

Barriers and Facilitators to Communication Accessibility as Perceived by People With Aphasia

Esther S. Kim, Kira Mauriks, Carlee Wilson, Leah Auch, Herman Koo, Daralynn Swensrude, Jessica Laccett, and Andrea Ruelling

Purpose: Communication access is a human right, but many individuals with communication impairments face challenges accessing their environments. As part of a larger study investigating barriers and facilitators to communication access in the retail/service industry, the purpose of the present study was to investigate the experiences of people with aphasia (PWA) accessing goods and services in their communities. **Methods:** Nine PWA were interviewed about their experiences accessing retail businesses and services. Interviews were coded and thematically analyzed to identify key themes related to barriers and facilitators to communication during business interactions. Stakeholders on the research team included two PWA, who provided input throughout the research process. **Results:** Three main themes were found: supporting communication, aphasia awareness and education, and respect for PWA. Codes within each theme comprised facilitators that led to positive experiences and barriers that led to negative business interactions. **Discussion/Conclusions:** People with aphasia identified tangible ways that retail businesses can be made more communicatively accessible. Stakeholders with aphasia made meaningful contributions to the research process. Future work will investigate how these findings, integrated with business perspectives, can be used to support businesses in applying strategies to become more communicatively accessible. **Key words:** *aphasia, communication access, communication impairment, patient partner, qualitative methodology, stakeholder-engaged research, supported communication*

Author Affiliations: Department of Communication Sciences and Disorders, Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Canada (Drs Kim and Wilson and Mss Mauriks, Auch, and Ruelling); Edmonton, Alberta, Canada (Mr Koo and Ms Swensrude); and Media and Technology Studies, Faculty of Arts, University of Alberta, Edmonton, Canada (Dr Laccetti).

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COMMUNICATION is fundamental to participating fully in all aspects of life and is an ability most people take for granted until they are faced with a communication impairment. Aphasia is a communication impairment caused by damage to language regions of the brain and can affect expressive and receptive language abilities in both spoken

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Corresponding Author: Esther S. Kim, PhD, R.SLP, CCC-SLP, 2-70 Corbett Hall, University of Alberta, Edmonton, AB T6G 2G4, Canada (esther.kim@ualberta.ca).

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and written modalities. Approximately 2.6 million people in North America are living with chronic aphasia (Simmons-Mackie, 2018), and may be unable to easily access goods and services in their daily lives due to their communication impairment.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) stipulates the importance of improving “access to different domains of the environment including buildings and roads, transportation, information, and *communication* [italics added]” (World Health Organization, 2011, p. 169). Indeed, inclusion and equal access are core principles within the CRPD, yet most individuals conceptualize accessibility only in terms of physical access (e.g., building ramps for wheelchair users). Although many jurisdictions have enacted human rights and antidiscrimination legislation to enforce principles of inclusion and equal access, implementation is often lacking—particularly when it comes to communication accessibility (Collier et al., 2012). In part, this may be due to a lack of information about the accessibility needs and requirements of individuals with communication impairments, as well as a lack of access to resources and information on how to make environments more communicatively accessible. Although the research literature on communication accessibility is growing (Anglade et al., 2019; Collier et al., 2012; Taylor et al., 2021), an exploration of the barriers and facilitators people with aphasia (PWA) face when accessing retail businesses, using a stakeholder-engaged research (SER) framework, is lacking.

COMMUNICATION ACCESS AND SOCIAL INCLUSION

Communication access refers to having supports and opportunities to communicate “effectively, meaningfully, accurately and authentically in order to get equal uncompromised access to goods and services” (Collier et al., 2012, p. 207). Having policies and structures in place to enforce adherence allows for the social inclusion of people with communication impairments in soci-

ety (Collier et al., 2012; Solarsh & Johnson, 2017). Just as wheelchair ramps help those with physical disabilities to access their environment, the concept of “communication ramps” to help those with communication disabilities access their environment has been used as an analogy to advocate for the social inclusion of individuals with communication needs. Parr (2007) discusses markers of social inclusion/exclusion as being infrastructural (e.g., employment opportunities, housing, and education), personal (e.g., identity, self-esteem, and motivation), and interpersonal (e.g., relationships with others). Both personal and interpersonal factors can be targets for intervention by speech–language pathologists (SLPs); creating enabling conditions at these levels can facilitate an increase in self-esteem, confidence, independence, mental health, and well-being, while also decreasing the stigma, negative attitudes, and discrimination toward individuals with communication impairments.

