frontiers | Frontiers in Communication

TYPE Original Research
PUBLISHED 16 November 2023
DOI 10.3389/fcomm.2023.1219331

Understanding the experience of users of communication aids and applications through focus group discussions with people with aphasia and family members

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RECEIVED 08 May 2023
ACCEPTED 03 October 2023
PUBLISHED 16 November 2023

CITATION
Azevedo N, Le Dorze G, Jarema G, Alary Gauvreau C, Ogourtsova T, Beaulieu S, Beaujard C, Yvon M and Kehayia E (2023) Understanding the experience of users of communication aids and applications through focus group discussions with people with aphasia and family members. *Front. Commun.* 8:1219331. doi: 10.3389/fcomm.2023.1219331

The present study sought to identify the communication needs of persons with aphasia (PWA) and of their spouses, that could ultimately be addressed with current communication aids or applications (CA/A). Among users of CA/A we solicited their opinions and experiences with current CA/A. In contrast, among those not using CA/A, we explored why they did not use CA/A. A qualitative experiential research design was used through two in-person focus groups, one in English and one in French, at a large rehabilitation hospital in the Greater Montréal region (Canada). Participants' responses were recorded, transcribed and analyzed. The thematic analysis that ensued allowed the identification of four main themes. The first theme reflects participants' observations and experiences when communicating with aphasia. The second theme regrouped responses related to successful communication with the help of CA/A. The participants' challenges and dissatisfaction with CA/A were grouped into the third theme. Lastly, a fourth theme included participants' general views about CA/A and their wishes for further development. Participants' experience with communication difficulties following aphasia and the barriers and potential facilitators to adoption of CA/A were brought to the forefront. They also highlighted those features necessary to ensuring functional uptake of CA/A by those who would benefit from it. Finally, the importance of providing training to the communication partner and sensitizing the public to the impact of aphasia on people's daily lives and on the potential benefits of using CA/A were raised as necessary future actions.

KEYWORDS

aphasia, family member, focus group, AAC, communication aids and applications

1. Introduction

Aphasia is an acquired language impairment that occurs as the result of a trauma to the brain. In Canada, approximately one-third of stroke survivors, or more than 100,000 people, are living with aphasia (The Heart and Stroke 2017 Stroke Report). This number is expected to double over the next 20 years with the aging of the population. While stroke is the most common cause of aphasia in people seen in the rehabilitation setting, it can also be caused by a traumatic head injury (TBI) or brain degeneration such as primary progressive aphasia (PPA). Aphasia symptoms can include varying levels of impairment in understanding or producing speech, in reading, or in producing written language (Koul, 2011). As a result, a person with acute-onset aphasia or PPA will often struggle when communicating with others.

Although one may take the use of language for granted, when the ability to easily communicate with others is compromised it can lead to devastating effects on interpersonal relationships and access to services in the community (Brown et al., 2006; Simmons-Mackie and Damico, 2007). The ability to communicate with others is essential in practically all aspects of a person's life since it underpins most interactions with others and permits people to express their feelings and to express decisions that affect their lives (Goldbart and Caton, 2010). Furthermore, communication promotes a person's autonomy in everyday life and is fundamental for participation in society (Morreale et al., 2000; Goldbart and Caton, 2010).

Given the importance of communication, living with aphasia can negatively affect a broad range of aspects in the person's life. For example, people with aphasia (PWA) can have more difficulty accessing support and health care (Carragher et al., 2021), their quality of life can be reduced (Lam and Wodchis, 2010; Bullier et al., 2020), their mental health may be affected (Baker et al., 2020; Azios et al., 2022), their relationships can suffer (Howe et al., 2012), and return to work can be challenging (Graham et al., 2011).

Moreover, having few interactions with others can reduce social participation in daily activities (Parr, 2007; Simmons-Mackie and Damico, 2007; Dalemans et al., 2010; Le Dorze et al., 2014). Social exclusion and the consequent loss of autonomy has also been shown to negatively impact the quality of life of PWA and often elicits emotional stress and psychosocial disturbance (Code et al., 1999; Code and Herrmann, 2003). According to Lam and Wodchis (2010), aphasia has an even more negative impact on a person's quality of life than many other diseases, including cancer.

Aphasia can also affect family members, especially the person's spouse, because they need to deal with multiple problems related to the consequences of aphasia, their concerns regarding the PWA, as well as dealing with their own unmet caregiving needs (Le Dorze and Brassard, 1995; Michallet et al., 2003; Le Dorze and Signori, 2010). Furthermore, family members should be considered and involved in aphasia interventions because of their role as a communication partner who is also affected by aphasia.

A central goal of speech and language therapy is for PWA to be able to communicate as effectively as possible in their day-to-day lives (Thompson et al., 2008; Wallace et al., 2017). This focus on functional communication (i.e., communication in real-life situations) has led speech-language therapists (SLPs) to try to improve not only the person's ability to talk but also to attempt to help facilitate communication by other means, including with the help of augmentative and alternative communication (AAC) methods.

AAC aids can range from basic communication boards to high-technology communication aids or applications. Low technology-based AAC strategies, i.e. picture boards, spelling boards, photo albums, drawings, and cue cards (Chavers et al., 2021) do not include any method of speech output when a message is selected (Koul, 2011). While these allow the PWA to express themselves by pointing to the relevant choice, these tables are reduced to a few basic ideas or messages and cannot sustain even a basic conversation. In response to the limitations of low-technology tools, various dedicated communication aids and applications (CA/A) have been developed to better support communication. Such applications can enable a computer or hand-held multipurpose electronic device (e.g., Apple iPad^{TM}, Google Android^{TM}) to be used as a communication aid. While there exists a large body of research showing that both low- and high-technology based communication strategies can facilitate communication for PWA (Koul and Harding, 1998; Koul and Lloyd, 1998; Koul et al., 2005, 2008; Nicholas et al., 2005; McKelvey et al., 2007; Wallace et al., 2012; Ball and Lasker, 2013; Dietz et al., 2018; Mooney et al., 2018; Alam et al., 2023), many high-technology devices and applications require that PWA be able to use a keyboard to express themselves or to be capable of navigating through sets of pictograms to build messages. In addition, although PWA can make use of these types of CA/A, there are drawbacks to their use as well.

Two scoping reviews have been published on the use of high-technology communication aids (including mobile devices and communication apps) by PWA (Baxter et al., 2012; Russo et al., 2017). In a review of studies investigating the usefulness of high-technology communication aids to enhance communication abilities in adults with aphasia following a stroke, Russo et al. (2017) found that individuals generally showed improvements in communication when these technologies were employed. However, they noted that while the use of these aids could be useful in improving communication and social participation, the practical application of interventions using a form of high-technology communication aid as a compensatory tool was still in the developmental stage. Baxter et al. (2012) explored the potential barriers and facilitators associated with high-technology communication aids with the aim of better understanding the factors that underpin use rather than effectiveness, from the point of view of users and of providers of these aids. They found that implementation of high-technology communication aid interventions was affected by many factors that could become barriers or facilitators to successful outcomes. These included the device's ease of use, reliability, availability of technical support voice/language of the device, decision-making process, time taken to generate a message, family perceptions and support, communication partner responses, service provision, and knowledge and skills of staff. Additionally, Pampoulou (2019) looked at factors influencing CA/A acceptance or abandonment by interviewing SLPs. While their findings do not relate specifically to PWA only, they do suggest that the process of accepting a CA/A is complex with many factors influencing acceptance, including time since onset and acceptance of disability, the person's attitude toward communication facilitators, and the perceptions of family members and people with an acquired communication disorder about CA/A.

2. Study aim

While some or even many PWA have communication aids at their disposal, clinical experience suggests that the learning process is arduous, and inconvenience associated with their use sometimes outweighs potential benefits. The goal of this study was to identify communication needs of PWA that could ultimately be addressed with current CA/A or with newer versions, considering the points of view of both users and non-users. Given the importance of family member support in the successful use of CA/A, we also wanted to include their opinions and experiences. Among users of CA/A we sought to solicit opinions and experiences with current CA/A. In contrast, among people not using CA/A, we were interested in exploring why they did not use CA/A, as well as their communication needs.

3. Methods

3.1. Study design

A qualitative experiential research design was used to explore users' experience and attitudes toward CA/A (Braun and Clarke, 2013). We held two in-person focus groups, one in English and one in French, at a large rehabilitation hospital in the Greater Montréal region (Canada). Despite communication issues, PWA have been shown to be able to participate in focus groups and we chose this method of data collection because it can allow for the observation of non-verbal communication, and also encourages participant interaction and calls attention to areas of agreement and or lack thereof in the group (Barbour, 2005). The study was approved by the research ethics board of the Center for Interdisciplinary Research in Rehabilitation of Greater Montréal (CRIR, REB # CRIR-1333-0518). All participants signed informed consent forms. Researchers and participants pledged to preserve the anonymity of participants and to not divulge personal information that was shared during the discussions.

