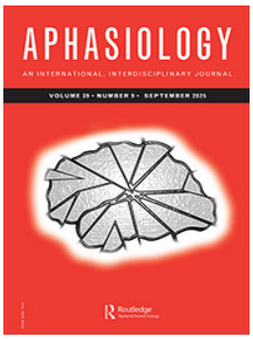

Aphasiology

ISSN: 0268-7038 (Print) 1464-5041 (Online) Journal homepage: www.tandfonline.com/journals/paph20

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To cite this article: Ingrid Henriksson, Charlotte Johansson-Malmeling, Catharina Gustavsson & Stefan Johansson (08 Sep 2025): Experiences of using the internet among people with aphasia: challenges and opportunities, Aphasiology, DOI: 10.1080/02687038.2025.2555865

To link to this article: https://doi.org/10.1080/02687038.2025.2555865

Published online: 08 Sep 2025.

APHASIOLOGY
https://doi.org/10.1080/02687038.2025.2555865

Routledge
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Experiences of using the internet among people with aphasia: challenges and opportunities

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ABSTRACT

"Digital participation" refers to being actively involved in the digital society and using information and communication technology, above all the internet. However, not everyone has access to this global network and the ability to use it.

The aim of the study was to explore experiences of using the internet and digital participation among people with aphasia (PWA) in Sweden by analysing data from an online survey undertaken in 2021.

Methods & Procedures: The study has a descriptive design using mixed methods. Sixty-four participants with self-reported aphasia and a reference group of 1116 members of the general public answered the same survey with questions related to internet use and the digital society. Answers from both groups to ten multiple-choice questions were analysed statistically, and the PWA's answers to eleven open-ended questions were analysed using reflexive thematic analysis.

Outcomes & Results: Quantitatively, the analysis showed that answers concerning internet use differed statistically significantly between the two groups. Qualitatively, the analysis identified two themes: "The internet imposes heavy demands" and "The internet provides opportunities", with various subthemes.

Conclusions: PWA described how the internet is very demanding. However, they also reported positive experiences and confidence in the potential of the technology. Even so, the internet can be exclusionary, and it is important to ensure that facilitating factors are considered in the development of technology and technology-mediated communication, so that communication opportunities for PWA and others will be enhanced.

ARTICLE HISTORY
Received 25 July 2024
Accepted 28 August 2025

KEYWORDS
Aphasia; internet; accessibility; digital inclusion

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Background

The internet provides new arenas for communication and is affecting almost all areas of life (van Deursen & Helsper, 2015), including social relations (DiGennaro & Dutton, 2007) and media consumption (Westlund, 2015). Community services and health-care services (Johansson, 2016) are increasingly managed digitally, which has made everyday life easier for many people. Moreover, opportunities to participate in democratic processes (Halupka, 2014) and education (Danchikov et al., 2021) as well as actions to mitigate health crises such as the COVID-19 pandemic (Chadwick et al., 2022) increasingly depend on the ability to use the internet. Hence it is crucial to ensure that all citizens are able to go online and fully exploit those opportunities (van Deursen & Helsper, 2015). Van Dijk and Hacker stated as early as in 2003 that a crucial task of societies in this context is to prevent inequalities in digital participation from becoming structural and thus persistent (van Dijk & Hacker, 2003). Over time, the focus of research into such inequalities has shifted from internet access (Haight et al., 2014) to internet skills (Hargittai et al., 2019; Zhong, 2011) and most recently to internet outcomes (Scheerder et al., 2017).

Digital participation and digital exclusion/inclusion are complex concepts, and it is not possible to single out any one factor that explains them. Rather, to obtain a comprehensive picture of a person's situation, it is necessary to consider several interacting factors pertaining to the individual and the surrounding society (Helsper & Reisdorf, 2013; van Dijk, 2012). Further, research also highlights that digital inclusion/exclusion is not constant across contexts and over time. A person may feel digitally included in some situations but excluded in others, and life changes such as illness or unemployment may lead to a shift from inclusion to exclusion (Helsper & Van Deursen, 2017).

Factors associated with a higher risk of digital exclusion include living in a rural area, having low socio-economic status, having obtained fewer years of education (Rao, 2005), being older (Helsper & Van Deursen, 2017; Menger et al., 2020) and having an impairment (Johansson et al., 2021; Menger, 2018; Menger et al., 2020; Pettersson et al., 2023). Further, there appears to be a connection between the type of impairment and the degree of exclusion experienced, and people with aphasia (PWA) have been reported to be at particularly high risk of digital exclusion (Johansson et al., 2021; Menger, 2018, 2020).

Most of the existing literature on aphasia and internet usage addresses issues related to eHealth (e.g., Braley et al., 2021; Choi et al., 2016; Øra et al., 2020). Online interventions have been found to be as effective as face-to-face ones (Cacciante et al., 2021; Cetinkaya et al., 2024). The interventions studied have usually been on an individual basis (however, see Pitt et al., 2019) and have mostly focused on multimodal aphasia treatment followed by lexical treatment (Cetinkaya et al., 2024). A review showed that PWA experienced training based on information and communication technology as acceptable (Kearns & Kelly, 2023). Several positive factors have been reported, including reduced costs and travel time (Cetinkaya et al., 2024; Øra et al., 2020). One overall conclusion from research on eHealth is that it has great potential in the right conditions – meaning that PWA must have basic computer skills (or be taught them) (Caute et al., 2019; Cruice et al., 2021; Kurland et al., 2018), that the interventions must be customised (Burke et al., 2022; Finch & Hill, 2014; Cruise et al., 2021; Kearns & Kelly, 2023) and that continuous support adapted to

each individual must be given (Burke et al., 2022; Finch & Hill, 2014). Finch and Hill (2014) suggest that, when making decisions regarding technology solutions and the focus of intervention, speech and language therapists must balance PWA's interest in computer-based training with the need for individually tailored support and ensure that interventions are performed within a supportive clinical environment.