Addressing personal and interpersonal factors contributing to social inclusion fits within a Life Participation Approach for Aphasia (LPAA) framework. The LPAA is a service delivery philosophy that emphasizes supporting PWA to fully engage and be included in society (Chapey et al., 2000). Interpersonal relationships between PWA and service providers in the community have a great impact on communication accessibility, with behaviors and attitudes of both parties acting as either barriers or facilitators to access. In a study employing naturalistic observation, Davidson et al. (2003) reported PWA spent far less time communicating with services/tradespeople than age-matched individuals without aphasia. They also had significantly more unsuccessful communication interactions than their nonaphasic peers. In part, these unsuccessful exchanges may relate to the behaviors and attitudes/beliefs of service providers. Service providers have been observed to demonstrate problematic behaviors such as patronization and disrespect when communicating with PWA (Parr, 2007). Taylor et al. (2021) noted that, in the retail sector, communication partners

tended to control conversations, leaving people with communication impairments insufficient time to respond, or ignoring them completely.

Although communication is a dyadic activity, where both partners are responsible for the success of the interaction, it seems that people with communication disorders often carry the burden of repairing or preventing communication breakdowns. For instance, self-advocacy skills and personal communication strategies adopted by PWA (e.g., bringing a printed list to a grocery store or using personal signage to ask communication partners to be patient) were facilitative to the communication interaction (Taylor et al., 2021). Businesses participating in Taylor and colleagues' 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 communication disabilities (Brown et al., 2006). Developing viable strategies for increasing social inclusion is important, as staff and employees often do not follow through with support strategies even when there are perceived positive outcomes (Simpligan et al., 2015). Thus, the importance of social inclusion needs to be recognized and prioritized at multiple levels within the community.

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 (Johnson et al., 2016; Solarsh & Johnson, 2017). The CAN considers environmental support as a key component 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 (both 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.

Similar frameworks, specifically designed for improving the community participation of people with communication impairments, have also been spearheaded by various organizations in other jurisdictions (e.g., Communication Disabilities Access Canada, Stroke Association UK, Aphasia Access) in other jurisdictions. However, the CAN project is distinctive in that the perspectives of both people with communication disabilities and business and service providers were integrated to develop concrete strategies for improving communication interactions. In Canada, a recently developed initiative called Aphasia Friendly Canada introduced the Aphasia-Friendly Business Campaign (AFBC), with the goal of helping businesses provide better communication accessibility (Aphasia Friendly Canada, 2012; Borsatto et al., 2022). The AFBC targets environmental factors through aphasia education, including supported communication strategies to enhance service delivery and social interactions. Outcomes of this program include increased public knowledge of aphasia and increased confidence of employees interacting with PWA (Borsatto et al., 2022). The success of programs, such as the CAN and AFBC, 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

To develop meaningful and practical solutions to improving communication access

for people with communication disorders, the priorities and perspectives of people impacted by the research outcomes (i.e., stakeholders) should guide the research. Stakeholder-engaged research methodology acknowledges that including stakeholders in research design, implementation, and dissemination leads to better achievement of desired research outcomes (Mackie et al., 2017). Typically, patients and members of the public come to mind when considering who is a stakeholder, but service providers, policy makers, payers, producers, and investigators can also be stakeholders in Patient Centered Outcomes Research (PCOR) (Concannon et al., 2012). In the field of aphasiology, PWA are increasingly being engaged as research partners to address research gaps of importance to people living with aphasia (Hersh et al., 2021; Hinckley et al., 2014). Indeed, as initiatives such as Project BRIDGE (Hinckley et al., 2019) and the Communication Research Registry (Rose et al., 2020) provide greater awareness, resources and education, the field will increasingly be enriched by the perspectives of PWA as research partners.

CURRENT STUDY

Communication access and social inclusion for individuals with communication disorders rely on enabling conditions at infrastructural, personal, and interpersonal levels. There is a growing body of evidence outlining barriers and facilitators to communication access. However, investigations with PWA as members of the research team using SER frameworks are lacking. The purpose of this study was to examine the experiences of PWA accessing goods and services in their communities. As part of a larger research endeavor aimed at improving social inclusion and communication access, results from this study will be used to provide recommendations and resources for businesses in the Edmonton region. A secondary purpose was to collaborate with individuals with aphasia as research partners in the examination

of barriers and facilitators to communication access. Using the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008) as a guide, this study explored barriers and facilitators to improving communication accessibility within the domain of the Communication and Language Environment as perceived by PWA. Our research questions were as follows:

1. What are barriers to communication accessibility in the business/retail sector as perceived by PWA?
2. What are facilitators to communication accessibility in the business/retail sector as perceived by PWA?