3.2. Participant inclusion criteria

Two types of participants were recruited: people with aphasia (PWA) and a family member, speakers of English and/or French. To be included in the focus group, participants had to be at least 18 years old, capable of giving informed consent, have aphasia resulting from stroke, or traumatic brain injury, or exhibit progressive primary aphasia. PWA could be receiving or could have previously received speech-language pathology services at a CRIR facility. The family member also had to be at least 18 years old and be a primary caregiver of a PWA.

3.3. Data collection

Each of the two focus groups was facilitated by a speech-language pathologist (SLP) with experience in leading focus groups with PWA (CAG) with the support of a second SLP with expertise in communication aids (SB). The facilitator had previously followed the "Supported communication for adults with aphasia" training from the Aphasia Institute. Most other members of the research team (NA, EK, GJ, MY, CB) were present to witness and take notes during the French focus group and many (NA, EK, GJ) were present for the English group as well. Each group session lasted ∼1.5 h and participants were compensated for their participation. The goal was to obtain feedback from both the PWA and family members through questions regarding their communication needs, their opinions regarding CA/A, and, for those who used CA/A, their individual experiences. The facilitator used a semi-structured question guide to ensure the coherence of the questions across the two groups (see Appendix A).

The SLP with CA/A expertise brought the following devices for demonstration purposes: an *iPad*^{TM}, a *Panasonic Toughbook CF-19* (https://na.panasonic.com/us/computers-tablets-handhelds/computers/laptops/toughbook-19) and a *Lightwriter* (https://www.abilia.com/en/our-products/communication/lightwriter-sl50). Participants were encouraged to bring their devices and tablets as well. Information regarding what CA/A they used (or had used), if any, is presented in Table 3. We note that while some of the technologies might have been sought out by the PWA or their family member, CA/A is prescribed by a specialized SLP assigned to the Technical Aids program as part of a treatment plan that includes training on the device and follow-up.

The sessions were video recorded and then transcribed verbatim by an individual who was not involved in data collection. Both transcripts were verified by the first author to ensure the accuracy of the transcription. Participants were assigned codes, PWA-X and SP-X to protect their anonymity. Moreover, in this paper we elected to use the gender-neutral pronouns "they/them" when referring to participants to further protect their anonymity.

3.4. Data analysis

In order to organize the data, the transcripts were uploaded to the NVivo 11 qualitative data analytic software (QSR International). The English and French transcripts were treated together and content analysis procedures were applied to both, using the six phases of thematic analysis proposed by Braun and Clarke (2006, 2013). Two members of the research team (NA, main researcher present at both discussions and TO, experienced in qualitative analysis and in using NVivo software), who are fluent in French and English, completed the initial stages of the thematic analysis and coded the transcripts independently. First, they each read the two transcripts to obtain a sense of the whole and familiarize themselves with each transcript. Then they each independently coded the data from both focus groups. Initial codes were generated in an inductive manner. As such, all segments of the data that were relevant to our research goals and questions were coded. Once this was completed, the two researchers met to discuss these codes and their meaning, and disagreements were resolved through discussion. Once a list of codes had been generated from the two transcripts, the researchers collaboratively identified potential categories and subcategories. Categories were predominately descriptive, i.e., they described patterns in the data that were pertinent to the research questions and goals. At the completion of this first analysis, we had created four major descriptive categories that allowed us to include all codes and extracts. The categories were: barriers, benefits, facilitators and optimal features of CA/A. Each category was defined and was further broken down into sub-categories. All of the information was included in an Excel file that organized all relevant extracts by category and subcategory.

Once this initial classification of extracts was complete, a process of member-checking was set up. Two couples, one from each discussion group, were sent a document by email describing each category and subcategory with detailed descriptive statements summarizing the information obtained from the transcriptions pertaining to the categories and subcategories. The document was created in French and English. Participants were asked their opinion as to whether we had understood the thoughts that were shared the day of the discussion. They were asked to respond to the email by indicating their agreement or disagreement, and whether something else should be added to the information. We obtained one response from one couple who agreed with the information that we sent them. The other couple did not respond even after a follow-up email.

We then undertook a second analysis in order to represent the participants' experience with CA/A and to derive themes. The following researchers were part of this process: NA, who had conducted the initial analysis and was present at both discussions and, GLD, a researcher in qualitative approaches with people with aphasia and family members with over 25 years of experience. They worked in a collaborative manner. GLD provided descriptions of the essential meaning of each extract. Together, they examined each extract and description with the aim of ensuring common understanding of the meaning of each extract as it had been spoken at the focus group. They also examined and coded anew each extract and proceeded to group together extracts that were similar in meaning. Codes, a synthetic and short description of the meaning across one or several extracts, were created to describe each extract, paying attention to how participants related their experience. All information was then grouped into Tables with tentative themes and subthemes. Initially there were eight themes that were merged into four, over time.

When writing up the results of this analysis, verification of the codes and extracts was often necessary. In this step, EK, GLD and NA chose extracts that would illustrate some of the codes for each subtheme and theme. The final selection of extracts was made collaboratively and these are included in the Results Section. At this point, verification of the extracts was conducted as needed to ensure truthfulness the citation and findings are summarized in Tables 4–7.

4. Results

The groups involved both PWA and spouses (SP), with experience with different communication aids or applications that ranged from "beginner" to "extensive." It is worth noting that, since all were recruited from a rehabilitation hospital, participants' experience with communication aids or apps was limited to those that were eligible for reimbursement by the Quebec Healthcare system at the time of the focus group. Three participants (1 couple and 1 PWA who came alone) did not have previous experience with communication aids or applications. In total, 10 people participated in the focus groups. The first group discussion held in French comprised three PWA and two SP: one couple and three individuals who came alone. The English group discussion had two PWA and three SP: two couples and one individual who was alone. Additional participant demographic information is presented in Tables 1, 2.

TABLE 1 Demographic information for the five PWA.

Variable	Count
Gender	
Men	2
Women	3
Age	
45–64 years	2
65+ years	3
Type of aphasia	
Non-fluent following stroke	3
Fluent following stroke	1
Non-fluent primary progressive aphasia (PPA)	1

TABLE 2 Demographic information for the five spouses.

Variable	Count
Gender	
Men	3
Women	2
Age	
45–64 years	2
65+ years	3
Spouse of a PWA with	
Non-fluent aphasia following stroke	2
Non-fluent aphasia following non stroke neurological event	1
Non-fluent primary progressive aphasia (PPA)	2

Furthermore, participants can be described in terms of their degree of experience with CA/A and available information regarding the types of CA/A that were prescribed by a SLP is included in Table 3 and described in the paragraphs below. However, while some participants also used applications of their phone or tablet that they had sought out themselves; information regarding these is not included in Table 3. Information regarding participants' experience with CA/A was provided by the collaborating SLPs.

TABLE 3 **Description of participants' experience with communication aids or applications (CA/A) and their attendance with or without their spouse.**

Experience with CA/A	Who attended		
	Couple	PWA alone	Spouse (SP) alone
Beginner			SP4: PWA has the *Grid Player* application on their tablet. Spouse encourages use but both report significant difficulties
Experienced	PWA2: Has applications (a dictionary application and a text-to-voice application but we are unaware of the specific application names) on their tablet but does not know how to use them effectively. The spouse would like the applications to be more tailored to spouse's challenges; seems to use them little	PWA1: Used a *Lightwriter first* that they did not like. Now uses two tablet applications, *Grid Player and Proloquo4Text*	SP7: The PWA has a very simple application on their tablet with a few choices of words and pictures (we are unaware of the specific application name). Not useful because of limited choices
	PWA5: Uses the *Grid Player* application on a tablet that appears to be ineffective. Also, they employ the word predictor on their cell phone. The spouse states that the application is not always effective		
Non-users	PWA6: Does not use any communication aid. The spouse admits to not being familiar with communication aids from the outset, but expressed interest	PWA3: No experience with communication aids but expressed interest. Uses word prediction when sending text messages to family members	

As shown in Table 3, two spouses came alone. One mentioned the PWA was a beginning user of the *Grid Player* app on a tablet (https://thinksmartbox.com/product/grid-player/). They both had significant difficulties in using the application. The second spouse who came alone spoke about their relatively negative experience with CA/A. They had however found that pictures worked the best to support their communication.

Two PWA came alone to the discussions as mentioned in Table 3. One was an experienced user of CA/A. This PWA had previously employed a *Lightwriter* that they later discontinued using and was now employing the *Grid Player* and *Proloquo4text* (https://www.assistiveware.com/products/proloquo4text) apps with a certain degree of satisfaction. The other PWA had no experience with communication aids but employed word prediction with a tablet when sending text messages and was quite interested in using CA/A.

Three couples attended as per Table 3. Two of these were experienced users of CA/A and one couple was a non-user. One experienced couple had various apps (including a dictionary and a text-to-speech application) on their tablet but none seemed to meet their needs. The spouse used them infrequently and wanted apps more tailored to the PWA's needs. Similarly, the other experienced couple had the *Grid Player* app on their tablet but it seemed ineffective. They had found other ways to communicate using pictures and had developed a seemingly good collaboration. They used word prediction on their cell phone with success.

