

## "My words were completely gone." A qualitative study of the information seeking behaviour of people with aphasia

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**Introduction.** Aphasia is an acquired language impairment, which affects the production and comprehension of speech, reading and writing. Aphasia is associated with great cognitive variation, but a common marker is impaired word retrieval. Searching for information requires several language related skills, such as naming, spelling and reading skills. Consequently, aphasia may have an impact on information seeking behaviour.

**Method.** Seven participants with aphasia were interviewed about their information seeking.

**Analysis.** The data were analysed and organized into categories, derived from themes in the interview guide and the dataset.

**Results.** Information needs were typically solved by asking someone, or through word mobilising search strategies. The participants reported extensive searching for images and synonyms, with the overall purpose to identify adequate query terms. Browsing was preferred over direct searching. Furthermore, certain information needs did not result in any information seeking, because searching activities were considered too strenuous.

**Conclusions.** The findings from this study suggest that an information architecture that facilitates browsing and image search can make Web content more accessible for people with aphasia. Moreover, there is a need for future research on search user interface design that better accommodate people with aphasia in general and impaired word retrieval skills in particular.

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### Introduction

Searching for information is a vital part of most people's lives. Information is easily available online and can be accessed through a variety of devices and services. Actually, information is so fundamental in our society that the rights to information is embedded in the Convention of the Rights of Persons with Disabilities ([United Nations, 2006, p. 2](#)). In this convention, information is referred to as one of the basic components for "*enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms*". Not all people, however, have easy or adequate access to information e.g., persons with various disabilities, such as people with aphasia. Nevertheless, little research has addressed this user group ([Berget and MacFarlane, 2020](#)).

According to Hilari ([2011](#)), the most common cause of long-term disabilities in the western world is stroke. While several studies have addressed the quality of life of people with stroke, aphasia is often excluded from such studies ([Hilari, 2011](#)). Although the study by Hilari ([2011](#)) was published a decade ago, this still seems to be a valid conclusion, and was confirmed in a review by Berget and MacFarlane ([2020](#)). Consequently, there is a need to know more about this cohort in many contexts, including information retrieval.

Aphasia can be described as "*the loss of or radical change in voluntary speech as a consequence of damage to the left cerebral hemisphere*" ([Spaccavento et al., 2014, p. 28](#)). There is a variety in impairment and task performance among people with aphasia, from mild challenges in finding words to a complete inability to understand and produce language ([Fridriksson et al., 2018](#); [van de Sandt-Koenderman et al., 2012](#)). Common for most people with aphasia is language and speech impairment related to reading, writing, auditory comprehension and verbal expression ([Spaccavento et al., 2014](#)).

All of these language impairments cause potential challenges during search, for instance when identifying proper search terms, inputting queries and reading through result lists. Consequently, many people may be excluded from activities such as searching and seeking for information and may also encounter various barriers when using search systems. This exclusion might cause a loss of empowerment and have serious issues in context of privacy protection, because many people with aphasia may be reliant on others to solve their information needs. Moreover, there is a risk of severe, unsolved information needs. These are among the issues addressed in this paper.

There is a variety in the loss of skills in reading, writing, auditory comprehension and verbal expression among people with aphasia ([van de Sandt-Koenderman et al., 2012](#)). This paper mainly focuses on participants with intact language comprehension, where the ability to form words and complete sentences, also referred to as word retrieval skills, are impaired. The overall goal is to get a better understanding of how this cognitive impairment impacts the information seeking behaviour. All the participants in this study had aphasia as a result of stroke, with mild to moderate communication/language challenges.

This paper reports the findings from a qualitative study comprising in-depth interviews with seven adults with aphasia, addressing the following research question:

*RQ: What is the impact of aphasia on information seeking?*

The main assumption was that impaired language skills would affect the information seeking behaviour. The overall purpose was to get a better understanding of potential challenges users with aphasia may experience when solving information needs. Another purpose was to identify key issues that could be addressed in a larger user study. It was also an aim to direct attention towards a heavily overlooked user group, and to provide some advice to researchers,

librarians or information specialists working with this cohort. The paper is structured as follows: first, the background will introduce aphasia and information seeking in context of cognitive characteristics and functional differences. This section is followed by methodological considerations, findings, a discussion, and a conclusion. The findings of this study have implications for both further research in this area and provide some advice on search user interface design.

