back to that attitude piece, hey?

P: Yes.

As well, P7 mentioned that generally women showed greater respect for him during business interactions than men:

P: Woman – good – a little bit – man – ahhh, yeaaah [tilts head side to side].

•••

I: You do notice a difference between men and women sometimes?

P: Yes, yeah. [nods head, yes]

I: ...do you just find that women are, like, more patient or understanding or -?

P: Patient. [nods, yes]

I: Um hmm, right.

P: And, men, ahhh – [shakes head, no]

I: Right, sometimes they just kind of want to move on?

P: Move on.

Discussion

External factors impact PWA's ability to access business and services in their communities, and can either impede or support social inclusion and life participation. This study aimed to answer two questions: 1) what do PWA perceive to be *barriers* to communication accessibility in business interactions and 2) what do PWA perceive to be *facilitators* to communication

accessibility in business interactions. Through thematic analysis of interviews with nine people with aphasia, four primary themes emerged that impacted PWA's experiences accessing business and services in their communities: 1) communication strategy use, 2) adapting communication, 3) aphasia education, and 4) respect for PWA. Participants largely discussed communication strategies and aphasia education as facilitators in positive business interactions. Conversely, the theme of respect was frequently discussed in negative experiences, where communication partners demonstrated a lack of respect for people with aphasia. Incidentally, barriers and facilitators were somewhat inextricable. Much like how a wheelchair ramp supports someone with physical limitations and the absence of that ramp is a barrier to accessibility, communication ramps facilitate access to businesses and services for PWA while the absence of those ramps acts as a communication barrier.

Strategies for Communication Partners

Using tangible strategies to support communication was the most commonly identified facilitator to communication accessibility from the perspective of people with aphasia. The three strategies that were discussed by the most participants were slowing down speech, giving them time during interactions, and using written supports to facilitate understanding. A strategy as simple as slowing down speech rate gives PWA more time to process what is being said to them and allows them to make important connections to what they are hearing and their knowledge of language. Giving time is a helpful strategy, as processing language for people with aphasia is effortful; understanding and producing language takes time. This is especially evident when alternative forms of communication are used such as writing a message or using an iPad to produce speech. In an analysis of 10 eight to twelve minute conversations by people with mild to moderate aphasia and their conversation partners, Leaman and Archer (2021) found 313 effortful

utterances. These were instances where people with aphasia commented on having difficulty, such as mentioning they were having trouble finding a word. In this study, which included participants with mild to severe aphasia, participants shared that demonstrating patience and allowing them time during business and service interactions reduced stress and feelings of embarrassment.

Many strategies identified by the participants in this study align with the SCA recommendations developed by the Aphasia Institute (2015), which include spoken and written keywords, body language and gestures, hand drawings, and pictographs. This adds ecological validity to the body of research supporting SCA strategies, as it demonstrates that people with aphasia find the use of communication partner strategies actually supportive to communication. Presently research has largely focused on measurable outcomes of SCA in interactions (e.g., PWA being perceived as more competent), as opposed to the first person perspectives of PWA about the benefit of strategy use. Based on reports from PWA in this study, slowing down speech rate, repetition, and giving PWA more time to respond should be considered when making recommendations for how to best support communication. These strategies could be easily incorporated into any conversation, as they do not require special skill or additional resources. Implementing these supportive communication strategies in conversation is a simple way to help improve communication accessibility - especially considering that PWA will frequently advocate for this during conversation, as reported by participants in this study.

Unlike slowing down, repetition, and allowing more time during interactions, other strategies suggested by participants in this study would require businesses and services to create additional resources to provide communication support for PWA. As demonstrated by participants' generally positive experiences going to restaurants, where menus offer written and

picture support for communication, it would additionally be facilitative for businesses to use written language in conjunction with speech as a support for comprehension and to have pictures available so PWA can make choices by pointing if they are experiencing word-finding difficulties and if they are having trouble speaking.

Self-Advocacy and Adapting Communication

As illustrated in the A-FROM, the experience of living with aphasia includes both personal and environmental factors. As an adaptation to their new reality, people with aphasia become advocates for their communication needs. This may include disclosing the story of their brain injury and their experience of living with aphasia, as well as asking communication partners to make adaptations during their interactions (i.e. use of the strategies discussed above). This self-advocacy would be considered a personal factor according to the A-FROM, and thus not a primary focus of this study. However, all nine participants described incidents of selfadvocacy when discussing their experiences accessing businesses and services in their communities. The prevalence of self-advocacy as a communication facilitator confirms Taylor and colleagues (2020) findings on social inclusion, where facilitators to inclusion were largely factors internal to the person with the communication impairment. This self-advocacy certainly benefits PWA's communicative interactions. However, as Taylor et al. highlighted, communication is a two-way street. As such, any advocacy behaviour has to be met with a communication partner willing to adapt their communication - a theme that was highlighted by participants in this study.