The last couple who came to the discussion had no prior experience with CA/A. The spouse admitted they were unfamiliar with CA/A and, at the onset, was reticent about the PWA using CA/A to communicate. The PWA had PPA and believed they did not need CA/A.

4.1. Themes

During the analyses, we noted that participants had spoken about aphasia and described the difficulties they ran into when engaging in communication. We were sensitized to the idea that they viewed their experience with CA/A in the context of the difficulties that aphasia created for them. This insight is reflected in themes 1 through 3.

Another meaningful distinction that became apparent to us was how PWA were attentive to their own process of communicating and how SP were both observers of how the PWA was doing when they were trying to communicate and experiencers of changes affecting communication with their family member who had aphasia. Some spouses also had a third role, helping the PWA communicate with and without CA/A. In the Tables we distinguish the data provided by SP from that of PWA.

As mentioned above, four (4) themes were identified, each is represented in a Table below. Each theme is described with related subthemes and codes (i.e., short expressions representing the essential meaning of the extract), for both types of participants. Representative extracts are included in the text below, at least one from each participant has been included. Extracts produced by French-speaking participants have been translated for the purpose of this publication.

The first theme reflects their observations and experiences with communicating with aphasia. The second theme regroups codes related to successful communication with the help of CA/A. The participants were not always successful in using their CA/A and experienced difficulties and dissatisfaction. These challenges were grouped into theme 3. Lastly, theme 4 includes participant views about CA/A and their wishes for further development.

TABLE 4 Subthemes and codes for theme 1: participants experience and observe communication and communication difficulties in daily life.

Subthemes	Codes	
	PWA	Spouse (SP)
Experiences of word finding difficulties and associated negative emotions	Experience of word finding difficulty, the word is in my mind but does not come out of my mouth. (PWA1; PWA2; PWA3; PWA5)	Observation of word finding difficulty. (SP2; SP4; SP5)
	Self-reported word-finding difficulties exacerbated by fatigue. (PWA6)	Sadness felt by spouse when PWA can't find the word they are looking for and the communication breaks down. (SP2)
	Frustration felt by PWA associated with words getting stuck in their mind. (PWA3; PWA5; PWA3; PWA1)	
	Anger and sadness felt by PWA when words don't come out. (PWA2; PWA2)	
Experiences when the PWA needs to understand something	PWA no longer understands the newspaper; attributes it to lack of interest can still understand TV. (PWA3)	Severe aphasia, cannot understand simple things. (SP7)
	When PWA reads text and doesn't understand a word, they search for the definition. (PWA2)	
Strategies when communicating together as a couple	Taking a break to stop, PWA needs to listen to the questions spouse is asking to get to what they want to say. (PWA3)	In the past, by using pictures around the house. (SP5)
		Trying again later. (SP2)
		Not correcting PWA's errors. (SP4)
		Goes along with what PWA is asking even though it is frustrating for both of them. (SP7)
		Have had to change how they communicate with spouse (SP7): • Using pictures or brand names and logos that PWA recognizes • Communication intent has to start with PWA, spouse can't start an interaction and expect PWA to understand but if PWA initiates then they can understand what PWA is saying • PWA cannot reliably use yes/no response but spouse continues to check with PWA • Spouse needs to call 4–5 times before PWA answers the phone, PWA can follow a simple message (e.g., go get their son)
When the PWA communicates with other people including strangers	Self-reported comprehension difficulties in a group setting worsened in their second language. (PWA2)	Spouse shares their experience of difficulties experienced in everyday life when in the presence of others. (SP4)
	PWA need to speak more slowly but others also need to speak more slowly for PWA to better understand. (PWA1; PWA2)	Spouse notes that PWA chooses to stop talking when with strangers. Embarrassment with communication breakdowns can lead the PWA to leave off communication, or becoming resigned to being silent. (SP4)
	Anger felt by PWA associated with having to speak well at all times. (PWA3)	Partner uses humor to diffuse the awkwardness that they perceive other people are feeling related to aphasia and to calm distress felt by PWA. (SP4)

4.1.1. Theme 1. Living and communicating with aphasia

Within theme 1, we grouped together participants' descriptions of their experience and observations about communication and communication difficulties in daily life when they communicated together as a couple and, when the person with aphasia interacted with other people including strangers (see Table 4). Participants described communication difficulties, i.e., expressive and word-finding problems and comprehension difficulties. These often led to communication breakdown and participants shared what they did to resolve difficulties. The solutions they tried depended on the specifics of the situation they were involved in and on what they believed was required. Word-finding difficulties were central to most participants' experience of aphasia.

4.1.1.1. Subtheme: experiences of word finding difficulties and associated negative emotions

As can be seen in the extracts below, participants with aphasia described how they had a word in mind, that it got stuck there and would not come out of their mouth. Both participants with aphasia and caregivers also expressed negative emotions, such as frustration, anger and sadness, that were associated with not being able to find words or observing such a phenomenon. Others also had negative emotions associated with their perception of having to speak well at all times, and with the underlying problem of saying the right word.

> *PWA3: It's going to be difficult. It's going to keep me uh keep...it's going to stay in my throat...in my brain a little bit.*
>
> *FAC: Hmmm.*
>
> *[...]*
>
> *PWA3: It's very frustrating. Because it exi- it exi-exists, it's there. But how do I do that I can't use it?*
>
> *FAC: Hummm.*
>
> *PWA3: That annoys me.*
>
> *FAC: I understand, I understand.*
>
> *[...]*
>
> *PWA2: I too have uh... like PWA3. A problem [gestures]. [a lack of words] Yeah [nods].*
>
> *FAC: And what does that create?*
>
> *PWA2: Ah... angry.*
>
> *FAC: It makes you angry?*
>
> *PWA2: Yes.*
>
> *FAC: What makes you angry?*
>
> *PWA2: It's uh... crying too, why, why doesn't it come out?*

One participant conveyed that word-finding difficulties were exacerbated by fatigue. Spousal participants had a shared understanding of the word-finding problems experienced by the PWA.

> *FAC: So, what do you do when you don't understand what they want to tell you? Or when you see that they can't say their word. What is your reflex?*
>
> *SP2: Well, it makes me sad, because they can't say that word, so I don't understand it either. Sometimes I ask, I ask simple questions, but no, they tell me no.*

4.1.1.2. Subtheme: experiences when the PWA needs to understand something

One participant reported occasionally needing to look up definitions of words in order to understand reading materials. A spouse commented on the fact that the PWA did not understand simple things, which made their communication difficult but not impossible because they found ways to ensure that they were correctly understanding what the PWA wanted to communicate. Another PWA mentioned how they now had a limited interest in reading their favorite newspaper and that they were more successful understanding television newscasts.

> *FAC: You're talking about TV, right?*
>
> *PWA3: Yes. I watch programs.*
>
> *FAC: You watch TV, you're interested in politics, sports, all that.*
>
> *PWA3: I have, I have all that, but I have this too. But I'm not able to buy [read] a newspaper. It doesn't have the same interest for me anymore.*
>
> *FAC: Hmmm. Okay, hard to understand what you're reading?*
>
> *PWA3: I have it, I still have it, but it m- ... I don't like it as much.*
>
> *FAC: Okay.*
>
> *PWA3: I don't like it as much. I like it, I don't like it, eh, I have a newspaper called Le Devoir, for example I have Le Devoir in front of me, it interests me, but much less.*
>
> *[...]*
>
> *PWA3: So, it's too much. So the whole reading is too much. Could reduce it, make it a bit more.... That's how I see it. That's how I see it. I don't want it!*

4.1.1.3. Subtheme: strategies when communicating together as a couple

Participants described various communication strategies. However, although it is essential for families to know strategies to help palliate aphasia and word-finding problems, not all spouses knew how to help the PWA. One spouse mentioned how they did not correct the aphasic person's speech especially when they succeeded in understanding them. Participants described how they needed to take a break when they experienced communication breakdowns. For one PWA this allowed them to better understand their spouse's questions so that their spouse could help them (the PWA) in what they wanted to say.

> *PWA3: That's so true. Because we misunderstand what-, I said something and it's misunderstood by me. It frustrates me because I say to myself "it doesn't make sense, yet I said it well." How is that possible? Then I learn how I do it. And I feel like I'm having a hard time understanding that. That they understand, and then I ask for a break. Give me a break. Explain. So, I say to my spouse: "Stop [name,] I can't do it, I can't do it!" So [gesture: points to themselves and to another person] it makes a difference for me, with my spouse.*

Another spouse described at length how the PWA had great difficulty to understand what was asked, for example: yes-no questions, simple requests, or when they (the spouse) initiated a conversation. This PWA had limited language and the spouse provided examples of how the PWA communicated. The PWA often only said the word "no" even though one could tell they meant "yes." Also, the PWA once made the spouse understand what was wanted by directing them to drive to a specific location, which unfortunately happened to be closed when they got there. The spouse thought this means of communication was too frustrating for both of them and too demanding. This individual described how instead they used pictures and logos for better communication.