Results indicate that persons who develop aphasia may become more likely to use computers after the onset of the disease but may then use them less frequently and for partly other purposes (Finch & Hill, 2014). PWA's difficulties using digital services and functions can partly be due to the fact that their design is not adapted for someone who finds it hard to comprehend and produce written language (Menger et al., 2020). However, there is research, mainly in the field of health literacy, addressing how written language can be made more "aphasia-friendly" through adjustments to content (e.g., use of high-frequency words) and form (e.g., use of bullet lists and numbering) (Egan et al., 2004; Rose et al., 2011). Further, difficulties producing written text may be dealt with by online writing support (Johansson-Malmeling et al., 2022; Marshall et al., 2019; Thiel et al., 2017).

Communication and interaction via social media thus cause problems for PWA owing to unsuitable interfaces and web designs (Egan et al., 2004; Elman, 2001). However, with adjustments based on careful analysis of user needs, even PWA have good opportunities for positive and meaningful interactions through aphasia-friendly social-networking applications (Buhr et al., 2017; Kurfess et al., 2023). There are also examples of how PWA themselves find individual solutions enabling them to use social media and the internet effectively for communication and interaction purposes (Menger et al., 2020; Taubner, 2019; Taubner et al., 2017).

In summary, the factors affecting PWA's opportunities for internet use and digital participation are multiple and complex. Menger et al. (2016) presented an analysis of facilitators and barriers for PWA's use of the internet based on the International Classification of Functioning, Disability and Health (ICF) framework (World Health Organization, 2001) in combination with the Communications Consumer Panel (CCP, 2010). Their study showed that the facilitators and barriers were due to the interrelationship among all ICF domains (body functions and structure; activity and participation; environmental factors; and personal factors) and that language difficulties, especially impaired reading and writing, had a significant negative impact on PWA's internet use.

The present study reflects the perspectives of PWA living in Sweden, a highly digitalised country where 94% of the population aged over 16 years used the internet on a daily basis in 2022 (Swedish Internet Foundation, 2023). The official statistics do not provide detailed information about the internet use of specific populations with impairments, but complementary data are gathered through biannual surveys by an organisation called Begripsam (begripsam.se). The survey ("Swedes with impairments and the internet", or SMFOI) (Johansson et al., 2021; Pettersson et al., 2023) includes 64 questions about experience of internet use, the digital society and access to the internet and technology. The questions have been developed through a co-design process in collaboration with individuals who themselves have some type of disability. In an effort to create an accessible survey with clear and comprehensible questions and response options, supplementary material featuring pictures

and easy-to-read explanations was developed to assist participants with reading difficulties. The target population for the survey comprises individuals with any type of impairment who use at least some form of the internet. Participants can self-report diagnoses, impairments, and difficulties through 44 predetermined options or provide their own responses via a free-text option. So far, the survey has been administered four times: in 2017, 2019, 2021, and 2023, to 771, 1631, 1410 and 1174 respondents, respectively. Since 2019, the SMFOI survey has been part of a research programme called Co-Design for Accessibility (www.codeac.se) and has been supplemented with a reference group of participants from the general population. For each participant in the SMFOI survey, six reference persons matching that participant in terms of gender, age and county of residence are drawn from the registry of the Swedish population (SPAR, 2021).

Analysis of the answers given in 2017 showed that respondents were more likely than the general Swedish population to report experiences of not being digitally included and that people with language difficulties had problems using the internet (Johansson et al., 2021). Similar findings were reported in a recent study based on the 2019 survey (Pettersson et al., 2023), which indicated that those least likely to use eHealth, and experiencing the greatest difficulties in doing so, were participants who reported challenges related to language, communication, mathematics, or intellectual impairments.

Data for the present study were collected during the COVID-19 pandemic. Although Sweden did not implement a strict lockdown policy, the government recommended restrictions to protect at-risk individuals (Söderberg et al., 2023). All citizens, particularly those at risk, were advised to use digital solutions for essential services such as buying groceries and medications (Folkhälsomyndigheten [Public Health Agency of Sweden], 2020). In healthcare, there was an extensive switch to digital health-care meetings and/or appointments over the telephone or via tablets or computers. This sudden switch to digital solutions placed heavy demands on individual citizens' ability to use the internet. Although neither the aim of the survey nor the questions asked were related to the COVID-19 pandemic, its effects probably influenced the participants' answers, especially to health-related questions. In addition, the ongoing pandemic also made it urgent to investigate how PWA were affected during a period when the internet and online solutions in general rapidly gained importance.

Aim and research questions

The aim of the study was to explore experiences of using the internet and digital participation among people with aphasia (PWA) in Sweden by analysing data from an online survey undertaken in 2021.

The research questions are the following:

(1) How did people with aphasia experience internet use and participation in the digital society?
(2) How did self-reported use of the internet and digital participation differ between people with aphasia and a reference group from the general population?

Table 1. Participants' age, gender and highest level of education.