## Background

### Aphasia

Berthier ([2005, p. 164](#)) defines aphasia as,

*a loss or impairment of the complex process of interpreting and formulating language symbols caused by acquired brain damage affecting a widely distributed network of cortical and subcortical structures of the language-dominant hemisphere.*

Examples of diseases or injuries that can cause brain damage are brain tumours, external head injuries, progressive diagnoses such as Alzheimer's disease or dementia, and stroke.

Stroke is the most common cause of aphasia ([Raymer and Gonzales Rothi, 2018](#)). According to Berthier ([2005](#)), 21-38% of stroke patients are diagnosed with aphasia. It is estimated that the prevalence of aphasia is approximately 0.1-0.4% of the population. It is assumed, however, that this number will increase due to longer life expectancies and a higher number of people who survive stroke ([Code and Petheram, 2011](#)).

Language challenges related to aphasia can manifest in various ways. Some people can produce long sentences, but the content often lacks meaning. In other cases, the language comprehension may be intact, but the ability to form words and complete sentences is impaired ([Hazamy and Obermeyer, 2020](#)). As aphasia affects communicative functioning, this condition impacts both performance and participation in many daily activities, such as reading, writing, listening, social participation ([Pitt et al., 2019](#)) and participating in work life, which can heavily affect quality of life ([Mozeiko and Pascariello, 2020](#)).

There are different stages or phases of aphasia. The first phase is the acute, which may also be referred to as the hospital phase ([Avent et al., 2005](#)). This is followed by the subacute phase, also named the rehabilitation phase, and finally the chronic phase, where the person returns home ([Avent et al., 2005](#)). This study is directed towards the chronic stage. According to Johnson et al. ([2019](#)), after entering the chronic stage of aphasia, language impairments remain quite stable.

Signs and symptoms of aphasia vary from mild to severe, depending on the location of the brain injury, the severity of the damage and type of aphasia. The

rehabilitation must therefore be individually tailored ([Vallumrød et al., 2016](#)). Further, the rehabilitation should be holistic to improve functional ability both linguistically, mentally, and socially to accommodate for active participation, self-realisation and communication. An interdisciplinary teamwork in the rehabilitation of aphasia is therefore needed, involving speech therapists, doctors, nurses, social workers, psychologists and occupational therapists ([Raymer and Gonzales Rothi, 2018](#); [Vallumrød et al., 2016](#)).

Although assistive technology may be helpful, it has been reported that software such as speech-to-text and word-prediction might be challenging to use for people with aphasia ([Kjellén et al., 2017](#)). Many people also rely on help from others for reading and writing support ([Knollman-Porter et al., 2015](#)). For several users, rehabilitation will not recover all previous skills. Therefore, it might not be a realistic goal to become completely independent of the help from others. It is, however, regarded as a goal to become autonomous ([Kjellén et al., 2017](#)).

## Approaches to information seeking

In the information-seeking framework developed by Marchionini and White ([2007, p. 207](#)), the information seeking process starts when the user '*recognizes a need for information and accepts the challenge to take action to fulfill the need*'. This initiation phase is predominantly cognitive and precedes contact with information systems. Consequently, little system support is given at this point. Marchionini and White ([2007](#)) argue that systems that are easy to use will support people in accepting more information needs, because they feel confident that they will manage to solve their need. Various tools can be applied when formulating information needs, such as thesauri, encyclopaedias or dictionaries. Where needs are not well formulated, however, Marchionini and White ([2007](#)) argue that browsing can be more efficient than searching.