> *SP7: Not so much using... cause I think... that it depends, it's personal, to their head PWA knows what they want... And no no no I tell you, look. You want to check uh. I go always to the pictures that you make uh XXX ...*
>
> *FAC: Yeah, yeah. Oh! The paper pictures, wow!*
>
> *SP7: Yes. And then they goe "no no no no no." To PWA, they know what they want. It's clear to their head, but not clear to me you know, so... Then, they start again and starts the guessing.*
>
> *FAC: Yeah*
>
> *SP7: Go there, go there. no.*
>
> *[...]*

> *SP7: That's it, yes that's what I tell you. No, no, no. "Tell me," and I go in my head and , "you want Dollarstore?" and all the things, put an order so...*
>
> *FAC: Ok, so you give a choice.*
>
> *SP7: We learn, we learn like [points to SP5 and PWA5] PWA learns, we learn to...*
>
> *FAC: To communicate*
>
> *SP7: Yeah, too communicate but no.. pictures, they work for us...*
>
> *[. . .]*
>
> *SP7: ...as long as they will point by themselves. Not when I ask PWA, it's more like uh... PWA knows what they want. But when I ask them the question then.... but for them to show me, yes ... go to...*

4.1.1.4. Subtheme: when the PWA communicates with other people including strangers

One PWA mentioned that speaking in another language, especially in a group setting, was challenging. Another PWA emphasized how they needed to speak more slowly to be successful in communication and how their speaking partners, other than family members, also needed to slow down in order for them to better understand.

> *PWA2: Also, slowly. Talking slowly is better for me. To understand better.*
>
> *FAC: So, you like it when people talk slower.*
>
> *PWA2: Yes.*
>
> *FAC: So that you understand better.*
>
> *PWA2: Yes.*

A spouse also described how the PWA was resigned to being silent in the face of negative emotions and communication breakdowns, especially in the presence of strangers. The spouse used humor to diffuse the awkwardness that they perceived other people were feeling when faced with the distress the PWA was displaying.

> *SP4: PWA can say the opposite, they will say the opposite. Like yesterday, the example, they wanted to talk about a dog, a big dog. They said it was small and had no hair. I knew that they wanted to talk about a big dog, a big dog full of hair. So they do the, they say the opposite. ... I know it, but for the others it's not obvious. Yeah, like I was saying yesterday, well no, that's not it, you know. So, uh, it's difficult, and sometimes I let him go because I want to, I realize sometimes that it's not necessary to make PWA understand that they are saying the opposite because it doesn't go well..*
>
> *FAC: So, if I understand correctly, you were with other people, you weren't alone?*
>
> *SP4: No, that's right. That's right.*
>
> *[...]*
>
> *SP4: It's not, it's not obvious. But I, my XXX. I try to play it down.*
>
> *FAC: Yeah.*
>
> *SP4: With crazy things. Like yesterday, I said, "Oh, I brought the wrong [spouse]!"*
>
> *ALL: (Laughter)*
>
> *SP4: So, you know, that's right, I do crazy things like that "phew..."*
>
> *FAC: To lighten the mood.*
>
> *SP4: To relax PWA a bit.*

4.1.2. Theme 2: successful communication with CA/A

Using CA/A did help with communication, be it within the couple, or with family members, such as adult children (see Table 5).

4.1.2.1. Subtheme: pathways to communication using CA/A when together as a couple or with a family member

Participants said that they employed CA/A because it did help them communicate better even though sometimes the quality of communication was not optimal. One individual used voice and word recognition functions to write and send text or email messages to her spouse. Some reported not using their cell phones to speak but to send text messages instead. Even though they knew there may be errors in the messages, they still reported a preference toward employing the texting function with word-prediction.

> *PWA1: Uh XX...the keypad. The keypad*
>
> *FAC: The keypad on your phone? Of your iPad^{TM}?*
>
> *PWA1: (gestures: points to iPad^{TM}) Yes, my phone.*
>
> *FAC: From your phone*
>
> *PWA1: Because I send my messages to XXX (my spouse?) to to ... to my two sons.*
>
> *FAC: To your two sons, to your spouse.*
>
> *PWA1: Yes.*
>
> *FAC: You send them text messages? ...*
>
> *PWA1: Yes*
>
> *FAC: ...and you use the word predictor?...*
>
> *PWA1: Yes, yes*
>
> *FAC: ... Does it work well?*
>
> *PWA1: Well, not all the time.*
>
> *FAC: Not all the time?*
>
> *PWA1: Sometimes, sometimes, they are..., I have it, but I don't know any more how to write.*

Several reported ingenious ways they used for word prediction when stuck with word-finding problems. For example, one spouse stated that they used word prediction to solve communication breakdown when face-to-face as it improved their "guessing game." One PWA used texting to send the word they could not say while talking over the phone with their daughter.

> *SP5: But PWA5 find ways, because they called our daughter a little while ago and was trying to tell her something on the phone, but on the phone it's difficult.*
>
> *PWA5: Yeah! Me I can't when, to I can't, so I go... [frustrated]*
>
> *SP5: So then they texted her, and... there was no way they would have been able to spell "razors" but they sent her a message*

TABLE 5 **Subthemes and codes for theme 2: successful communication with CA/A.**

Subthemes	Codes	
	PWA	Spouse (SP)
Pathways to communication using CA/A when together as a couple or a family member	Uses voice/word recognition function to write and send messages (text or email) to spouse. (PWA2)	Description of how they communicate in daily life, with help from the app to provide cues for the guessing game. (SP5)
		Uses word prediction to solve communication breakdown when face to face (improves guessing game). (SP5)
		Observes that PWA uses word prediction to solve communication breakdown when talking over the phone (looks up and texts the word that the predictor helped them find). (SP5)
		Word definition feature works well if the partner is assisting the PWA (when alone cannot always use it). (SP2)
	Use word prediction to send text messages, despite some errors they still use it even though they are not always understood. (PWA-1; PWA-3; SP-5)	
Pathways to communication using CA/A with other people, including strangers	Uses CA/A with partner and at the Aphasia Association only. (PWA1)	Description of how they communicate in daily life on Facebook in a novel way. (SP5)
	Can communicate better over the phone than in person. (PWA1)	
	Uses pre-made lists of words and names that they created that are personally relevant. (PWA2)	
	Cannot use the cell phone to talk but uses it to send text messages to adult children. (PWA3)	
	Description of how and where they use their device with others. (PWA1)	
Benefits of using CA/A	General acknowledgment of CA/A usefulness. (PWA2)	Couple use CA/A to practice language skills. (SP5; SP6)
	Uses CA/A to find words when they have word finding difficulties. (PWA1)	Observations of overcoming word finding difficulties in another (less dominant) language. (SP5; SP6)
	PWA and spouse believe that using iPad has helped improve communication. (PWA5; SP5)	
	Feels that they can communicate better since they have their CA/A. (PWA1)	Personally relevant pictures are helpful when they cannot find the word. (SP5)
	Pictograms occasionally work, this is positive for the PWA on these occasions when it does work. (PWA3)	

> *"razors," so it had to have been the predictor and it was exactly what they needed. They needed "razors" and since she was out at the pharmacy ...*

Some spouses stated that they were quite involved in using CA/A to help the PWA communicate. In fact, they expressed that needed to help the PWA because they could often not use the device or app on their own. One spouse assisted the PWA to use a word definition feature on the CA/A device.

4.1.2.2. Subtheme: pathways to communication using CA/A with other people, including strangers

One individual said that they used their CA/A device with their partner or when at Aphasia Association meetings, where such devices are common among attendees. Another individual noted that they could communicate better over the phone rather than in person, so this was a preferred mode of communication. Another had listed family member names on their iPad™ that they could easily access in conversation.

One PWA used Facebook to communicate with others. To express themselves, they initially copied messages that others were sending and, over time, they were able to send messages more easily without having to copy other messages.

> *SP5: Yes or no I think because PWA5 will look, like say they want to say something about someone's picture like, on Facebook, they will look at other people's comment, and retype somebody's comment. But from that we have noticed, like certain words like "happy b-day" they now do it automatically because they have copied it so many times.*

A spouse was able to describe how the PWA used several ways to support communication with others by using texting and by having personally relevant pictures on their phone.

> *SP5: A couple of letters, or like, you know, they know Walmart it's the "w," they know the "pa" they doe the "p," you know so we have adapted as well so we know. And umm... they find other ways. They use the phone a lot as well. So, the phone helps them. Because, like there's pictures of their truck on there and stuff. So, when somebody doesn't understand this and they can't get the word "truck" out, they go in their phone and find the truck.*

TABLE 6 Subthemes and codes for theme 3: communication difficulties and dissatisfaction with CA/A.