Participants	Aphasia ($n = 64$)	Reference group ($n = 1116$)
Age (years)	$M = 61.3$ (SD = 12.9)	$M = 60.4$ (SD = 12.3)
Females	53.1% ($n = 34$)	68.5% ($n = 764$)
Highest level of education:		
comprehensive (lower-secondary) school	6.3% ($n = 4$)	6.6% ($n = 72$)
upper-secondary school	23.4% ($n = 15$)	22.5% ($n = 251$)
vocational school	14.1% ($n = 9$)	13.6% ($n = 152$)
university	42.2% ($n = 27$)	53.9% ($n = 654$)
other	1.6% ($n = 1$)	1.6% ($n = 18$)

Note: The age-variable is derived from 1113 answers from persons in the reference group and 55 answers from persons in the aphasia group.

Method

The study had a descriptive design and used mixed methods with a convergent approach (Creswell & Clark, 2017) by analysing both quantitative and qualitative survey data to investigate experiences of using the internet among PWA in Sweden.

Participants

This study used data from respondents to the 2021 SMFOI survey who self-reported having aphasia (respondents reported diagnoses, impairments and difficulties using 44 fixed options and one free-text option). Participants were recruited using snowball-sampling methods (Kalton & Anderson, 1986; Potter, 2011).

In the 2021 SMFOI survey, 64 participants had self-reported aphasia. Of those, 78.1% ($n = 50$) were native speakers of Swedish. The reference group included 1116 participants, of whom 89.5% ($n = 994$) were native speakers of Swedish. There was no significant difference between the groups' demographics in terms of age ($t = .533$; df = 1166; $p = .765$), gender ($\chi^2 = 2.023$; df = 1; $p = .155$) or level of education ($\chi^2 = 2.850$; df = 7; $p = .899$) (see Table 1).

Of the 64 participating PWA, 82.8% ($n = 53$) answered all survey questions. In the reference group, 87.3% ($n = 974$) of all participants answered all survey questions.

Materials and procedure

Information about the survey was distributed through large information campaigns on social media, by disability-rights organisations (such as the national aphasia association), through mailing lists, at physical meetings and during online events. In addition, research assistants visited aphasia centres to help PWA answer the survey.

The SMFOI survey consists of 53 questions with fixed or multiple-choice response options and 11 questions with free-text response options. The questions used in the

Table 2. Questions used in the study.

Multiple-choice questions	Open-ended questions (asked, where appropriate, after each multiple-choice question listed)
Do you use the internet?	Please tell us more about your attitude to using the internet.
Do you often ask someone for help to do things on the internet?	What do you usually ask for help with?
Do you have access to a smartphone?	Are there any apps on your smartphone that you find very helpful?
Do you have access to a computer in your home?	Are there any programs on your computer that you find very helpful?
Do you have access to a tablet?	Are there any apps on your tablet that you find very helpful?
Have you used the part of the national online health-care portal ('1177') that does not require a password?	How well do you think it works? Please describe in your own words.
Have you used the part of the national online health-care portal ('1177') that requires a password?	How well do you think it works? Please describe in your own words.
Do you think it is difficult to use the internet?	Please describe in more detail why the internet is difficult to use.
Have you used video health-care appointments?	Please tell us more about your attitude to using video health-care appointments.
Do you feel included in the digital society?	Please describe your thoughts about your participation in the digital society.
	[Closing question:] Is there anything else you would like to tell us?

present study were 10 questions with fixed or multiple-choice response options and all 11 questions with free-text response options, as presented in Table 2. In line with the mixed-methods approach, both quantitative and qualitative data were collected. The questions with qualitative free-text response options followed the quantitative questions with fixed or multiple-choice response options and were intended to provide a deeper understanding of how the participants perceived using the internet and how they perceived themselves as participants in the digital society. For example, one initial question with fixed response options was "Do you often ask someone for help to do things on the internet?" Respondents who answered "yes" to that question were asked the following question with free-text response options: "What do you usually ask for help with?"

Data analysis

Owing to the differences in group size, the non-parametric Chi-square test of independence was used to analyse the association between groups and the distribution of answers for five multiple-choice questions. The other questions were analysed using descriptive statistics.

The answers to the questions with free-text response options were analysed using Thematic Analysis (TA), a reflexive approach where themes are developed from codes (Braun & Clarke, 2006, 2021). TA was used since it is a method that is flexible, describes data in detail and is particularly suitable for a research area where present knowledge is limited (Braun & Clarke, 2006). The themes developed reflect issues identified by the researcher as significant in relation to the research questions but do not necessarily reflect a high frequency of similar descriptions given by different participants in the dataset. The analysis was based on the aim of the study, which yielded a deductive perspective, but

Table 3. Example of analysis from meaning unit to theme.

Meaning unit	Condensed meaning unit	Code	Sub-theme	Theme
The internet gives me better opportunities to get an overview of appointments and that sort of thing	Good to have an overview thanks to the internet, for example of appointments	The internet gives me an overview	Compensatory strategies exploiting the internet	The internet provides opportunities

this was combined with an inductive perspective taking the empirical data as its starting point. The analysis was an iterative process. The codes were generated as the understanding of the data developed, and they were repeatedly reflected upon during the different steps of the analysis (Braun & Clarke, 2021).

The third and fourth authors were responsible for developing the first version of the survey, for the continuous development of the questionnaire and for the choice of sampling methods. The first author performed the initial data analysis. All authors participated in discussing and elaborating the analysis and in interpreting the findings.