METHODS

This study employed the methodological approach of qualitative, SER. Two stakeholders with aphasia (hereafter referred to as patient partners) were engaged as members of the research team at the participation level (Deverka et al., 2012), indicating that information was exchanged between stakeholders and researchers within an environment of reciprocal learning and shared decision-making. The methodology was informed and selected based on the researchers' constructivist philosophical perspective. Constructivism is a theoretical position that assumes reality depends on perspective and is created through context-specific interactions (Denzin & Lincoln, 2005). The intention was that including multiple PWA's perspectives (i.e., research participants and patient partners) would allow for a more accurate portrayal of the realities of the experiences of those with aphasia accessing goods and services in their communities.

Procedures for engaging patient partners in the research process

Our research team comprised SLPs (E.K. and A.R.), graduate students in Speech-Language Pathology/Rehabilitation Sciences (K.M., C.W., and L.A.), an academic and entrepreneur with expertise in marketing/communications (J.L.), and 2 individuals with

lived experience of aphasia (H.K. and D.S.). Both individuals acquired aphasia as a result of brain injury and had been living with aphasia for 3 and 7 years, respectively, at the time of the study. H.K. was recruited as a patient partner as he had expressed interest in contributing to research and had taken part in training through Project Bridge (Hinckley et al., 2019). D.S. had been actively involved in giving presentations and training to health care workers on communication access, based on her experiences with the health care system. Both individuals lived alone and had many experiences accessing goods and services in their communities as individuals with communication challenges.

Our framework for patient partner inclusions was based on the Canadian Strategy for Patient-Oriented Research (Canadian Institutes of Health Research, 2014), design principles outlined in Boaz et al. (2018) and recommendations by Dalemans et al. (2009). This study was a master's thesis project for K.M., as such, the research questions were determined prior to recruiting our patient partners. An initial meeting with all members of the research team was held to describe the purpose of the study, outline responsibilities/expectations, and hear patient partners' experiences when accessing different retail businesses. Information from this initial meeting was used to refine our methodology and procedures. Subsequent meetings with patient partners where shared decision-making took place on various aspects of the research (recruitment, materials development, interview questions, and data analysis). Agendas and written materials were circulated prior to the meetings and written/picture supports on screen-shared documents were used to support patient partners' communication during the meetings. Five meetings with patient partners took place over the course of the research project; an honorarium was provided for their participation in this research.

Participants

Nine people with aphasia were recruited as research participants for this study through

programs that serve adults with aphasia in the Edmonton area. No restrictions on type or severity of aphasia were placed, but participants were required to be at least 2 years post-onset of aphasia. This requirement was to ensure participants had experiences accessing businesses and services in their communities prior to the start of the COVID-19 pandemic. Purposive recruitment occurred to include a diversity of characteristics related to age, aphasia type, severity, and primary method of communication. See Table 1 for details. Participants received a \$10 gift card for participating in this study. The study received ethics approval from the University of Alberta Health Research Ethics Board.

Data collection

As this study took place during the COVID-19 pandemic, all procedures were conducted remotely using Zoom videoconferencing software (Zoom Video Communications Inc, 2021). Participants took part in two to three virtual sessions; the Western Aphasia Battery Revised (WAB-R; Kertesz, 2007) and the Assessment for Living with Aphasia (ALA-2; Kagan et al., 2011) were completed in the first one to two sessions and a semi-structured interview comprised the final session. Interviews lasted between 30 and 75 min with an average of 50 min. K.M. and L.A., who received training in qualitative methods and clinical assessments with PWA by E.K. and C.W., conducted all of the assessments and interviews. Interview questions focused on gaining an in-depth understanding of PWA's experiences accessing businesses in their communities, including insight into external factors related to communication access (e.g., environmental supports, communication behaviors of communication partners). Interview questions (see Table 2) were tailored to the participant based on responses gleaned from their responses on the ALA-2. For instance, if a participant indicated they frequented a particular type of business during the ALA-2, they would be asked about those experiences, in addition to the general questions in the interview guide. Principles