Subthemes	Codes	
	PWA	Spouse (SP)
Dissatisfaction using CA/A when communicating with other people including strangers, do not use outside the home	Do not want to use the CA/A outside of home because it is too complicated and causes shame. (PWA1; SP5)	
	Negative experience when interacting with strangers while using an app on their tablet to communicate. (PWA3)	
Mismatch between what the PWA needs and what the CA/A can provide	CA/A does not always work for them, reveals language problems, or requires abilities that are no longer present. This causes frustration and therefore they do not always use it. (PWA1; PWA2; PWA5; SP4; SP5; SP7)	
	CA/A does not always work for them, reveals language problems, or requires abilities that are no longer present. This may cause frustration however they do still use it because it is somewhat useful in certain situations. (PWA2; SP4; SP5)	
	Difficulty finding or recognizing the correct pictograms (PWA3; PWA5) or confined to the list of pictograms available which is not always the one for the word they are looking for. (PWA3)	iPad app does not support conversation because spouse guesses what PWA wants to say before they can find the message with the iPad. (SP4)
Limitation of the general design of CA/A	CA/A device is too big and cumbersome. Size inappropriate and not useful. (PWA1)	
	CA/A is difficult to use: PWA cannot use the CA/A, does not understand why (PWA5); technical issues with CA/A (PWA2)	
	Prefers to use the male voice output, uses the app successfully but quality of communication may be impacted. (PWA1)	

4.1.2.3. Subtheme: benefits of using CA/A

Participants believed that using CA/A provided opportunities to practice and overcome word-finding difficulties. CA/A had helped them improve their communication, and that they now communicated better. In this extract the spouse recognizes that the CA/A helped and provided practice opportunities

> *SP5: So, yes, it's something to help, but if it can have a dual purpose of also helping...*
>
> *SLP: Practicing*
>
> *SP5: Exactly. And we see that with certain things already, like the repetition of writing the words, because of the repetition they are sticking and... yeah, I just lost my train of thought*
>
> *SP6: Thank you for saying that, because I think that sometimes we tell ourselves "no, I cannot do a certain thing, no I can't XXX. We told ourselves that she couldn't speak English anymore." Sometimes we tell ourselves "No I cannot do something" but my god, yes we can!*
>
> *[. . .]*
>
> *PWA5: Because, me I can't... I don't know, better, I talk. But uhh...*
>
> *FAC: You know more than you can say, right?*
>
> *PWA5: Well, me I, me I can't. NO uh, no It's... good, it's good. Before, euh, me, euh, like that. Am, can, euh... am... I'm [sigh] When I first like that. I go like, First like, little bit, but now, I'm get better and better. And also, me and you, is good.*
>
> *[. . .]*
>
> *FAC: You can talk much more.*
>
> *PWA5: Ya ya ya.*
>
> *FAC: And that's why you need that less and less. That's what I understood from your spouse. [Observer note: they are referring to the communication device they were given]*
>
> *PWA5: Yes, I know I know, and also...this one too [pointing to an iPad*^{TM}*], like 1,2 ok.*
>
> *FAC: The reading?*
>
> *PWA5: But now it's 1,2,3,4,5*
>
> *SP5: Yes, you're getting better by reading.*
>
> *PWA5: Ya.*
>
> *FAC: The reading is getting better too.*
>
> *PWA5: When I first, like that, when I first like that [gesturing a flat line] it's maybe. But then, after like that. [gesturing the motion of "up"]*
>
> *FAC: Much better.*
>
> *PWA5: And now, after here, like that. [gesturing the motion of "higher up"]*

One PWA specifically used CA/A when they had word-finding difficulties and thought that the device had helped them speak better.

> *FAC: Okay. In what circumstances do you use your communication aid?*
>
> *PWA1: When I feel—I am searching for my words.*
>
> *FAC: Yes*
>
> *PWA1: And I can't find them.*
>
> *FAC: Hmmm ok.*
>
> *[...]*
>
> *FAC: Okay. And what is, uh, what is a communication aid for you?*
>
> *PWA1: Oh my God, it helps- helps me a lot!*
>
> *FAC: It helps you a lot?*
>
> *PWA1: Yes. Erm, if er, if er I mark.*
>
> *FAC: Okay.*
>
> *PWA1: Uh... Let's say I want to... uh, nothing, uh, no, uh, no. Uh, dentist.*
>
> *FAC: Yeah, for example.*
>
> *PWA1: Everything uh. Like everything is... [showing an app on their device]*

> *[...]*
> *PWA1: There's a lot, a lot. Since I got it, I speak much better.*
> *FAC: Yes? So, do you find that it has really helped you?*
> *PWA1: Yes. Yes, yes*

Although many participants had found pathways to communication using CA/A, CA/A did not always work for them and frustration and dissatisfaction were expressed, as presented in theme 3.

4.1.3. Theme 3: communication difficulties and dissatisfaction with CA/A

Three subthemes were created for this theme and include circumstances when participants did not use CA/A, experiences of mismatch between what the PWA needs to communication and what the CA/A provides as well as comments referring to limitations of the design of CA/A (see Table 6).

4.1.3.1. Subtheme: dissatisfaction using CA/A when communicating with other people including strangers, do not use outside the home

Some individuals spoke about their negative experiences, such as shame and a feeling that CA/A was very complicated to manage when outside their home. Some had decided to not employ CA/A outside their home. Moreover, most participants reported dissatisfaction and frustration with how CA/A did not work for them all the time. Some CA/A devices revealed further language problems or required abilities that were no longer present exposing a mismatch between what the PWA needed and what the CA/A could provide.

> *FAC: That's perfect, because I was naturally turning to you,*
>
> *FAC: so if you want to tell us about your spouse's communication assistance.*
>
> *SP4: Uh, well [NAME] there's been a tablet for about 1 month, but there's a lot of difficulty using it because they are not able to read or write anymore. Uh, talking is starting to be difficult, like PWA3 said, it's there [point to head], but it's not getting there.*
>
> *SP4: It's true that at the beginning PWA didn't use it, but I said, you're going to sit with it and you're going to listen to [them], you're going to pitch, you're going to concentrate on it, but still, their sight is not sufficient. Well, in fact, it's that they don't recognize the images. You can see a bottle there [touches the bottle on the table], I say look for the bottle, it's there, it's all alone, but their brain misses it. So for PWA, for the moment, as I said to SLP, let it be for the programming because for the moment I don't see any improvement.*
>
> *SP4: To the rest of us, PWA has deteriorated, it's difficult for them and it's doubly frustrating because it's hard for them to see things and to recognize things on their tablet. So, they use it more or less.*

4.1.3.2. Subtheme: mismatch between what the PWA needs and what the CA/A can provide

Difficulties with CA/A that participants talked about included not knowing how to overcome a problem, experiencing a technical issue, difficulty in finding the correct pictogram to express their idea and, sometimes, the pictogram did not even exist. Another individual spoke about the resources required to actually find what they wanted to say and how they would forget the word they were looking for while scrolling through pictograms.

> *SP5: We worked with [SLP], to come up with this, it was a couple of years ago. And at that point, PWA5's language and comprehension were not at the level it is now. So, what we found is, um like...They would know something, like if they wanted to eat an apple, by the time they got through the first screen, they had forgot what they were searching for. So, we ended up stopping this and then, you know, we used a lot of pictures around the house and a lot of, you know, the hands gestures and things like that. And honestly, we haven't come back to it.*

4.1.3.3. Subtheme: limitation of the general design of CA/A

One female PWA said she preferred the male voice for spoken output, because it was easier to understand compared to the female voice, impacting the quality of communication. While the PWA preferred the male voice option, people often responded negatively to this because the voice did not match the person's gender. The PWA would have preferred to have more choices in voices instead of just one female option. Some participants described CA/A devices they no longer used consequent to difficulties experienced. For example, when a PWA used an app provided on their tablet for conversation, the PWA had such difficulty finding the words they were searching for in a timely manner that the spouse was able to guess what the PWA wanted to say before they were able to find the words. Those who had abandoned their device said they had found other options. One spouse spoke about using pictures and pictograms in the home.

One individual pointed out another source of dissatisfaction, i.e., the large size of their device (a *Lightwriter)* that led to them to abandoning it.

> *PWA1: I used to [points to the Lightwriter]. Oh, my goodness.*
> *FAC: You used to have that?*
> *PWA1: Oh, God! [rubs head].*
> *FAC: No?*
> *PWA1: Yes, yes, I had that [hand gesture of discouragement].*
> *FAC: And why wasn't it good?*
> *PWA1: Well, oh, [gestures with hand of discouragement], there's uh... [gestures to wait with hand]. Because I didn't have uh...to spell.*
> *FAC: It was more difficult you couldn't spell the writing?*
> *[...]*
> *FAC: It wasn't helpful at all?*
> *PWA1: No. T-t-t at all. Much t- too big.*
> *FAC: Way too big?*
> *PWA2: Okay. Did you ever used it?*
> *PWA1: A little bit.*
> *FAC: A little bit.*
> *PWA1: XXX no... I didn't like it.*

TABLE 7 Subthemes and codes for theme 4: views and expectations about CA/A.