In the analysis of themes and sub-themes, the Miro digital whiteboard (https://miro.com/index/) was used as an online collaboration tool. See Table 3 for an example of the analysis from a participant's written answer to one of the themes.

The six steps of thematic analysis described in Braun and Clarke (2006), p. 87) were followed throughout:

(1) *Familiarising yourself with your data*: Transcription of spoken data often serves the double purpose of helping researchers familiarise themselves with the data. In the absence of an initial transcription sub-step, extra emphasis was here instead placed on reading and re-reading of the data by the first author. Notes were taken during reading and a first draft involving tentative analysis was made, documenting some general ideas for themes, such as 'technology is difficult' and 'my family help me'.
(2) *Generating initial codes*: All text (i.e., all participants' answers) in the dataset was analysed into different meaning units and then further into condensed meaning units. Each condensed meaning unit was highlighted and given a code. The approach to coding involved close interaction with the text in the sense that the wording of the codes included at least some words that were also found in the relevant meaning unit. During the analysis of meaning units, the analysis of condensed meaning units and the generating of codes, the draft notes from step 1 about general ideas about themes were progressively updated and edited.
(3) *Searching for themes*: The first author formulated suggestions for themes based on the codes. The full answers were re-read to ensure the ecological validity of the suggestions. The first analysis yielded four themes.
(4) *Reviewing themes*: All authors together discussed the themes and worked on the analysis. The coding process was thoroughly discussed until the group reached a consensus on the various codes, particularly those appearing in multiple responses across questions and participants. The initial four themes became two themes, each with three associated sub-themes.
(5) *Defining and naming themes*: The first author suggested names for themes and sub-themes which were discussed by all authors. Some sub-themes were merged, and

some names were changed. For example, since participants did not answer only for themselves but also for users in general, some personal pronouns were removed: 'the internet imposes heavy demands on *me as a user*' became 'the internet imposes heavy demands on *the user*'.

(6) *Producing the report*: The first author had primary responsibility for writing the manuscript, but the work was conducted in close collaboration with the other authors.

Ethical considerations

The present study was approved by the Swedish Ethical Review Authority (Ref. No. 2022–00184–1). Before the analysis began, all proper names appearing in the answers to the open-ended questions were deleted to prevent identification of participants.

Results

Results from multiple-choice questions

The distribution of answers regarding internet use differed statistically significantly between the two groups, with 90.6% of the PWA group but 96.8% of the reference group answering that they used the internet ($\chi^2 = 12.167$; $df = 1$; $p < .001$). There was a similar picture as regards often asking for help when using the internet, with 43.8% of the PWA group and 14.0% of the reference group answering that they did so ($\chi^2 = 40.835$; $df = 2$; $p < .001$).

In terms of the availability of technology, 73.4% of the PWA group had access to a smartphone, 62.5% had access to a tablet and 82.8% had access to a computer in their home. The corresponding numbers for the reference group were 94.8% for smartphones, 66.1% for tablets and 92.4% for computers.

Further, 60.9% of the PWA group and 85.0% of the reference group answered that they had used the national online health-care portal, called 1177, to receive public information

Table 4. Percentages of positive answers to seven of the multiple-choice questions.

	Yes	
Internet use, access to devices and use of the national online health-care portal	PWA (n)	Reference (n)
"Do you use the internet?"	90.6% (58)	96.8% (1080)
"Do you often ask someone for help to do things on the internet?"	43.8% (28)	14% (156)
"Do you have access to a smartphone?"	73.4% (47)	94.8% (1058)
"Do you have access to a computer in your home?"	82.8% (53)	92.4% (1031)
"Do you have access to a tablet?"	62.5% (40)	66.1% (738)
"Have you used the part of the national online health-care portal ('1177') that does not require a password?"	60.9% (39)	85% (949)
"Have you used the part of the national online health-care portal ('1177') that requires a password?"	51.6% (33)	85.8% (957)

Notes: Results are presented as percentages with the corresponding numbers in brackets.

Table 5. Negative answers to the question: "do you think it is difficult to use the internet?" and positive answers to response options for the follow-up question: "Please describe in more detail why the internet is difficult to use".

	PWA (n)	Reference (n)
"I do not think it is difficult to use the internet"	37.5% (24)	78.7% (878)
"Finding information is difficult"	17.2% (11)	1.2% (13)
"Navigating is difficult"	23.4% (15)	3.2% (36)
"Using services (for example ordering things) is difficult"	26.6% (17)	3.1% (35)
"Understanding the content is difficult"	21.9% (14)	1.3% (14)
"Passwords are difficult"	34.4% (22)	5.1% (57)
"It's difficult because the design and layout is disturbing"	17.2% (11)	1.1% (12)
"It's difficult because it doesn't work with my aids"	3.1% (2)	0.1% (1)
"It's difficult but I can't explain why"	7.8% (5)	1.1% (12)
"Don't know"	4.7% (4)	0.4% (5)

Notes: Results are presented as percentages with the corresponding numbers in brackets.

about health. From the same portal it is possible to log in to reach eHealth services and 51.6% of the PWA group and 85.8% of the reference group answered that they had used the part of that portal where a login is required to reach certain eHealth services (see Table 4).

The distribution of answers regarding the perceived difficulty of internet use differed statistically significantly between the two groups, with 37.5% of the PWA group but 78.7% of the reference group answering that they did not find it difficult to use the internet ($\chi^2 = 56.979$; $df = 1$; $p < .001$).