Table 1. Participant characteristics

Participant	Gender	Race	Age	Highest Level of Education	Years Post-Stroke	WAB AQ	Aphasia Type	Primary Mode of Communication
01	M	White	62	2 years Postsecondary	7	87	Anomic	Speech
02	F	White	51	2-year associate's degree	10	91	Anomic	Speech
03	M	White	52	2-year diploma	7	79	Conduction	Speech
04	M	White	31	Bachelor's degree	11	80	Anomic	Speech
05	M	White	67	GED	9	79	Transcortical motor	Short utterances + descriptive gestures
06	F	White	62	2-year associate's degree	14	55	Broca's	Single words + writing
07	M	White	47	2-year associate's degree	6	56	Broca's	Single words/short phrases + text-to-speech iPad application
08	F	White	61	Bachelor's degree	7	61	Conduction	Speech
09	F	Mixed race	43	2.5 years postsecondary	2	95	None	Speech

Note. F = female; M = male; WAB AQ = Western Aphasia Battery-Revised Aphasia Quotient.

Table 2. Interview 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 yourself? b. Where do you go by yourself?
3. What businesses do you go to often?	a. Are these places that you go to by yourself? b. Where do you go by yourself?
4. What businesses make you feel safe/competent/comfortable?	a. Can you describe that experience?
5. Are there any service providers that come to your home? ^a	
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?	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?	
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.

of qualitative data collection for PWA (Wilson & Kim, 2021) were employed throughout the data collection process, including (but not limited to) providing an aphasia-friendly interview guide beforehand and using supported communication strategies throughout. All interviews were audio and video recorded using the Zoom platform and each interview was transcribed verbatim orthographically, including nonverbal aspects of communication (e.g., gestures, facial expressions, and writing).

Analysis procedures

Reflexive thematic analysis (Braun & Clarke, 2006; 2022) was used to analyze interview transcripts and 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 con-

texts in which they emerged (Ponterotto, 2002). Central concepts (i.e., communication access, social inclusion) were front of mind when interpreting interviews. To meaningfully involve patient partners in data analysis without overwhelming them, the following process was followed for coding interviews:

1. *Initial coding.* Each interview transcript was independently reviewed and coded by K.M. and L.A. (Padgett, 2011). NVivo software (NVivo, 2021) was used for analyses. Initial codes were determined as transcripts were reviewed; initial ideas, codes, and emerging themes were discussed between reviewers.
2. *Patient partner review.* Prior to organizing codes into themes, a sampling of quotes from the first six interviews was presented to patient partners. These materials were provided prior to analysis meetings and read aloud to partners

during the meeting to facilitate comprehension. Partners shared their interpretations of the passages and provided guidance for thematic analysis going forward by offering perspectives into motivations of participants and highlighting situations where there may have been misunderstandings between interviewers and participants. Input from patient partners was integrated into further analyses.

3. *Theming.* Following patient partner meetings, codes were then compiled into key themes based on their relevance to communication facilitators and barriers. After generating themes at the semantic level, data were analyzed using a latent approach to relate back to the concepts of communication access and social inclusion. Themes were then discussed among all members of the research team.

Reflexivity and rigor

As with all qualitative research, it is important to acknowledge how the researchers' perspectives may influence the research process. In this study, the qualitative analyses were supported through the research team members' theoretical sensitivity about communication access and social inclusion for PWA. Team members had varying degrees of experience and perspectives on the difficulties that PWA can encounter when interacting with retailers, ranging from lived experience to clinical and industry-based experience. These perspectives were integrated throughout the process of generating themes from the data.

Lincoln and Guba's (1985) trustworthiness criteria (i.e., credibility, transferability, dependability, and confirmability) served to ensure rigor. To ensure credibility, at least two members of the research team (K.M. and L.A.) were present at all interviews and debriefed with each other following each session. Regular supervisory meetings occurred during data collection and analyses, where relevant interactions were considered

through the research and clinical lenses of the research team members. In addition, incorporating patient partners in coding and thematic analysis contributed to credibility of data. The recruitment of participants with a variety of demographic characteristics increased transferability of results. Dependability was achieved in part by keeping rigorous notes throughout various stages of data collection and analysis. Finally, we aim to provide sufficient detail in this article regarding data analysis to demonstrate the relevance of our results, ensuring their confirmability.