Subthemes	Codes	
	PWA	Spouse (SP)
Negative views related to CA/A	Has a negative attitude to using CA/A in public and believes it's best to try to speak in public without CA/A because they have the words. (PWA1)	SP believes that the CA/A will become a crutch for PWA. Afraid of it because they do not know about it. (SP6)
	Having a CA/A would not help them to talk faster. Communication required them to talk slowly and others too (a device cannot do that in their opinion). (PWA1)	
	CA/A would be difficult to use because information there is not organized like they are used to. (PWA3)	
Positive views about CA/A	Learn about a new CA/A they may want to try. (PWA2; PWA3; PWA6; SP2; SP6)	
	Interest in learning how to use an app to compose messages. (PWA3)	Changed their perspective on CA/A and now are open to trying one. (SP6)
	Positive perception of premade messages that were demonstrated by FAC. (PWA2)	CA/A can be good for someone who does not speak at all. (SP7)
		SP believes that having a CA/A could help PWA be less frustrated and more autonomous. (SP4)
		SP believes that a word predictor could help PWA with a blockage with not being able to say the word in their mind. (SP6)
Wishes for CA/A development	More pictograms or pictures that are meaningful enough to convey a variety of ideas and that are personally relevant. (PWA3; SP7)	
	Pictograms organized in groups in a personalized fashion that are meaningful to the person, according to interest. (PWA3)	More public awareness of aphasia and CA/A. (SP4)
	For the world to communicate in pictograms instead of only words. With more pictograms in the world, the PWA would be able to communicate better because pictograms can convey a lot of information without the need for words. (PWA3)	Premade message programmed to be used in stressful situations explaining that they have aphasia (SP5)
	CA/A that allows ideas to be conveyed with short messages. (PWA3).	
	Would like an app that conveyed precisely what they wanted to say and can correctly interpret what is being said. (PWA3)	
	Having CA/A find the missing word or wrong word for them. (PWA1)	
	CA/A that translates a voice message to text because they cannot write the message but can speak it. (PWA2)	

Considering these experiences and their dissatisfaction, participants expressed their views about CA/A, which are presented in theme 4.

4.1.4. Theme 4: views and expectations about CA/A

Overall, participants expressed both positive and negative views about CA/A (see Table 7).

4.1.4.1. Subtheme: positive views about CA/A

All participants expressed that they could see how CA/A could be useful for someone who had aphasia and could help reduce frustration and increase autonomy. They also mentioned that CA/A could be helpful for someone who did not speak at all and could help with word blocks, when a word in mind could not be spoken.

One participant expressed an interest in learning how to use an app to compose messages and another thought premade messages could be useful. Many participants, i.e., two couples and one PWA, expressed interest in trying a new CA/A they learned about during the discussion. One spouse changed their opinion regarding CA/A as a result of participating in the group discussion. They initially stated that they were afraid that CA/A would become a crutch for the PWA, but that they had no knowledge and experience with CA/A. The following extract shows their change of mind.

> *SP6: I have an impression, uh and that's new for me, and I am learning here, a lot! A thousand times by the mile. I am sure that this machine over there, I don't know how you call it...*
>
> *SLP: This one, the Lightwriter?*
>
> *SP6: Yeah, I think that that one might be useful to PWA6, because they may have lost their..., part of their vocabulary and uh, this is made to measure. This is really made to measure. If PWA6 wants to say something, they only have to type it and out it comes really. Isn't it?*
>
> *FAC: [nods]*
>
> *SP6: So that might be helpful.*
>
> *PWA6: Yes, I write euh... everyday, everyday, my euh...*
>
> *FAC: Diary*
>
> *PWA6: Journal.*
>
> *FAC: Diary. Yes, I know, you're good.*
>
> *PWA6: And euh... I can write euh..*

4.1.4.2. Subtheme: negative views about CA/A

One PWA explained that having a CA/A could not help them because going slowly was the best strategy they employed for communication and one they needed other people to adopt when speaking with them. Thus, the PWA did not believe that having a CA/A could help them speak more quickly, an aim they would not try to pursue in the first place. The PWA also believed that in public situations it was preferable to speak, rather than use CA/A. The same individual mentioned that they wanted to speak to people instead of using CA/A.

> *PWA1: Look, well... Before the C-V-which a- a- XX [stroke] [points to arm].*
> *FAC: Your stroke.*
> *PWA1: I was talking very fast!*
> *FAC: Ahhh.*
> *PWA1: And then, not at all! I have to speak very, very slowly.*
> *FAC: Ok, so, now you speak more slowly.*
> *PWA3: Yes.*
> *PWA1: Yes!*
> *FAC: Would a communication aid help with the speed at which you speak?*
> *PWA1: No, not at all*
> *FAC: No?*
> *PWA1: ...because to get to the reality and XXX the... the [picks up, gestures to stop]. Wait*
> *FAC: Take your time.*
> *PWA1: To get there, it's good to talk quickly- no. Slowly.*
> *FAC: Okay.*
> *PWA1: Slowly*
> *FAC: In order to make yourself understood, you mean?*
> *PWA1: Yes, to understand, I don't understand anything (?).*
> *FAC: To understand people, people have to speak slower?*
> *PWA1: Otherwise yes*
> *FAC: Okay, so it goes both ways. You speak slower, but you also need people around you to speak slower.*
> *PWA1 Yes, yes yes*

4.1.4.3. Subtheme: wishes for CA/A development

Participants were also asked what they wished for in future apps. Spouses were mindful of the difficulties that the PWA had when interacting with others and with the general public. One spouse wanted more public awareness about aphasia and CA/A, as well as premade messages the PWA could use for specific and potentially difficult situations, i.e., such as interacting with the police when pulled over.

> *SP5 And uh... but I think it's something, cause now PWA5 has uh, they got their licence back by the way.*
> *FAC: Wow!*
> *SP5: Their car had to be adapted.*
> *FAC: Congratulations!*
> *SP5: But, I always got a fear, that if they are pulled over by police, and you know ...*
> *PWA5: No. Not me.*
> *SP5: I know. But you never know, just a spot check, whatever...*
> *FAC: Oh yeah...*
> *SP5: You know, So if PWA5 had this [pointing to the iPad^{TM}] with them, so, like the first thing is "I'm [says their name], I suffer from aphasia," you know, it would be something that-*
> *FAC: It would be good to at least have this as a backup plan as you say. Mm, ok.*
> *SP5: Yeah, because in stressful situations the, you know...*
> *FAC: Sometimes the speech is not coming.*
> *SP5: Yeah.*

PWA had several suggestions concerning pictograms and mentioned the following: (1) a greater variety of pictograms, (2) more pictograms that are personally relevant, (3) pictograms that conveyed a variety of ideas, (4) pictograms organized according to the interests of a person and (5) pictograms that conveyed a lot of information without the need for words. One individual also wanted a voice-to-text app that could help her send texts, because she could speak better than write. They wished for CA/A that could be more succinct in expressing what they intended to say and could correctly interpret what was being said to them. They wanted CA/A that could help them find the words they wanted to say and provide feedback if the word produced was not the right one.

> *FAC: ...what would you like it to do for you, a communication aid?*
> *[PWA2 does not respond after a few seconds]*
> *PWA1: Let it speak for me! [Laughter].*
> *FAC: That it speaks for you? All the time?*
> *PWA1: No no no!*
> *FAC: Because earlier you told us...*
> *PWA1: No, but when I don't know... XXX XXX... but it didn't do it then [pointing to their iPad^{TM}].*
> *FAC: Okay, so, as soon as you block, when you don't know, let it speak for you, just. Let it fill the hole.*
> *PWA1: No, not, not that much.*
> *FAC: Not that much. Well, explain it to us.*
> *PWA1: Because when I don't understand it, it writes another word.*
> *FAC: Let's put it this way, you said another word.*
> *PWA1: Well, say another word, then I'm- I'm trying to [makes fist gesture] then I, the more I think about it the more there [gestures to take out a word] not.*
> *FAC: The more you think about it, sometimes you can't find it.*
> *PWA1: Lord [gesture deep breath and stop]*
> *FAC: So, it's maybe at that moment, when you got the word wrong, that you would like it to correct you, for example.*
> *PWA1: Yes*
> *FAC: Is that what I understand?*
> *PWA1: Yes.*
> *FAC: Okay.*
> *PWA1: But, I shouldn't correct it too hard, because when I (laughs).*
> *FAC: You shouldn't try too hard to correct yourself?*
> *PWA1: Yeah.*
> *FAC: So it could be the communication aid correcting you.*
> *PWA1: Yes.*

5. Interpretation and discussion

The present work sought to identify communication needs of PWA (both users and non-users of CA/A) and family members that could ultimately be addressed with CA/A. Our study responds to a gap identified by Pampoulou (2019) that underscores the importance of capturing the views of CA/A users of their family when reflecting upon CA/A acceptance and abandonment.