As regards what they considered difficult about the internet, 34.4% of the PWA group and 5.1% of the reference group mentioned the use of passwords. Other aspects mentioned include finding information, navigating, using services and understanding content

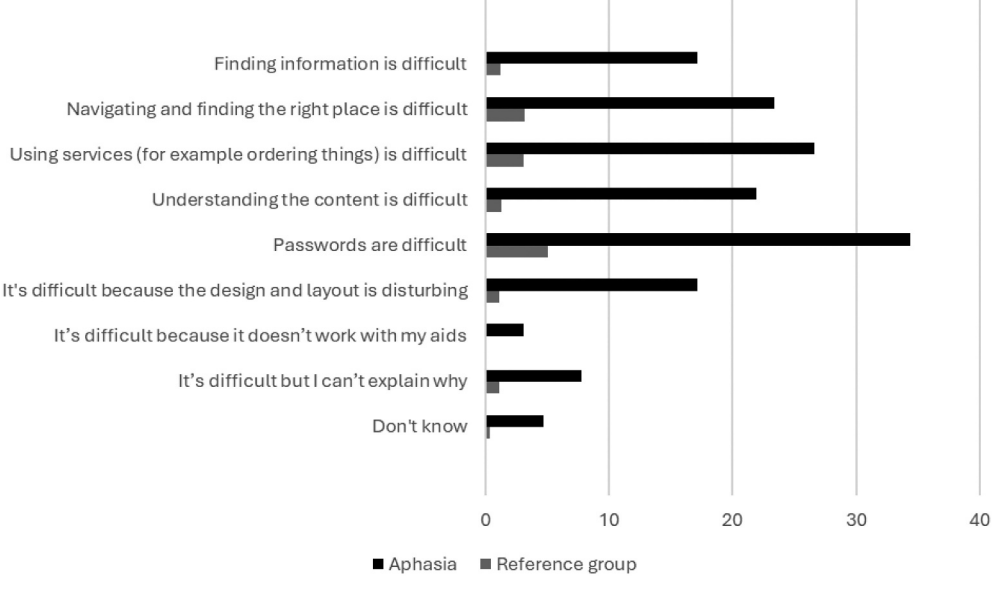

Figure 1. "Please describe in more detail why the internet is difficult to use". The figure shows the distribution of the positive answers to the above question, in percentages, for each group.

Table 6. Positive answers to the question: "have you used video health care-appointments?" and mention of the COVID-19 pandemic in answers to the follow-up question: "Please tell us more about your attitude to using video health-care appointments"..

"Have you used video health care-appointments?"		
	PWA (n)	Reference (n)
"Yes"	57.8% (37)	74.7% (834)
Yes, before the COVID-19 pandemic	12.5% (8)	9.4% (105)
Yes, during the COVID-19 pandemic	23.4% (15)	18.5% (207)

Notes: Results are presented as percentages with the corresponding numbers in brackets.

Table 7. Answers to the question: "do you feel included in the digital society?".

"Do you feel included in the digital society?"	PWA (n)	Reference (n)
"Yes"	43.8% (28)	78.8% (879)
"Partially"	28.1% (18)	17.2% (192)
"No"	15.6% (10)	2.4% (192)
"Don't know"	0% (0)	0.7% (8)

Notes: Results are presented as percentages with the corresponding numbers in brackets.

as well as the appropriateness of design and layout. These were rated as difficult by between 17.2 and 26.6% of the PWA group and by between 1.1 and 3.2% of the reference group (see Table 5 and Figure 1).

The distribution of answers regarding the use of online video health-care appointments differed statistically significantly between the two groups, with 57.8% of the PWA group and 74.7% of the reference group answering that they had used such appointments ($\chi^2 = 8.964$; $df = 1$; $p = .003$). Further, 12.5% of the PWA group and 9.4% of the reference group answered that they had used video health-care appointments before the COVID-19 pandemic, while 23.4% of the PWA group and 18.5% of the reference group reported that they had used them during the pandemic (see Table 6).

Finally, as regards to inclusion, 43.8% of the PWA group and 78.8% of the reference group answered that they felt included in the digital society. Further, 28.1% of the PWA group answered that they felt partially included and 15.6% that they did not feel included at all. The corresponding figures for the reference group are 17.2 and 2.4%, respectively. The distribution of the answers concerning digital inclusion differed statistically significantly between the two groups ($\chi^2 = 52.565$; $df = 3$; $p < .001$), with PWA less likely to report feeling fully or partially included than members of the reference group (see Table 7).

Table 8. Overview of findings from answers to open-ended questions.

Themes and sub-themes	
Theme 1	The internet imposes heavy demands
	Sub-theme: Heavy demands on the user
	Sub-theme: Heavy demands on technology
	Sub-theme: Strong need for training and access to support
Theme 2	The internet provides opportunities
	Sub-theme: Services via the internet
	Sub-theme: Social relationships via the internet
	Sub-theme: Compensatory strategies exploiting the internet

Findings from open-ended questions

The data from the open-ended questions were grouped into two themes: *The internet imposes heavy demands* and *The internet provides opportunities* (see Table 8).

The two themes, along with their associated sub-themes, are presented below. The quotations have been translated from Swedish into English by a professional translator and are intended to be as authentic as possible. However, it was not considered meaningful to attempt to reflect misspellings. Hence the English versions of the quotations are correctly spelled. The number after each quotation refers to the participant's survey ID.