Search behaviour is closely associated with type of information needs. According to Ingwersen ([2000](#)), there are three types of information needs, which may result in various forms of information retrieval behaviour. These needs are verificative needs, conscious topical needs and muddled or ill-defined needs. Ingwersen ([2000](#)) also divided information needs into a matrix, and defined information needs as well-defined or ill-defined and stable or variable. In this matrix, both types of well-defined information needs are solved through searching, whereas ill-defined variable information needs result in browsing. The browsing is, among others, related to cognitive uncertainty ([Borlund and Dreier, 2014](#)).

Bates related browsing to information being '*recognized as relevant only upon discovery*' ([Bates, 2007, Introduction](#)). This phenomenon is in accordance with the basic principle of recognition over recall within the field of human-computer interaction ([Norman, 2019](#)). According to Bates ([2007, Introduction](#)), '*browsing is often the only way to locate information and resources that cannot be readily described by index terms*'. Searching requires planning, knowledge of search

terminology, query formulations and knowledge of the information system. In contrast, browsing entails less cognitive load ([Marchionini, 1995](#); [Rosenfeld et al., 2015](#)). According to Xie ([2017](#)), a highly organized information environment is required, however, to support low cognitive effort in browsing.

## Information seeking and cognitive skills

Information seeking is closely related to literacy. Reading and writing skills are required for various search related activities, such as inputting queries in search systems, assessing result lists and reading through documents ([Berget and MacFarlane, 2020](#)). People with aphasia often experience challenges with reading and writing, among others due to impaired technical skills ([Kjellén et al., 2017](#)). Abilities to read and write are closely connected to the severity of the aphasia and level of recovery ([Kjellén et al., 2017](#); [Knollman-Porter et al., 2015](#)). There are variations according to diagnosis. Nevertheless, many people experience difficulties understanding word meanings and/or object identities, dissolution of syntax, and/or language form, phonological impairment, or simplified grammar ([Lee and Wu, 2013](#)).

Literacy skills among people with aphasia may, however, improve through rehabilitation. Many people have a great motivation to regain some of these skills, among others by engaging in work related activities or through reading as a social practice ([Lynch et al., 2013](#)). Another goal is to be able to retrieve relevant information about topics such as aphasia, health services and rehabilitation ([Worrall et al., 2011](#)). Consequently, information seeking is an important aspect to address for this cohort.

Word retrieval skills are also required for many information seeking activities, such as formulating queries. A common marker for aphasia is anomia, or impairment in word retrieval. Anomia results in challenges retrieving certain words during production of text or in conversations ([Lavoie et al., 2016](#)). Anomia is experienced by most people with aphasia independent of diagnosis type. Finding the proper words are important when expressing information needs and formulating search queries. Previous research has shown that query formulation may be challenging for all types of users. The challenge of formulating vague information needs or unfamiliar topics where the user does not know the form of the answer has been discussed for decades within the field of information retrieval by many researchers, such as Belkin et al. ([1982](#)), Ingwersen ([2000](#)), Marchionini and White ([2007](#)), Taylor ([1968](#)) and Wilson ([1999](#)), to name a few. Based on the premise that users in general may have challenges in expressing needs, one may assume it is even more challenging for people with anomia.

## Information seeking and functional differences

Although there is little knowledge concerning how aphasia affects information seeking ([Berget and MacFarlane, 2020](#)), there are studies showing that aphasia results in increased needs for health information regarding stroke, aphasia

([Worrall et al., 2011](#)) and rehabilitation ([Dixon et al., 2007](#)). Mangset et al. (2008) found that dialogue and exchange of information were important for people with aphasia, and closely related to being treated with dignity and respect. Many of the participants in the study by Mangset et al. (2008) reported that they had unanswered questions, and that it was challenging to ask questions regarding sensitive topics. Others have addressed the quality and accessibility of information about aphasia ([Hinckley et al., 2013](#); [Rose et al., 2010](#); [Rose et al., 2011](#)). The need for clearer guidelines regarding aphasia information from the perspective of family members has also been addressed ([Avent et al., 2005](#)).