Among users of CA/A we sought to solicit opinions and experiences with current communication aids while among people not using CA/A, we were interested in exploring their opinions regarding CA/A, as well as their communication needs. In two focus group discussions, users and non-users of CA/A provided their perceptions and experience of living and communicating with aphasia with and without CA/A.

The interview outline included three topics related to the participants' degree of familiarity with communication aids, their experiences with communication aids and what they wanted in future aids. Transcriptions of participants' discussions responses were analyzed using a qualitative thematic analysis. Codes of extracts were grouped into four themes. The first theme describes the experience of living and communicating with aphasia, the second presents successful communication with CA/A while the third theme discusses difficulties and dissatisfaction with CA/A. Finally, the fourth theme presents view and expectations from CA/A.

While we centered the focus group discussion on communication aids, across all themes PWA spoke about their word-finding difficulties as the most central feature of their experience of living with aphasia. This was also emphasized by their partners. CA/A was experienced as a facilitator for overcoming word-finding difficulties. When confronted with word-finding difficulties and searching for a word on their device or app, some individuals were dissatisfied due to the lack of results, leading them to abandon the CA/A. Finally, when discussing what they expected future aids to do for them, they imagined that a CA/A could speak for them when they blocked or correct errors they might have made. The next sections discuss the major findings, as outlined above, in light of available literature.

5.1. Word-finding difficulties, a basic challenge

The focus group participants spoke mainly of word finding problems as the source of difficulties in communication and the main reason for which they needed communication assistance. They had varied types of aphasia as well as diverse levels of severity. Some participants had sudden onset aphasia while others had PPA and their experience of aphasia ranged from relatively recent to several years. Given the qualitative nature of the study and our interest in participants' subjective experience, we did not try to make associations between their experience with CA/A and aphasia type and severity, the latter considered objective elements. Consequently, all participants interested in the topic were included in one of the discussion sessions, without specific exclusion or inclusion criteria or intent to represent the different types and degree of severity of aphasia. However, not having an easy access to the words they wanted to say was their main problem, which we found to be both surprising and not surprising.

Word-finding difficulties have long been reported in the literature (Le Dorze and Nespoulous, 1989) and the experience of aphasia as told by those who have it does include word-finding problems (Mooney et al., 2018). However, having aphasia also includes other dimensions that touch on how communication limitations affect relationships and curtail them (Mc Menamin et al., 2015). Moreover, the lived experience of aphasia is often described, but only in part, as a problem with speaking (Le Dorze and Brassard, 1995), and more generally experienced as various limitations in conversation and changed speaker and listener roles with new negative emotions not normally present in communication (Croteau et al., 2020). An international study conducted by Wallace et al. (2019) found that, in addition to findings related to life participation, societal attitudes, wellbeing, and health and support services, having better word finding abilities was only one of several wishes concerning communication that PWA and SP wanted to change about how aphasia affected their lives. In other words, people living with aphasia and their spouses do not usually put forth word-finding problems as the main impact of aphasia on their lives. As such, our result concerning the central role of word-finding difficulties in the participants' experience was not anticipated. Within the qualitative design and the conduct of focus group discussions, we did not anticipate and therefore did not explore the reasons why word-finding problems were highlighted to the extent that they were. One possible explanation is that their experience with communication aids may have highlighted this particular difficulty. For example, an app such as *Grid Player* presents a repertoire of illustrated concepts associated with content words. Also, a word-corrector on a smart phone proposes potential words as letters are typed in, which may help them finding the word that they want to express. Consequently, participants using such CA/A may deduce that their main difficulty is with finding the correct words when expressing themselves.

5.2. Communication aids and apps do help with communication

In speaking about the positive effects of CA/A, both PWA and spouses spoke of the usefulness of CA/A and of how communication and word finding difficulties were lessened through CA/A. One PWA uses voice/word recognition function on their tablet to write and send messages while another uses word prediction to solve communication breakdown and in face-to-face communication. In spite of occasional errors, word prediction is still useful in communication as per several PWA. Spouses describe how the app provides cues and facilitates the "guessing game" and how word prediction can solve communication breakdown over the phone. Some spouses had developed their own low-tech CA/A using pictures and pictograms around the house when their devices or apps had not fulfilled their needs. These findings underscore the role of family members, in this case spouses, in successful communication with the PWA using CA/A (Rayer et al., 2022). Although none of the spouses had been involved in a specific communication partner training program, it was obvious that several of them had become positively involved in communicating in a manner adapted to the PWA's limitations. One individual with aphasia who came to the focus group discussion alone recalled their spouse's unsuccessful attempts to assist them when they were searching for a word. This created stress and frustration and required that they remove themselves from the situation before trying again. This finding is also consistent with the idea that the main communication partner is critical to successful CA/A use and that this individual should participate in a training program where they would learn to facilitate communication through CA/A (Mc Menamin et al., 2015).

We note that PWA were reticent to use their CA/A outside their home or a protected environment where such aids were common, like attending an Aphasia Association activity. Participants did not like to feel shame or feel the discomfort of other people who were unacquainted with CA/A, leading them to use CA/A mainly in facilitating environments such as their home and with their spouse but adopting a silent posture in many social situations. Most comfortable users of CA/A were supported by their spouse who was quite involved in making communication work for both of them (Rayer et al., 2022).

A couple in the group uses CA/A to practice language skills. Some participants note that CA/A helped them beyond the singular moment of overcoming word-finding problems. They believed that using CA/A had improved communication over time and helped the PWA recover language skills after the neurological incident causing aphasia. This observation is in line with Dietz et al. (2018) who indicated that AAC treatment assist in compensating for language loss in communication situations and also, can support language recovery.

Facilitating features of CA/A mentioned by PWA and spouses are the word corrector, having a word definition feature, pictograms as well as contextually and personally relevant pictures and pre-made word lists. These comments support Rayer et al. (2022) conclusions that AAC interventions using individualized visual screen displays are more effective for several reasons, including the biographical and contextual organization of the information and reduced cognitive demands associated with traditional semantically-organized grids.

Finally, it is also possible that coaching provided by the specialized SLP was critical in helping participants successfully adopt the specific CA/A devices. Although not directly discussed during the focus group, it is possible to imagine that users of CA/A had not found the devices and aids they liked to use on their own, except for those who had extrapolated what their devices did for them to other situations. Findings from an ongoing study with SLP participants who were interested in discussing this topic will help us further explore the role and issues that SLPs encounter when suggesting devices and software and when training PWA and family members with CA/A.

5.3. What happens when CA/A do not work for them

All of the above notwithstanding, PWA also spoke of their negative experience when using CA/A. When confronted with problems in word-finding compounded by difficulties in having to search for a word with their device or app, some individuals were dissatisfied with the lack of results. This often led them to abandon the CA/A. The major issue with some CA/A was the difficulty of mobilizing the necessary linguistic or other cognitive resources, such as working memory and attention, required to make efficient use of the CA/A. There were moments when a mismatch was obvious for them, when using the app required them to keep in mind their idea while scrolling through pages of pictures or not knowing which semantic category was the one they should look up to find the specific word they were looking for. Sometimes, the provided pictograms were not relevant, also causing dissatisfaction. Other reasons for abandoning a CA/A was the less than desirable design, such as the size, which made the use of the device cumbersome and ineffective. A spouse also mentioned that they would sometimes end up guessing what the PWA wanted to say before them finding their word with the CA/A, again underlining the importance of the involved partner or spouse in using CA/A. In this particular case, the spouse had to find other ways to improve communication with the PWA. Pampoulou (2019) found that AAC systems that require too much effort and lost abilities, such as motor impairment related to hemiparesis, may be abandoned. Other factors such as attitudes toward CA/A, other caregiving demands, acceptance of disability, and the high cost of the CA/A may also contribute to negatively influence CA/A acceptance and use (Pampoulou, 2019). Some CA/A users may be dependent on a partner initiating the use of the device or app and supporting them in successful identification of the words they want to say. Such dependent users and their partners may require feedback to acknowledge the albeit limited, benefits of CA/A use (Taylor et al., 2019).

The reluctance to accept and adopt CA/A is also mentioned in the literature (Taylor et al., 2019). Factors such as attitudes toward CA/A, other caregiving demands, acceptance of disability, and the high cost of the CA/A, may also contribute to negatively influencing of CA/A acceptance and use (Pampoulou, 2019). In the case of a couple who participated in the focus group, the spouse was quite negatively disposed toward CA/A use. The spouse felt that CA/A was a replacement for their partner's speech and would become a crutch for the PWA. However, when confronted with the potential benefits of CA/A as discussed by some users of CA/A, they recognized that a CA/A could potentially help, especially if personalized, and assist with word finding. They met with the facilitator and specialized SLP after the discussion to further explore CA/A options for them. Despite the limitations in CA/A, we found that hearing about how CA/A can help people communicate directly from PWA, and not just from an SLP, can change people's negative outlook toward CA/A and promote their acceptance.