Theme 1: the internet imposes heavy demands

The PWA described how the internet imposes heavy demands both on users and on their technological equipment. They identified associated challenges and highlighted the need for a continuous learning process and access to support. This theme has three sub-themes : *Heavy demands on the user*, *Heavy demands on and from technology* and *Strong need for training and access to support*.

Sub-theme: heavy demands on the user

Many of the PWA described how using the internet placed high demands on the user in several ways and how they often experienced using the internet as a big challenge. Using services and functions on the internet was often described as difficult and could involve feelings of inadequacy and frustration. The difficulties could be related to a variety of causes: "It's difficult to see the full whole, I don't understand the IT language, I'm slow, I don't write correctly, I make spelling mistakes" (455). Similar difficulties recurred regardless of the services, functions, apps or software discussed in the participants' answers. However, their experiences were not static but seemed to change depending on the activity, that is, depending on the specific service or function used, and also very much depending on whether the person was having a good or bad day: "Works a bit. But get quite a lot of help. Different" (866). The same dynamics applied to the experience of inclusion in the digital society, where sometimes the experience was of being left out: 'No, I'm behind and I've always been, I feel left out' (445). Even where the feeling was of digital inclusion, there could be variation: 'Reasonably well engaged in the digital society, with variations' (838). Some of the participants partly ascribed their experiences to symptoms associated with their brain damage, including fatigue and a reduced ability to concentrate: 'If I haven't done something for a long time, I forget about it' (925); 'A bit up and down. Depends on if fatigue. Then it doesn't work' (866). Further, the internet was experienced as a very fast-paced environment. It could be difficult for users to maintain the high speed required, and the fast pace meant that they needed a quiet environment when using the internet.

Difficulties related to navigation were reflected in the answers to several questions; this was a general problem. Participants described how navigation was made difficult because pages contained too much information and/or had too complicated a structure. Moreover, participants also experienced that the internet required good language skills and that many of their problems could be related to language difficulties associated with aphasia. A reduced ability to read and write posed major problems for them as internet

users, and being confronted with too much written information was a recurring problem. In addition, the information was often in a language other than their own (i.e., in English): [If yes, what do you usually ask for help with?] "Sometimes when there's a lot to go through, it's important to ensure that everything's completely correct, especially if it's something that's very important and written in English" (958).

Further, the participants described how communication with the health-care services could be slow and poor, and how it could take too long to receive a (written) answer to a (written) question: 'If you send messages to the local health centre, it often takes several days before you get an answer. Once the answer comes, you can't communicate. What you get is an answer that you can't respond to if there are misunderstandings' (1597). The participants stated that good language skills were also a prerequisite for participation in spoken online meetings. They described how video health-care appointments could pose major challenges for them, especially if several people were involved in the same meeting. The video meetings imposed heavy demands in terms of communicative skills not only on themselves as users but also on other meeting participants, that is, health-care professionals. They had experiences of health-care professionals failing to adapt their own communication during video health-care appointments involving a PWA: 'In addition, the health-care workers talk too fast and don't take my disability into account' (173). Adequate language skills together with an ability to adapt one's communication were highlighted as important, both since the meeting was online and based on who were involved in it. The language requirements thus applied to the participants themselves as well as to others who took part in online meetings.

Sub-theme: heavy demands on and from technology

The participants experienced that internet use imposed heavy demands on the technological equipment they used, and also that familiarising oneself with new and changing aspects of that technology could be very time-consuming and tiresome. Some of the participants described how they did not always have sufficient knowledge about available devices and technology nor about how to obtain them. Further, in the participants' experience, not only did the internet require them to have devices that were fundamentally adequate, but those devices also had to be updated to work effectively, and this could be problematic. For example, changing to a new smartphone and thus having to move apps, content and adaptations was described as something avoided if possible: 'Now I'm worried about possibly changing phones, moving apps, and so on' (445). Further, the participants described how content and applications required a high storage capacity to function efficiently: 'I've got a planning aid but it doesn't work as it should and this may have something to do with storage' (414). What is more, in cases where there was not enough storage space, the storage capacity had to be extended, and this could cause additional problems.

Issues related to logging in and to passwords were described as a general problem in the answers. Sometimes the means of identifying oneself required technological solutions that were not available on all devices. For example, the scanning of QR codes requires an online camera. The participants also described how, for example, a login function might suddenly require them to split their focus and pay attention to changes in the interface that were not always easy to follow: 'Often a completely new tab is started when I've

logged in and it sometimes takes a while before I understand that the new tab is the one where I need to log in.' (567). The responses also revealed some concern that there could be certain risks associated with using the internet: 'There are risks, be careful what you say and buy' (516). In this context, the participants described uncertainty about what combination of devices, operating systems and applications could provide sufficient internet security.

Sub-theme: strong need for training and access to support

The participants experienced that both training and continuous support were required for them to be able to use the internet. Staying updated and continuously trying to learn everything new was described in terms of hard work: 'But it's a kind of "work", it takes energy, brain fatigue' (523), or as 'finding your way through a jungle' (445). The participants described how it took them a long time to get started, both with using the internet in general and every time they connected to the internet. They could require a long start-up period upon "re-entry": they had to (re-)learn the technology and how the service or function in question worked. In their experience, they needed – and were sometimes completely dependent on – help and support from others, especially at the beginning, although there was also a need for continuous support. Family members provided help and support for many of the participants: 'my sister' (925), 'my husband' (875) or 'my wife' (838), but the participants also mentioned others, such as health-care professionals who had taught them how to use the internet and supported them in doing so. Some participants had been offered online courses. However, participating in them was described as difficult owing to the fast pace followed and the fact that the level was generally too high.