P1's interview provided interesting insight into the topic of communication partners adapting communication. He was hesitant to provide any suggestions for how businesses could support his communication, frequently asserting that he was responsible for his own

communication. Even when explicitly asked if certain strategies may be helpful in a business interaction, P1 was adamant that people would not be willing to adjust their communication so it was his responsibility to adapt. This participant's response is likely influenced in part by a strong sense of personal responsibility and independence. However, Taylor et al. (2020) highlighted that communication partners believe people with communication impairments to be primarily responsible for successful communicative interactions. As such, P1 may have internalized this attitude. P4 was also hesitant to provide suggestions for how communication partners could support his communication in business interactions. Similarly to P1, he placed a great deal of personal responsibility on the success of a conversation.

Respect

This theme was primarily born out of analysis of discussions surrounding negative business experiences. When participants were asked to describe a negative business experience, they often mentioned the attitude of the employee they encountered. Although it may seem relatively obvious that respect facilitates positive interactions, the sheer number of different ways respect was discussed during interviews should highlight the importance of respect in communicative interactions. As was clear in P2's interview, if a communication partner were to do anything during a business interaction to support communication and facilitate feelings of competence and inclusion, treating a PWA with respect is imperative. In Worrall et al.'s (2011) investigation into the goals of PWA, 'respect and dignity' was identified as one of nine primary goals. Interacting with disrespectful or condescending communication partners does not serve to acknowledge the competence and autonomy that PWA have despite their communication challenges.

Importance of Aphasia Education

Participants in this study shared that knowledge of aphasia is a facilitator to

communication access, confirming Parr's (2007) conclusions that aphasia education for people who interact with PWA is necessary to support communication access and inclusion. Participants also shared that poor support for communication is likely due to lack of knowledge of aphasia on the part of businesses and service providers. This lack of public knowledge of aphasia has been highlighted in the literature. In Ontario, a survey analyzing public knowledge of aphasia determined only 5.7% of respondents had basic knowledge of aphasia. That is, they could identify brain damage as the primary cause and they were able to identify that the hallmark characteristics of aphasia were related to difficulty with speech, language, or communication (Patterson et al., 2015). Public knowledge of aphasia greatly differs from other comparable neurologically based communication disorders, such as communication impairments related to Parkinson's disease (PD). While a specific estimate is not available, according to Parkinson Canada (2022), over 100,000 Canadians are living with PD. This is slightly less than the prevalence of aphasia, which affects 137,700 Canadians (Simmons-Mackie, 2018). Respondents to a survey done in the United Kingdom demonstrated that they knew significantly less about aphasia as compared to PD in terms of merely hearing of the condition, its definition, cause, and common symptoms (Flynn et al., 2009). This should highlight even more the importance of aphasia education, as aphasia is *more* prevalent than PD but *less* understood by the general public. By extension, if employees at businesses and services are not informed about aphasia, how can they be equipped to support the communication of customers and clients with aphasia? Education on aphasia, and communication impairments, should consider the areas of importance identified by participants in this study. That is - education should not solely focus on how to recognize when someone has aphasia, but also provide tangible strategies on how to support

communication interactions with people who have communication differences, including aphasia, as this research has endeavored to do. The AFBC has acknowledged the importance of providing strategies and resources as part of aphasia education to businesses; to reflect this, their educational content has incorporated aspects of the Aphasia Institute's supported conversation training program (Borsatto, Buchanan, & Pineault, 2021). The strategies to support communication suggested in this study can support communication as a whole, therefore impacting the experiences of a large population of individuals with communication differences, not just PWA. Other populations that could benefit from the outcomes of this research include second language learners, aging populations, and those with other communication impairments.

Limitations

This study was conducted with certain limitations. Nine participants with aphasia were selected to reflect the diversity of experiences and communication styles of people with aphasia. However, each participant could only speak on their perspectives of communication accessibility and the results of this study cannot be generalized to all people with aphasia. As well, due to the fact that our participants have a communication impairment that affects their expressive and receptive language it was difficult to obtain exact word-for-word quotes from some participants. A strategy to support communication is verifying understanding, and in verifying this understanding it was possible that participants agreed with statements even if they did not precisely reflect their experiences. To mitigate the possibility of misinterpretation, we discussed analysis with stakeholders to help identify possible leading questions and comments.