Barriers related to invisible disabilities, such as aphasia, were discussed by Muir, Thompson and Qayyum (2019) in a library context. Muir et al. (2019) pointed out challenges in being able to ask questions to library staff due to language impairments and emphasised a need to look more closely at staff behaviour and attitudes. Menger et al. (2017) address general challenges related to using the Web for people with aphasia and stress a need for more accessible technical solutions.

There is a huge gap in research regarding this cohort and information retrieval ([Berget and MacFarlane, 2020](#)). Nevertheless, there is research on other users with cognitive impairments that may be relevant. Dyslexia and aphasia are associated with some similar characteristics. Impaired phonological skills is also a common marker for dyslexia, resulting in challenges with reading, and writing ([Richlan, 2020](#)). Dyslexia is further associated with impaired naming skills and reduced short-term memory capacity ([Smith-Spark and Fisk, 2007](#)).

In dyslexia research, spelling skills have been found to affect query formulations in systems with low tolerance for spelling errors ([Berget and Sandnes, 2015](#)). Search engines, such as Google, are typically preferred, due to tools like autocomplete and image search. Reduced short-term memory capacity and impaired reading skills may have an impact on result list assessment ([Kvikne and Berget, 2019](#); [MacFarlane et al., 2010](#); [MacFarlane et al., 2012](#)). Images have also been reported as a useful aid in assessing result lists ([Berget, Mulvey and Sandnes, 2016](#); [Morris et al., 2018](#)). People with dementia are another potentially relevant user group. This is, however, also a cohort that has been heavily overlooked within the field of information retrieval ([Berget and MacFarlane, 2020](#)). Consequently, there is little research from this field with transfer value to aphasia.

## Method

### Participants

The sample comprised seven adults; four men and three women aged 50-68 years (see Table 1). They were all diagnosed with aphasia due to stroke, occurring in the period 2010-2019. The degree of language impairment varied according to the severity of the stroke and rehabilitation stage. All the participants were in the

chronic phase. This sampling may have caused a recruitment bias. However, people in the acute or sub-acute stage may not have adequate language skills or a state of health that makes it ethically sound to include them in a research project.

Five participants were recruited with assistance from the Norwegian Aphasia Association (Afasiforbundet) and two from an extended network. The inclusion criteria comprised the ability to give informed consent and have sufficient language skills to complete an interview.

Participant	Sex	Age	Diagnosis year
P1	F	51	2017
P2	M	67	2012
P3	F	50	2016
P4	M	65	2015
P5	M	61	2017
P6	F	56	2019
P7	M	68	2010

**Table 1: Participant data**

Before the interviews, the participants conducted a test called *Dagliglivetsten*, which is a simple screening test for anomia. This test made it possible to confirm a certain level of impaired word retrieval skills without consulting sensitive medical journals. *Dagliglivetsten* (*The daily life test*) consisted of fifteen photos of common objects ([Statped, 2021](#)). The participants were given twenty seconds to name the object in each photo. Time and precision were measured.

The participants were at different stages of the rehabilitation process. The naming test showed variations both in percentage score and time spent but were all indicative of impaired word retrieval skills at some level (see Table 2). There are no reference values for this test, so there is no method to categorize the participants further. They can, however, provide an idea of the degree of impairment of word retrieval skills based on a low score and/or high time usage. For instance, there were huge differences between participant P2, P5 and P7 compared to the other participants, which indicate a higher level of word retrieval skills. This was a screening test applied to confirm impaired word retrieval skills, and not a comprehensive diagnostic test. Consequently, these data were not used directly in the data analysis, except for confirming the inclusion of the participants in this study.