The participants had also experienced that support functions required specialist knowledge and expertise on the part of the user, who had to be able to describe the problem well enough to receive adequate help, noting that they lacked such expertise and/or were not able to express it. When the participants were asked to specify what they needed help with, they described a variety of issues. They needed help with technical issues, computer problems and dealing with system or software updates. They also described how support was often needed for navigating, logging in and using passwords as well as for reading information. Further, support was needed to contact authorities, the health-care services and insurance companies, and to engage in online shopping.

Theme 2: the internet provides opportunities

The participants described how internet use could provide new opportunities for interaction and how the internet could simplify everyday life in various ways. This theme has three sub-themes: *Services via the internet*, *Social relationships via the internet* and *Compensatory strategies exploiting the internet*.

Sub-theme: services via the internet

The participants described using internet services provided by government authorities such as the Social Insurance Agency and the Police, as well as websites with health-care information: 'Good, in principle easy to use' (455). Further, the internet was used for

contacts with insurance companies and for online shopping. The participants also noted that good apps were needed to use the services in question and that their smartphones were their primary internet devices. They used their smartphones and tablets to stream online content and to listen to audiobooks, and they used their computers when they needed to print something on paper. The computers were also used for aphasia-treatment software.

Sub-theme: social relationships via the internet

Some of the participants described using the internet to maintain social relationships and to stay in touch with friends and family: 'It helps me to keep in touch with people I can no longer see because they live far away' (1597). They described positive experiences of communicating through texting, chat functions, Messenger and e-mail as well as online video meetings, using their smartphones and sometimes tablets. The participants said they were active on various social media and communication platforms such as Facebook, Instagram, WhatsApp and Messenger. Further, using the internet could give them access to places far away.

Sub-theme: compensatory strategies exploiting the internet

The participants described how the internet could make everyday life easier, noting that they had found strategies to exploit the internet in order to partially compensate for difficulties caused by their aphasia. The internet made it possible to obtain an overview of, for example, booked doctor's appointments and items bought, and it also enabled the participants to do their own market research and find the best prices. The participants liked being able to ask for home delivery: "It's nice that I can stay at home, search for information and then order things delivered to my doorstep" (1756). Further, they appreciated how the internet gave access to written information, expressing that it was good to be able to choose writing instead of speaking on some occasions. In addition, they exploited online writing support such as speech-to-text software (voice recognition) and used the internet for support when needing to perform calculations. Video health-care appointments were perceived as a good complement to physical meetings: 'I prefer physical meetings, but I see video meetings as a good complement if a physical appointment is difficult' (657). Other positive aspects of video health-care appointments included avoiding trips to and from the hospital and not having to wait in a telephone queue. Constantly learning new things and encountering new online phenomena was often experienced as a struggle, but the descriptions also reflected a strong motivation to learn more and to overcome difficulties: 'Once you learn to use them, they are fantastic aids!' (838). The participants additionally mentioned a wish to encourage others and teach them about the internet.

Discussion

The aim of the study was to explore experiences of using the internet and digital participation among people with aphasia (PWA) in Sweden by analysing data from an online survey undertaken in 2021. Over 90% of the PWA answered that they used the internet. However, this is a significantly smaller proportion than in the reference group, and the PWA were also less likely to report feeling fully or partially included

in the digital society than the members of the reference group. There were differences between the groups in access to various devices such as smartphones, tablets and computers at home. However, access to the internet and digital devices seemed not be the main obstacle to digital participation for the PWA. Rather, what caused them problems was a combination of different factors, including in particular the constant need to learn and re-learn how to use internet technology in general. The PWA in this study describe how constant updates, the introduction of new technological solutions for emerging services, and the discontinuation of older services all place heavy demands on users as well as on technology. This is in line with earlier research indicating that the pace and ever-changing dynamics of the internet make it hard to use, preventing PWA and others with cognitive limitations from enjoying and benefiting from all the opportunities offered (Chadwick et al., 2022; Danchikov et al., 2021; Halupka, 2014; Johansson, 2016; van Deursen & Helsper, 2015; Westlund, 2015). Hence the findings of this study are consistent with previous research, which highlights that internet usage and internet access are complex issues involving numerous interrelated factors (e.g., Johansson et al., 2021; Menger, 2018; van Dijk, 2012).

One area that may be of particular interest, given that data collection took place during the COVID-19 pandemic, is whether PWA benefit from the use of eHealth. Previous research by Cacciante et al. (2021) and Cetinkaya et al. (2024) has shown its potential for treatment, and there are benefits such as reduced costs and less time spent travelling (Cetinkaya et al., 2024; Øra et al., 2020). However, the results of this study indicate that this potential is not yet realised, at least not in a Swedish context. The PWA reported a lower level of engagement with online health-care information and eHealth services than the members of the reference group, and the difference was greater for contexts where passwords were required. Difficulties in accessing online health-care information are probably due to a combination of factors, including the use of passwords. In the case of online interaction with health-care professionals, however, a particular challenge concerns the need for those professionals to become better at communicating in ways that facilitate online communication and make it more accessible to PWA. Even so, it is worth noting that, although the reference group used video health-care appointments to a statistically significantly greater extent than PWA, the results suggest that PWA did increase their use of such services during the pandemic.