This study was conducted during the Covid-19 pandemic. As such, many participants did not have a wealth of recent experiences accessing businesses and services. We asked participants to think back to experiences prior to the start of the pandemic, which may have resulted in less

detailed accounts of business interactions. We adapted the inclusion criteria of our study from 6 months post-stroke to 2 years post-stroke to ensure that participants had pre-Covid experience of living with aphasia.

Stakeholder participation was an invaluable component of this research. However, due to the time limitations of a master's level thesis, the amount of collaboration possible with stakeholders was limited. Having stakeholders involved in analysis of all nine interviews would have resulted in even greater assurance that the perspectives of participants were being accurately analyzed and described. As well, future stakeholder engaged research with aphasic populations could consider including participants as stakeholders, where analysis of results is brought back to participants to ensure the accuracy of interpretations made. This could reduce the amount of researcher bias impacting the research findings.

Future Directions

Interview analysis revealed some additional interesting perspectives that were not specifically related to the research questions of this project and therefore not investigated during this project. In particular, personal factors such as internalized negative attitudes surrounding communication impairments could provide some insight into how to best support the social inclusion of PWA. As well, research has shown that communication partners act as though people with communication impairments are primarily responsible for successful business and service interactions (Taylor et al., 2020). Results from the current study suggest that some PWA may also hold this belief. Currently, there is research being conducted with a subset of the participants from this study that focuses on personal factors acting as barriers and facilitators to access. Outcomes from that research project will complement the results of this study to build a

more complete picture of how to support communication accessibility and the social inclusion of PWA.

To enact real change for PWA and those with other communication challenges, the importance of improving communication access needs to be recognized by business owners/service providers and policy makers. Therefore, future research investigating the benefits of improved communication access at a structural level may be beneficial to create buy-in from these additional stakeholders. Potentially, improving communication access may have some economic benefit by reducing the need for social assistance and therefore reducing government spending in this area. Many of our participants discussed business and service interactions they were unable to conduct themselves (e.g., renewing mortgages, conducting banking transactions, medical appointments). Supporting communication in these contexts will support the independence of individuals with communication disorders and reduce the reliance on both formal (e.g., home-care providers) and informal (e.g., family members) caregivers. It has always been the intention that future research stemming from this study will incorporate business owners and service providers as stakeholders. However, additional research into the specific economic and social benefits of improved communication access may also be necessary to mobilize change in the business sector.

Conclusion

Communication accessibility contributes to the social inclusion of some 137,700 Canadians living with aphasia. Interpersonal factors, an aspect of the communication environment according to the A-FROM, can be both enabling and disabling to inclusion. This study employed the method of qualitative, stakeholder engaged research to investigate what aspects of interpersonal business and service interactions are facilitators to communication accessibility and

what aspects are barriers to communication accessibility. Nine participants with aphasia were interviewed about their experiences accessing businesses and services in their communities. This research revealed the priorities of people with aphasia in improving communication access. Participants suggested that greater knowledge of what aphasia is, implementation of supportive communication strategies, the willingness to incorporate these strategies into business interactions, and an overall greater respect and understanding for those with communication impairments will contribute to positive business interactions.

Ultimately, gaining insight into what factors impact business interactions for PWA is the first step to improving communication accessibility in their communities. The purpose of this research was to begin the development of actionable steps businesses can take to improve their service to those with communication impairments. Future projects stemming from this research should be used to develop a report for local businesses providing recommendations on ways to improve communication accessibility, as well as a promotion of resources available for enhancing accessibility, such as those included in the CAN and the AFBC. Western Canada currently lacks initiatives that involve businesses and services in making communication access for individuals with communication impairments is integral to their well-being. Communication barriers are tightly tied to the concept of social exclusion and building communication ramps in the community supports the societal inclusion, and therefore happiness, mental health, and wellbeing of individuals with communication disorders.

References

Aphasia Friendly Canada. (2012). Aphasia Friendly Canada. https://aphasiafriendlycanada.ca/ Aphasia Institute. (2015). Communication tools: Communicative access & supported conversation for adults with aphasia (SCA). <u>https://www.aphasia.ca/communication-</u> tools-communicative-access-sca/.

American Speech-Language-Hearing Association (n.d.). *Aphasia* (Practice Portal). <u>https://www.asha.org/Practice-Portal/Clinical-Topics/Aphasia/</u>.