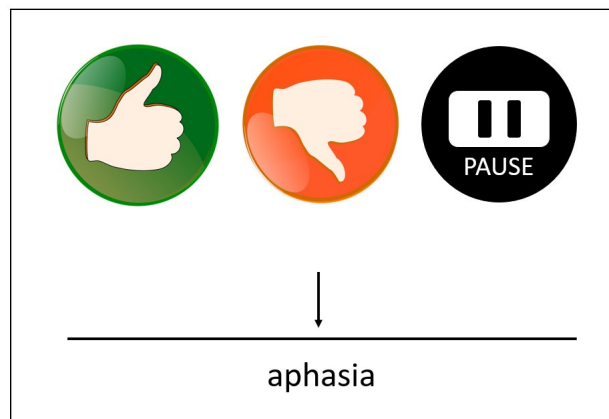
Participant	Score	Time
P1	93%	1 min. 55 sec.
P2	100%	50 sec.
P3	87%	1 min. 21 sec.
P4	93%	1 min. 43 sec.
P5	100%	50 sec.
P6	100%	1 min. 03 sec.
P7	100%	40 sec.

**Table 2: Word retrieval test results**

## Procedure

The overall purpose was to better understand how aphasia affects information behaviour from a user perspective. Considering the lack of research in this field ([Berget and MacFarlane, 2020](#)), the research question was explored through in-depth interviews using a semi-structured interview guide. Due to varying communication skills, supportive conversation techniques were applied. Examples of such communication support strategies were printed sheets showing icons and a time scale (see Fig. 1), writing materials and blank sheets of paper for drawing in addition to handouts with all the questions and topics in the interview guide. The latter was prepared to provide participants with additional input in form of reading to ensure a proper understanding of each question. This strategy was suggested by a speech therapist during the initial planning of the research design.

Technical devices were not included in the research design. Nevertheless, five participants used their smart phone when they had challenges expressing themselves or remembering words. In these cases, the participants showed examples of, for instance, apps they often applied when they did not remember the name. The descriptions of what the participants showed on their phones were included in the transcribed interviews and included in the analysis.



**Figure 1: Communication sheet used at the interviews**

The interview guide addressed a few essential topics, such as perceived changes in information behaviour, digital search strategies, preferences in user interfaces and social participation. Examples of question asked were:

- How do you experience information searching after being diagnosed with aphasia?
- How are you using digital information systems, such as computers, tablets or smart phones now, compared to before being diagnosed with aphasia?
- How do you prefer solving different information needs?
- Have (possible) changes in search behaviour somehow had any influence on social participation?
- Do (if established) word mobilizing challenges somehow affect the search process? If so, in what way?



In addition, the interview guide consisted of a more detailed list of questions as support for the interviewer. The questions were formulated in several different ways, in case the participants needed reformulations or synonyms to grasp the questions. An example of this was as follows: What do you do / how do you proceed if you struggle / have challenges with word mobilizing / cannot find the desired word / name when searching / solving information needs?

Comprehensive questions and response alternatives were also included in the interview guide, in case they were needed. These alternatives, however, were only used if the participant struggled with finding the word after several attempts. This is in accordance with the suggestions put forward by Luck and Rose ([2007, p. 208](#)) regarding interviewing people with aphasia: '*with participants with aphasia, the researcher is required to step out of the traditional role of the qualitative interviewer by altering questioning style, offering ideas to participants, and using supportive conversation techniques*'.

There were no time limits for the interviews, and the participants could take as many breaks as needed. The overall session comprising the naming test and interview lasted from half an hour to one-and-a-half hours and were executed in February 2020. Four of the interviews were completed at a speech therapists office, while three were in the homes of the participants. Communication aids brought by the interviewer were frequently used, as well as the participants' own smart phones to illustrate topics they were talking about, e.g., search strategies.

Interviews were recorded and later transcribed and anonymized. The transcribed interviews were manually coded according to categories included in a codebook based on predefined categories extracted from the interview guide and theoretical concepts. A few categories were added in the codebook based on the thematic analysis.

## Ethics

The research project was approved by NSD, the Norwegian Social Science Data Services with project number 292602. Data collection, storage of data and anonymization were carried out in accordance with guidelines from NSD. The participants were informed about the study through an information letter, also available in a simplified version. The participants were informed about voluntary participation, the possibility to withdraw without negative consequences, anonymization and storing and deletion of data.