The internet typically requires its users to have highly functioning language skills in both reading and writing (Menger, 2018; Menger et al., 2020). These are functions strongly affected by aphasia, making PWA a group that struggles with the use of the internet. This is reflected in the fact that the PWA in this study were statistically significantly more likely to report general difficulties using the internet, as has also been reported by others (Johansson et al., 2021; Menger, 2018). Functions that many users perform quickly and effectively, such as finding information, navigating, using passwords and processing content, were reported as difficult by many more PWA than members of the reference group.

Difficulties due to general problems with reading and writing may then be exacerbated by difficulties related to the use of a specific service and the design of that service. Studies have shown that many PWA have a restricted autonomy and are dependent on others when using the internet (Finch & Hill, 2014, Cruise et al., 2021; Burke et al., 2022). Further, that support must be continuous and tailored to each person's needs (Finch & Hill, 2014,

Cruise et al., 2020; Burke et al., 2022). Similar findings emerged in this study, where the results indicated statistically significant differences in the need for assistance. While more than 40% of the PWA reported that they required help using the internet, only approximately 15% in the reference group did.

As mentioned earlier, the PWA in this study felt included in the digital society to a lesser degree than the members of the reference group. However, they also emphasised that, even though internet use is time consuming and often associated with hard work, they also had positive experiences and considered that the internet can make everyday life easier, for example when it comes to keeping in touch with family members living far away and having items bought online delivered directly to one's home. In addition, they also believed that the internet could partially compensate for their aphasic difficulties.

Strengths and limitations

To achieve trustworthiness, a detailed and transparent description was provided of the research process, which includes a structured analytic procedure and the presentation of quotes from participants (Lincoln & Guba, 1985). One strength of the study is its use of mixed methods with a convergent design including the collection of both quantitative and qualitative data. The underlying assumption was that the analysis of data from the qualitative analysis of free-text responses would complement the quantitative analysis of responses to questions with fixed or multiple-choice response options by yielding a deeper understanding of why and in what ways PWA have difficulty using the internet and of how they experienced living in a digital society. One weakness is that, since the participants in the study had self-reported aphasia, no information is available about the type or degree of aphasia or about time post-onset. However, the fact that the survey was distributed through the national aphasia association may have contributed to strengthening reliability in terms of ensuring that participants really had aphasia. Transferability is influenced by the very special circumstances obtaining at the time of data collection: Data were collected in 2021, when the COVID-19 pandemic was having a major impact on society. Most aphasia centres in Sweden were closed during this period and the activities of the Swedish Aphasia Association were largely cancelled. This had an impact on opportunities for on-site sampling of answers, entailing that the majority of PWA participants were internet users and so cannot be considered to represent all people with aphasia, especially not those with extensive language difficulties.

Implications and future directions

The problems using the internet reported by PWA could be indicative of similar problems experienced by people with other cognitive impairments, especially people with reading and writing difficulties. Involving PWA in the design of web services and the production of content for such services has been tried successfully (Roper & Skeat, 2022; Roper et al., 2024), and such co-design processes involving PWA could potentially benefit a far broader population. In that sense, PWA could be seen as representing an extreme user perspective that could help ensure more usable web services for all. In other words, a web design that makes the internet easier for PWA may make it easier for many others as well. If interfaces had a more usable and accessible design, and if the content were easier to understand,

more PWA would probably be able to use the internet without having to increase their skills. Here it should be noted that "increasing one's skills" is a double process for PWA: It involves not only becoming better at using the internet but also becoming better at underlying basic skills. Shifting the focus from access to skills (Hargittai et al., 2019), and further to "internet outcomes" (Scheerder et al., 2017), provides a nuanced understanding of the complex phenomena of participation in the digital society. Since most surveys do not report either aggregated or disaggregated data regarding impairment, it is important to draw upon national (SCB, 2024; Swedish Internet Foundation, 2023) or transnational (Eurostat, 2024) surveys to explore the situation for small populations such as PWA (Johansson, 2019).

We suggest that the path to a more accessible and usable internet for PWA involves a three-fold approach: (i) enhancing the skills of PWA; (ii) providing a support system adapted to PWA's demands; and (iii) calling upon the web-design community to enhance the quality of design outcomes in order to make the internet usable for a wider range of the population. Producing designs that will benefit PWA taps into the broader concept of cognitive accessibility (International Organization for Standardization [ISO], 2020). Efforts to achieve this will benefit from growing knowledge about how to design for people with a variety of cognitive impairments (Gartland et al., 2022).

Conclusion

PWA are a group at risk of having only limited opportunities for digital participation. Although the level of internet use reported by the PWA who participated in this study is fairly high, it remains significantly lower than that of the reference group. The PWA report significant challenges in using the internet, while simultaneously expressing a clear and strong desire to engage with it for a diverse range of purposes. Rather than simply accepting that the internet is often too challenging for PWA, it may be more beneficial to focus on developing web designs and support systems that work for all users, PWA included.

Acknowledgements

The authors thank all the people who so willingly answered the survey. Special thanks to the two former speech and language therapy students, Linda Eriksson and Therese Westlin, who conducted the initial analysis of the survey as part of their Master's thesis in speech and language therapy.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the the Swedish Aphasia Association; the Swedish Stroke Association; FORTE – Swedish Research Council for Health, Working Life and Welfare [Grant number 2021-01875]; Center for Clinical Research Dalarna.

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