- Borsatto, J., Buchanan, L., & Pineault, L. (2021). Aphasia friendly Canada: The aphasia friendly business campaign. *Aphasiology*, 1-20.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.
- Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons Mackie, N. (2000). Life participation approach to aphasia: A statement of values for the future. *The ASHA Leader*, 5(3), 4-6.
- Collier, B., Blackstone, S. W., & Taylor, A. (2012). Communication Access to Businesses and Organizations for People with Complex Communication Needs. *Augmentative and Alternative Communication*, 205-218.
- Communication Disabilities Access Canada. (2020). *People who have communication disabilities*. <u>https://www.cdacanada.com/resources/communication-disabilities/statistics/</u>
- Denzin, N. & Lincoln, S. (2005). Introduction: The discipline and practice of qualitative research. In *Handbook of qualitative research*, (3rd edn), Edited by: Denzin, N.
 K. and Lincoln, Y. S. Thousand Oaks, CA: Sage Publications.

- Deverka, P. A., Lavallee, D. C., Desai, P. J., Esmail, L. C., Ramsey, S. D., Veenstra, D. L., & Tunis, S. R. (2012). Stakeholder participation in comparative effectiveness research: defining a framework for effective engagement. *Journal of comparative effectiveness research*, *1*(2), 181-194.
- Kagan, A. (1999). Supported conversation for adults with aphasia § T § M, methods and evaluation (Doctoral dissertation).
- Kagan, A., Black, S. E., Duchan, J. F., Simmons-Mackie, N., & Square, P. (2001). Training volunteers as conversation partners using "Supported Conversation for Adults with Aphasia" (SCA). *Journal of Speech, Language, and Hearing Research*.
- Leaman, M. & Archer, B. (2021). Linguistic Analysis of Effortful Utterances in Spontaneous Conversations Between People with and Without Aphasia: Form, Content, and Use. *Easy Chair Pre-print*.
- Le Dorze, G., Salois-Bellerose, E., Alepins, M., Croteau, C., & Hallé M. (2013). A description of the personal and environmental determinants of participation several years post-stroke according to the views of people who have aphasia. *Aphasiology*, *28*(4), 421-439.
- Mackie, T. I., Sheldrick, R. C., De Ferranti, S. D., Saunders, T., Rojas, E. G., & Leslie, L. K. (2017). Stakeholders' Perspectives on Stakeholder-engaged Research (SER). *Medical care*, 55(1), 19-30.
- Ozanne, J. L., & Saatcioglu, B. (2008). Participatory action research. *Journal of consumer* research, 35(3), 423-439.

Padgett, D. K. (2011). *Qualitative and mixed methods in public health*. Sage publications.Parkinson Canada. (2022). *Parkinson's Disease*. https://www.parkinson.ca/about-parkinsons/

- Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, 21(1), 98-123.
- Simmons-Mackie, N. (2018). Aphasia in North America. Aphasia Access.
- Simplican, S. C., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in developmental disabilities*, 38, 18-29.
- Solarsh, B., & Johnson, H. (2017). Developing communication access standards to maximize community inclusion for people with communication support needs. *Topics in language disorders*, 52-66.
- Taylor, S., Wilson, E., Murfitt, K., & Balandin, S. (2020). Communication access in the retail environment for people with complex communication needs. *Disability and rehabilitation*, 1-10.
- United Nations. (2006). *Convention on the rights of persons with disabilities*. United nations human rights: Office of the high commissioner.

https://www.ohchr.org/en/hrbodies/crpd/pages/conventionrightspersonswithdisabilities.as px

- Wilson, C. & Kim, E. S. (2021). Qualitative Data Collection: Considerations for People with Aphasia. Aphasiology, 35(3), 314-333.
- Worrall, L., Sherratt, S., Rogers, P., Howe, Tami., Hersh, D., Ferguson, A., & Davidson, B.
 (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, 25(3), 309-322.
- Zoom Video Communications Inc. (2021). Retrieved from: https://zoom.us

Appendix A

Participant Intake Questionnaire

Name of Participant:	Date you are filling this form out:	
Address:	Contact Name:	
Telephone Number:	Contact Relationship: Contact Email Address:	
Email Address:		

Date of Birth:	Age:	Gender: Male Female Transgender Male Transgender Femal Other Not reported	e	
What racial and/or ethnic origins do Indigenous Black Latin/Hispa				Not reported

Primary Language: Other languages spokes (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	If you wear hearing aids – they are worn (in the): Left Ear Right Ear Bilaterally
Diagnosis: Stroke Brain Injury Other	Date of event:(dd/mm/yyyy)
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:	Are you currently participating in speech therapy or treatment? No Yes If yes, please elaborate:
This form was completed by:	

Appendix B



Appendix B. Common Classification of Aphasia. Taken from The American Speech-Language-Hearing Association (n.d).