All participants had language challenges. Therefore, the information in the recruitment letter was also presented orally before participants signed consent forms. Clear and plain language was highly emphasised in all documents and conversations. During the interviews, references were often made to work tasks related to the occupation or education of the participants. These data were removed during transcription, due to privacy protection. The key file was stored separately from the data material and deleted in accordance with the guidelines

from NSD.

## Findings

The starting point for this study was the research question: *What is the impact of aphasia on information seeking?* Main topics were how information needs were solved, preferred information sources, user interface design, search strategies and potential barriers. Other topics discussed were more general in nature, and addressed more abstract concepts, such as outsidersness and self-esteem. In this findings section, the topics related to barriers and information seeking strategies are presented first, followed by the more general topics.

Due to impaired word retrieval skills, many participants spent much time during the interview to answer each question. In the citations below, three dots are added to indicate particularly long pauses. Content in brackets describes what the participant did during the interview or specifies the word the participant tried to express.

### Relying on help from others

All participants reported changes in their information seeking behaviour after being diagnosed with aphasia. The acute and subacute phases were described as particularly difficult due to challenges with word retrieval. P7 described the situation like this: *'My words were completely gone'*. Information retrieval was not a main activity in these phases, due to impaired word retrieval, fatigue, disorientation, and paralysis. Nevertheless, various information needs gradually emerged, and it was important to find strategies to solve them.

A total of five out of seven participants relied on other people when seeking information. P5 said:

*I had to ask people. It was unrealistic for me to search anywhere. I needed help. After a while I was offered a rehabilitation team from the local authority. They helped me with practical things like searching. And the speech therapist gave me search tasks.*

P7 emphasised that in the early stages after the stroke, other things were more important than information retrieval:

*No, I did not use the web for searching, I had my hands full.*

This was also discussed by P1:

*To begin with, I asked someone. My language was almost completely gone. I didn't search for anything the first months.*

Other people were typically consulted to do the actual search, as P2 reported:

*My partner helps me. Yes, she searches for me.*

P3 had the same experience:

*It depends on what it is, but I still often ask my son who is helpful and searches quickly on his phone.*

## Expressing the information need

The information seeking behaviour varied according to type of information need and the degree of anomia. A total of six participants described a need for a 'pre-search' before the actual search. This strategy resulted in two searches. The purpose of the first search was to retrieve the precise words to be able to express the information need. The second search was the actual query formulation inputted in the search system to solve the information need. This approach was a radical change in their search behaviour prior to the aphasia. When asked about potential changes in search behaviour due to aphasia, P6 said:

*The way I search... Now I search for ways to search more than I used to before.*

Google was the preferred source in this initial 'word retrieval phase'. Reasons for this choice were, among others, the autocomplete function, autocorrect and the image filters. These tools were useful because many participants reported impaired naming skills due to aphasia:

*I start typing a word then Google suggests things. Or sometimes it says 'did you mean' or Google just corrects it (P3).*

A frequently applied strategy in the word retrieval phase was to input synonyms or sentences that describe a situation into the search box. P6 explained the process as follows:

*I'm trying to search for related words, because I know a specific concept exists that buzzes around in my head.*

Both single words and sentences could be applied in this process:

*If I am trying to find a word, I might search for a word that is similar, or that I think might be similar. I try to find a synonym, for example, or something related. It may be that I use a sentence, describing that situation for example or something like that (P6).*

Having a repertoire of synonyms was also described as useful:

*The problem was that I knew what I was going to search for but couldn't find the word. But as I memorized synonyms, the words came back to me (P5).*

In certain situations, both word retrieval and spelling were regarded as

challenging. In these cases, image search was regarded as purposeful, i.e., to filter on images and select relevant images from the result list. This search behaviour resulted in retrieving relevant words and seeing their spelling. All participants referred to examples of such situations. P5 explained this approach as follows:

*Because if you don't have reading skills or don't understand words, images can be very helpful. It is a favourable approach. You can find the words via images. It's a detour, but for me it was the only way. And it helped me out of my struggles. Images, or icons were essential.*