RESULTS

Analysis of the nine interviews generated several codes, which emerged as barriers and facilitators to communication accessibility. These were organized into three main themes: supporting communication, aphasia awareness and education, and respect for PWA. Table 3 summarizes the codes extracted from the interviews that were relevant to the main themes. *N* refers to the number of codes associated with a particular theme, and *n* denotes the number of times a specific code was used.

Supporting communication

The first theme referred to the use (or lack thereof) of specific communication strategies by communication partners that PWA encountered during retail and business transactions. Most codes referenced concrete actions taken by employees (e.g., slowing down, simplifying language), but also related to the environment in which the interaction took place (e.g., having a quiet space to complete paperwork). Seven participants described having to ask communication partners to use a specific strategy, such as repeating themselves speaking slowly or writing something down. These strategies were mentioned by participants 67 distinct times throughout the interviews. For instance, in reference to a phone conversation with a telemarketer, P3 stated, "I said—I told him that uh 'can you slow down?,' and he did.

Table 3. Themes and associated barrier and facilitator codes arising from thematic analysis

Theme	Barrier Codes	Facilitator Codes
Supporting communication (<i>N</i> = 90)	Only auditory info (<i>n</i> = 1) CP not adapting or ignoring bid for communication (<i>n</i> = 3)	Slowing down (<i>n</i> = 21) Repetition (<i>n</i> = 17) Writing helps understanding (<i>n</i> = 12) Giving extra time (<i>n</i> = 9) Alternate modalities (<i>n</i> = 4) Simpler language (<i>n</i> = 2) Quiet spaces to reduce pressure (<i>n</i> = 1) Verifying understanding (<i>n</i> = 1) Adapting communication (<i>n</i> = 19)
Aphasia awareness and education (<i>N</i> = 27)	Lack of understanding of aphasia (<i>n</i> = 5) Lack of education leads to reduced participation (<i>n</i> = 2)	Aphasia education is important (<i>n</i> = 11) Everyone with aphasia is different (<i>n</i> = 3) People read aphasia card/pin (<i>n</i> = 3) Asking what accommodations are necessary (<i>n</i> = 1)
Respect for PWA (<i>n</i> = 31)	Lack of CP effort (<i>n</i> = 3) Negative attitudes or behaviors of CP (<i>n</i> = 6) Ignoring PWA (<i>n</i> = 2) Lack of communication partner patience (<i>n</i> = 4) Assuming incompetence (<i>n</i> = 1) Defaulting to care partners (<i>n</i> = 1) Younger people don't care (<i>n</i> = 1)	Comfort with supporting communication (<i>n</i> = 1) Reducing stigma (<i>n</i> = 1) Treating me like normal (<i>n</i> = 4) Attitudes impact interactions (<i>n</i> = 2) Being treated with respect (<i>n</i> = 2) Older people more considerate (<i>n</i> = 1) Patience helps communication (<i>n</i> = 4)

Note. CP = communication partner; *N* = number of codes associated with theme; *n* = number of times a specific code was used; PWA = people with aphasia.

He sound perfect.” However, when communication partners spontaneously employed a strategy such as writing, this was very much appreciated, as illustrated by this quote from P9’s interview:

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.

Four participants (P2, P3, P5, and P6) shared that allowing adequate time for understanding and responding is a strategy that communication partners can employ to improve interactions ($n = 9$). Participants discussed having more time, in terms of the communication partner leaving more time between utterances so PWA could respond. 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.” Participants also discussed having more time scheduled for an interaction when an individual has aphasia. This notion is represented in this exchange from P6’s interview:

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

P6: Yeah. . . . Yes. [writes down on notepad – 20 mins, yes]

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

P6: Right.

Aphasia awareness and education

The theme of aphasia awareness and education referred to the impact that general aphasia awareness has on social inclusion and communication access. Eight participants identified lack of knowledge of aphasia as the 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.” P3 described how he leads off interactions with disclosing that he has aphasia to gauge the communication partner’s response: “I say uh ‘I had a stroke with aphasia’ and uh I’m waiting I’m waiting to see if they understand the aphasia because most people probably don’t know what it means.” He then described that he would go on to ask people to give him more time, or slow down if didn’t know what aphasia was. P3 described an interaction he had signing up for a gym membership that was facilitated by the employee’s understanding of aphasia:

I told that with the the girl that um I had aphasia with the or stroke with aphasia and she says “okay that’s fine” and so she just slowed us slowed down um and she got me to sign it all out and um . . . there was any problems having a hard time to do it so she did understand that, that I had a problem so she did slow down.