Finally, the group approach where different people share their experiences appears to have allowed participants to go beyond their specific experience and offered both PWA and spouses the opportunity to see perspectives that they may not have previously contemplated. The group approach also offered the opportunity to learn from one another and to feel at ease to express their views. The exchange of experiences, needs, obstacles and facilitators, demystified CA/A and their use.

5.4. What would an ideal future communication aid be for PWA and their spouses

In the context of this study and the existing stipulations of the healthcare system in which the participants and clinicians interacted, the CA/A presented were part of the pool of those eligible for reimbursement. Options that would need to be paid out of pocket at the time the focus group was conducted were not included. Based on all of the findings to date and those specific to this theme it is clear that one must think outside the box as one attempts to conceptualize functional and usable CA/A. It has been clear for a while that, just like with other interventions, "one size does not fit all." Rather, CA/A needs to be personalized to the user's profile, interests, leisure activities and life roles. It should also be versatile and dynamic, with the possibility to change over time to reflect changes in the user's abilities. It would be preferable to organize words by conversational topics that are relevant to the user, and not by semantic categories. To address PWA's word finding difficulties, CA/A should act as a cue, offering a feature like the "word predictor" that may be written or spoken. Furthermore, it would be desirable if the CA/A would also identify and correct mistakes that the user is making. Going beyond the word level, it would be preferable if CA/A would use short and simple sentences for input as well as for output. The inclusion of pictures/pictograms is also thought to be a helpful feature. Regarding speech output, having the option of choosing speed of vocal output as well as different accents and voices (various male/female) was desired. Thinking outside the box also applies to the physical appearance of a CA/A that needs to be light weight, small in size, and take into account that a PWA may have left or right upper limb paresis or paralysis. Lastly, PWA requested that CA/A could be programmed to be used as a tool in their aphasia rehabilitation.

While to date, the CA/A the participants currently used did not incorporate many of the features appearing in the participants' wish list above, rapid advances in artificial intelligence (AI) and its integration in aphasia rehabilitation can bring us closer to the realization of what appears, at the moment, to be a "dream" or "utopia" (Azevedo et al., 2023). Although it is possible that some of these features are already available in one or several CA/A, in our current setting in Quebec (a province of Canada) these were not available through provincial financing. Any advances in CA/A need to pass through the slow process of government approval as this is the only way to receive compensation or reimbursement. Further research on this topic can contribute to promote uptake of recent and performant CA/A for PWA and their family, including those that could use AI.

Furthermore, in line with the current research topic of this special issue, our findings may indicate that people living with aphasia had limited digital participation, meaning that their participation in society through the use of digital media and modern technologies such as smartphones was restricted for most, if not all, important life areas. Nevertheless, there was evidence that some participants who employed a smartphone for texting and social media wished to maintain relationships with family members not living with them, a notable aspect of participation. We did not uncover other digital participation goals that participants pursued with CA/A. Further studies with other participants who recently completed rehabilitation may provide a more optimistic and compelling portrayal of the digital participation of PWA, presuming that pre-aphasia digital participation will increase in the general population of older adults, i.e., aged 60 years or more at the time of aphasia onset due to brain injury or PPA. We also conclude that within aphasia rehabilitation, be it focused on language recovery or on employing CA/A to compensate for language limitations, the overarching and ultimate goal should more explicitly focus on participation (Laliberté et al., 2016; Alary Gauvreau et al., 2019; Alary Gauvreau and Le Dorze, 2022; Escher et al., 2022), despite significant challenges with this population (Berg et al., 2019). Re-learning to use CA/A to enable PWA to successfully access social media and to compose and read e-mail and text messages may be worthy rehabilitation goals leading to PWA being more independent and better able to participate in significant aspects of their social and community digital lives.

6. Limitations and further research

The findings we report were obtained from 10 participants, both spouses of a PWA and PWA. Although we emphasized depth of understanding when conducting the time intensive analyses, considering the small sample size, it is important to consider the present findings as preliminary. Further validation through studies with larger samples and more information regarding aphasia type and severity, conducted in other countries, can help determine the extent to which the results presented here are similar or different to those experienced elsewhere. Clinical practices related to CA/A probably differ according to geographical region, thus potentially influencing the experience that PWA and their families have regarding when CA/A is presented to them as a potential therapeutic tool. In the province of Quebec, where this study was conducted, PWA could have access to an iPad with specific language apps or to a dedicated CA/A device as part of their treatment plan. However, this required a referral to the Technical Aids program, consulting with a specialized SLP, and then finally obtaining a CA/A, steps each of which incur important time delays. This time-consuming process may differ in other Canadian provinces and in other countries. Furthermore, the inclusion of participants who had access to newer CA/A, including those not reimbursed by provincial financing, could enrich our understanding of the usefulness and limitations of CA/A as experienced by people with aphasia and their family members.

As is common in studies with PWA, recruitment was another limitation. Potential participants who were users of CA/A were sought to be recruited if they were no longer receiving rehabilitation at the time of the study. However, one PWA included in the study was still receiving rehabilitation services. Furthermore, while we initially sought to recruit only users of CA/A, we finally included one PWA and one couple who were non-users of CA/A. This was because these three had initially refused to consider CA/A as a treatment option for the PWA and we were interested in understanding their experience and reasons for refusal. One of the difficulties in recruitment had to do with the fact that within the clinical facility where participants were recruited, the CA/A program is separate from other programs such as stroke and neurological rehabilitation. Therefore, referral to CA/A occurs after rehabilitation ends, if it occurs at all. Moreover, at the time this study was conducted, potential clients entered a wait list, sometimes as long as 1-year long, before accessing CA/A services. Hence, most CA/A users had waited several months before accessing their device. For people who had PPA this was a greater problem because their abilities declined over time while waiting to access their CA/A, thus running the risk that having a CA/A was no longer optimal for the person and their particular linguistic and cognitive abilities. We believe this may have influenced their experiences and perceptions about CA/A. Had they received CA/A early, as part of their rehabilitation plan, the results would have been different, but from our understanding, such a practice may not be generalized to all areas of the world (Dietz et al., 2020). In addition, in future studies, it would be useful to have additional information regarding how PWA receive training in using their CA/A once they receive it.

We did not assess general media competence or comfort with technology, as part of the study but this is generally done by the SLP as part of the treatment plan and when determining whether a CA/A should be prescribed. Thus participants who were using a CA/A had been deemed able to learn how to use it and could use it, potentially with assistance from a family member. In future research about CA/A, it may be useful to report digital media competence of both PWA and the family member. Despite the belief that aging can negatively affect digital media competence, we did not observe variations in their experience that could be attributed to aging.

7. Conclusions

In this study, the PWA and spouses' experience has brought to the forefront the barriers and potential facilitators to use of CA/A. It has also highlighted those features necessary to ensure functional uptake of CA/A by those who would benefit from it. In parallel to improving currently available devices and software, it is important that training be provided to the communication partner and that the public is sensitized on the impact that aphasia can have on people's daily lives and on the potential benefits of using CA/A not only for improving language and word-finding difficulties but more importantly, for access to digital participation in their life and society.

Data availability statement

The datasets presented in this article are not readily available because no dataset will be made available for the focus groups. Requests to access the datasets should be directed at: nancy.azevedo@mail.mcgill.ca.

Ethics statement

The studies involving humans were approved by the Research Ethics Board (REB) en Readaptation et en Déficience Physique (RDP). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Funding

This work was supported by the Center for Interdisciplinary Research in Rehabilitation of Greater Montréal (CRIR) [New initiatives grant].

Conflict of interest

MY and CB are employed by IBM France.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Appendix A

Question guide for focus group.

Question guide

Question 1—Are you familiar with communication aids? In your opinion, what is a communication aid?
Sub-questions:

- What do you know about communication aids?
- Have you ever used one? If yes, how have you used it? If no, why not?
- Did using a communication aid help you speak with someone (ask them to specify the communication partners; caregivers/family, strangers, friends, children, at the shopping center, etc.) In what context?
- How well does this work in everyday life?

Question 2—What are your experiences with communication aids? Sub-questions:

- Give concrete examples
- If you do not use communication, why is this the case?
- Give me an example of a time when it went well and an example of a time when it did not go well.
- Are there contexts that are more enabling for using a communication aid and others that are less enabling? (at home, at the store, with a family member/caregiver, with strangers?) Why?
- Do you use an application, word prediction on your phone, speech recognition, etc?

Question 3—What would you like your—or a—communication aid to do for you that it currently does not do? Sub-questions:

- What would an ideal communication aid be like? We can dream here, what is your wish list when it comes to communication aids?
- How could we improve the communication aids that you currently use or that you are familiar with? For you and for your family/caregiver.
- If you do not use one, what would you like a communication aid to do for you and for your family/caregiver?

Note for facilitator: Points to consider, if necessary: Speech recognition, artificial intelligence for word prediction, possibility of learning a person's vocabulary, dynamic processing, application for a phone, etc.