Respect for people with aphasia

The theme of respect for PWA referenced how the attitudes or behaviors of communication partners acted as facilitators or established a barrier to their ability to access the business or service. 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. The communication partners’ willingness to adapt their communication, or being patient, demonstrated inherent respect for the PWA that led to positive interactions. Conversely, barriers included disrespectful behaviors such as the communication partner rolling their eyes, speaking in a condescending tone or treating the PWA differently from those without a communication impairment.

Two participants (P6 and P7) described having different experiences in terms of respect shown to them based on the age or gender of the communication partner. For instance, P6 shared that she had had interactions with younger employees who rolled their eyes or demonstrated other

disrespectful behaviors. P7 described how women generally showed greater respect toward him during business interactions than men:

P7: Woman—good—a little bit—man—ahhh, yeaah [tilts head side to side]. . . .

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

P7: Yes, yeah. [nods head, yes]

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

P7: Patient. [nods, yes]

I: Um hmm, right.

P7: And, men, ahhh . . . [shakes head, no]

Some participants (P1, P2, P6, and P7) referenced communication partners' willingness or lack of willingness to adapt their communication as impacting the success of the interaction, particularly for those using alternative modalities (e.g., text to speech apps and writing). For example, P7 describes an incident of being ignored while at a hardware store:

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

P7: Yeah—no. [shakes head, no]

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

P7: 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?

P7: Yeah.

Outcomes of patient partner engagement in data analysis

Patient partners reviewed quotes selected from participant interviews after initial codes were generated. In many cases, patient partners related the experiences back to similar ones they had encountered and elaborated further on contextual factors. For instance, they agreed that not all interactions required the same degree of communication interaction. Checking out at a grocery store is

more transactional and can be accomplished with minimal communication (Anglade et al., 2019) whereas ordering a meal at a restaurant requires more communication supports. In some cases, patient partners highlighted situations where alternative interpretations to interview segments could be offered and provided constructive feedback related to how a question may have been misunderstood. Finally, patient partners offered perspectives from their lived experiences that were integrated into latent codes and themes presented here. During a particularly poignant discussion of a quote where a participant was advocating for an employee to use communication strategies, D.S. stated, “[PWA] want to feel like a normal person whether [they] have aphasia or not.” This led to a discussion between patient partners about whether it was more important to “feel normal” or “feel heard” because they both admitted that it doesn't feel normal to ask someone to write down keywords even if they know it can facilitate their comprehension.

DISCUSSION

This study aimed to examine what PWA perceived to be barriers and facilitators to communication accessibility in business interactions, and to do so in collaboration with PWA as members of the research team. The focus was on the impact of factors in the communication and language environment on PWA's ability to access business and services in their communities. Through reflexive thematic analysis of interviews with nine PWA, three primary themes emerged related to facilitators and barriers of communication access.

Facilitators of communication access

Using tangible strategies to support communication was the most identified facilitator to communication accessibility from the perspective of PWA. The strategies that were most frequently identified by PWA were a desire for their communication partners to slow down their speech, be patient, use written

supports, and repeat when appropriate. In a recent study by Leaman and Archer (2021), PWA reported reduced stress and fewer feelings of embarrassment when communication partners incorporated some of these strategies during business and service interactions. These strategies, identified by participants as being facilitative, align with principles of Supported Conversation for Aphasia (SCA) (Aphasia Institute, 2015). Many research studies have highlighted the beneficial impact of implementing SCA and other communication partner training programs (Simmons-Mackie et al., 2016); our results add first-person perspectives of PWA on the perceived benefits of strategy use.

Although this study was focused on environmental factors impacting communication access, a salient finding was that PWA frequently advocated for their communication needs when interacting with service providers. For most participants, this involved self-disclosing they had aphasia and asking explicitly for communication supports (e.g., repeating or slowing down). P5 reported always wearing a pin stating that aphasia is a “loss of language, not intellect” whenever he went out into the community and showing it to communication partners when disclosing that he has aphasia. Our results confirming self-advocacy as a communication facilitator align with the literature identifying the impact of personal factors of the PWA on the success of communication interactions (Brown et al., 2006; Taylor et al., 2019, 2021). Certainly, personal factors and self-advocacy can lead to more successful communication interactions, but as highlighted by Taylor et al. (2021), communication is a two-way street. As such, any advocacy behavior must be met with a communication partner willing to adapt their communication, and having the education, resources, and attitudes to do so.

Barriers to communication access

PWA identified lack of respect on the part of the communication partner as a significant barrier to their communication access.

Although it may seem relatively obvious that behaviors demonstrating respect facilitate positive interactions, the sheer number of different ways respect was identified in interviews highlights the importance PWA place on this construct. In Worrall et al.’s (2011) investigation into the goals of PWA, “respect and dignity” was identified as one of nine primary goals. Disrespectful or condescending behaviors do not serve to acknowledge the competence and autonomy that PWA have despite their communication challenges.

In a recent review, Taylor et al. (2019) reviewed research on retail customer service communication with people with complex communication needs and impacts on their social inclusion. The primary environmental factor that impacted communication access identified in their review was the behaviors of customer service employees. Retail service employees in Brown et al.’s (2006) study also discussed negative attitudes as a barrier to communication access but identified lack of awareness of aphasia and misconceptions about intellectual abilities of PWA contributed to these barriers. Indeed, lack of aphasia awareness is not a new issue (Hill et al., 2019; Simmons-Mackie et al., 2002). Many studies have identified the impact that lack of knowledge of aphasia has on communication interactions (Brown et al., 2006; Parr, 2007; Taylor et al., 2019, 2021). With recent celebrity disclosures of aphasia, awareness of this condition seems to be on the rise (National Aphasia Association, 2022). However, access to training and resources in communicating with PWA needs to be made more widely available to translate the impact of greater awareness into tangible outcomes for social inclusion for PWA. Undoubtedly, resources such as the free training modules by the Aphasia Institute (Kagan et al., 2019) and other training programs for businesses (e.g., AFBC, Borsatto et al., 2022) are useful in this regard.

Limitations and future directions

Participants in our study were recruited to reflect a diversity of experiences and

communication styles of PWA. As with qualitative research with PWA, richness of the data was dependent on the skill of the interviewers in supporting communication (Wilson & Kim, 2021). Interviewers were MSc SLP graduate students who had qualitative research and communication partner training, but it is possible that participants agreed with statements even if they did not precisely reflect their experiences. To mitigate the possibility of misinterpretation, we conducted analyses with patient partner input 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. Related to this, all study procedures were conducted remotely. By nature, this excludes participants without access to technology. Our participants were also relatively homogeneous in regard to race and socioeconomic status. Therefore, we recognize the intersectionality that PWA from different backgrounds may experience is not adequately represented in our study.

Our study focused on environmental factors (external to PWA) impacting communication access. However, interviews revealed personal factors, such as internalized negative attitudes surrounding communication impairments, also influence many PWA's communication interactions. Research on the effect of personal factors on communication interactions is currently being conducted with a subset of participants from this study and could provide insight into how to best support the social inclusion of PWA. The next step in this program of research is to examine barriers and facilitators to communication access from the perspective of businesses. In collaboration with our stakeholders, the ultimate goal is to provide tangible recommendations and resources for businesses to implement.

Reflections on patient partner engagement

The active participation of our patient partners was invaluable to all components of this research project. Their input provided a perspective that enriched data collection, analysis, and interpretations, but there are areas for improvement. First, due to the time constraints of a master's thesis project, the research topic was already selected prior to patient partner involvement. Similarly, time constraints limited the level of participation of patient partners. Future studies could employ patient partners as interviewers, as doing so may elicit information (Warr et al., 2011) that is not disclosed to interviewers who are not seen as peers. Our data analysis methods with our patient partners reflected our time constraints; future studies incorporating more robust participation (e.g., Kwok et al., 2022) would be beneficial. Finally, data analysis sessions with patient partners revealed rich discussions and extension themes generated from interview transcripts. Although these analysis sessions were not transcribed, future studies could incorporate these as an additional source of data to enhance credibility, dependability, and confirmability.

CONCLUSIONS

Communication accessibility contributes to the social inclusion of people, including those living with aphasia. Our study revealed that PWA desired more communicatively accessible environments. Participants in our study suggested greater knowledge of aphasia, implementation of supportive communication strategies, and an overall greater respect and understanding for those with communication impairments will contribute to positive business interactions. These actions would allow PWA and other communication impairments to have greater access to their communities, thus serving as "communication ramps" to support societal inclusion and overall well-being of individuals with communication disorders. Advocates for increased

communication access must now take steps to actively reduce barriers and institute facilitators—doing so in partnership with

PWA as key stakeholders will ensure the utility and relevance of this work to the individuals they are intended to support.

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