P5 elaborated on this:

*It is all about finding the right key to find the information. To find as many keys as possible. In my opinion, one of those keys are images. Another is synonyms. To me, the first year, images and synonyms, those two keys were decisive for finding any information at all.*

P1 referred to searches via more general concepts and images:

*It happens all the time... I describe something similar. If the word I cannot find is 'oatmeal', for example, then I search for porridge. Then I look at the result list, in most cases images are best. Probably an image of oatmeal porridge will appear among them. Then I check some of them out and hopefully the term 'oatmeal' will appear. I do things like that.*

If the missing word was of a more abstract nature, however, the strategy was less helpful. P1 referred to an example where she wanted to learn about the phenomenon of 'true crime' and wanted to refine a search by using the search term 'genre'. She could not remember the word 'genre' and searching by images was not appropriate:

*Images don't help much if the word I'm looking for is abstract. Like 'genre'. If only I had remembered the first syllable or come up with a synonym. But I didn't (P1).*

The purpose of the initial searches was to find keywords and spelling. This process could be long and time-consuming and consist of several steps. P4 recalled an example of a recent information need and the consequent search behaviour. He wanted to learn more about a singer he was very fond of. He could not remember her name but knew she had been a contestant in the Eurovision Song Contest as P4 explained:

*Let me say ... like this.... Saturday or another time. It is gra ... melody? [pause, trying to recall a word. He asks the interviewer and discusses potential words. It turned out to be Melodi Grand Prix (translates the Eurovision Song Contest)] I was thinking... She was good I read and I read, tried to find. Then I do this... google ...images [inputs 'Melodi grand prix 2020' in Google's search box and shows it to the interviewer] Then this happens, and I choose among images and [recognizes her in one of the images and clicks on it]. This one... [points at her] it is her... from Trondheim. I look at it [looks at the text, clicks on the text] it says: Here*

*are the fina... [finalists] and I read the words that say 'Kristin Husøy'. Aha!... That was 2020, she's 19. That's what I do. Every day, 3-4-5 times. Husøy, I remember that now. I didn't remember until now. One time, two times, three times, maybe 20 times, and there it is! Husøy!*

When the proper search terms were identified, the participants described additional challenges with query formulations due to spelling challenges. The participants had experienced impaired spelling skills after the stroke, and five mentioned this as a particular challenge. For instance, P3 claimed:

*I can no longer spell correctly.*

Another participant said:

*If I can't remember how something is spelled, I browse until I find the word and paste it in Google, because I quickly forget how something is spelled. It's not worth trying, because it is easier for me just to cut and paste (P1).*

## Browsing over searching

The participants described how different apps were often easier to use than search systems in web browsers. Examples of useful apps were apps for buying tickets to public transport, maps, podcasts and traffic information. The possibility to select or browse information, rather than inputting a query in a search box, was described as both useful and preferential. Particularly P1, P3 and P4, the participants with lowest scores and most time spent on the naming test, preferred this strategy. P3 said that she often deliberately avoided searching:

*I do what's easiest at the time. Where it is possible, I avoid searching. I look through newspapers. I use apps. Of course, I use Google at times. But I can't spell correctly. That's how I do it. But I can't always find what I'm looking for. For example, If I want to read about that virus [Covid19], I search through the online newspapers until I find it. I don't search, I browse.*

Various apps, and the way the content was presented in these apps were also discussed. According to P1, clear and distinct categories made navigation easy:

*Information [searching] it is difficult. To find something in a hurry. Apps are easier because then I can choose from what is in there. In this podcast-app I basically don't have to write, I just look at the categories and start selecting.*

P4 preferred iPhone or iPad over a PC due to touch screens:

*I used to use PC. Now it's mostly iPad... can touch there and here.*

He displayed different apps he found particularly useful, such as 'Maps', where it is possible to navigate in the map to retrieve names of countries and cities:

*Look here... [navigates on the map and finds different places]. There is Vietnam! And there is Bangkok! There it was yes! It's called Bangkok! Or I can touch the screen on a city and then comes... map... then the name... Where is that? and that? Then I find it here, it is: Oman!*

## Rejected information needs

The participants also described various unsolved information needs. The presumed effort of solving an information need in a search system had a huge impact on the decision to follow up an information need with actual information seeking. Five of the participants mentioned information needs they had rejected. For instance, P3 said:

*Sometimes I don't even bother to search because I know in advance that it won't work. To make a search for that thing for example... [points at a mobile phone case] Where do I begin?*

Further, printed publications were sometimes preferred over digital formats to avoid searching. P3 provided an example of this:

*Bills of rights and treatment... I've got pamphlets to read so I don't have to search for these things.*

A similar point was made by P6:

*Some days I do not bother to try to search for things, I know I won't succeed anyway. For example, if I can't come up with the words I need, or only have a vague idea of the term I need to search.*

P6 elaborated on how searching sometimes was terminated without being solved:

*I was about to subs... that word is still a problem... I was about to buy or pay to get a food magazine sent to my mailbox... subscription! [suddenly recalls the word] It's called a subscription! But... I didn't remember that word, subscription. So, I was going to search for a food magazine, but the result list was just weird [shows the result list on her phone]. Then I input 'Aftenposten' [name of online newspaper] to have a look there, because I know they have a weekly magazine or monthly magazine about food that you can subscribe to. But could not find anything. Then I just quit.*

## Outsiderness

According to all the participants, access to information was closely related to participation, empowerment and outsidersness. For two of the participants, however, these topics were more difficult to discuss due to impaired language.

Information and exclusion were closely connected. P5 stated:

*to be without information feels like being excluded from society... You cannot participate in work life, family life or leisure activities. Access to information is related to all of this. Because you do not have access to*

*social media like before, hobbies etc. etc. You become quite isolated.*

P1 also related the use of search systems and technology at work to outsidersness:

*I cannot participate in work life... I would struggle with the systems, searching there... It would never have worked out!*

## Selfesteem

The lack of information seeking skills or reduced access to information were also related to feeling discouraged or dispirited. Participant P1 described certain days as worse than others, which made it particularly challenging to retrieve information due to a need for repeated searching:

*Memory and concentration can be reduced at certain days. I forget what I... or I search again and again... for instance about the same things again and again. It is annoying.*

P3 also mentioned certain days as much worse than others, and related this to, among others, work:

*then I am just in the way*

To explore complex information needs was an activity P6 appreciated before she got aphasia, but this was no longer related to delight:

*before, I never used to give up! I like to search and explore. Figure things out. Now it often stops. I become discouraged*

## Discussion

People with aphasia are a potentially challenging cohort to interview due to language impairments and a reduced state of health. Based on the experiences from this study, however, it is possible to conduct successful interviews if the researchers are well prepared and bring purposeful communication aids. Moreover, interviews must be scheduled so the participants are given enough time to communicate and the possibility to take breaks when needed.

Many of the quotes included in this study took time and strenuous effort from the participants' side, which is not possible to illustrate adequately when citing them. Nevertheless, they seemed to manage to express both barriers and needs in a purposeful way. The participants in this study expressed a desire to be more self-reliant. This finding is in compliance with Worrall et al. (2011) and Kjellén et al. (2017), and seems especially important in the context of sensitive information needs (Mangset et al., 2008). Consequently, there is a need to include people with aphasia in research so they can express their needs. Such studies can provide researchers with a better understanding of how to support the information seeking behaviour of people with aphasia. Information needs related

to being diagnosed with aphasia ([Dixon et al., 2007](#); [Worrall et al., 2011](#)) and the wish to be self-reliant are also arguments for including information literacy in rehabilitation programmes.

Common markers of aphasia are impaired language ([Hazamy and Obermeyer, 2020](#)) skills, including word retrieval ([Lynch et al., 2013](#)) and spelling ([Knollman-Porter et al., 2015](#)). These are characteristics which to some degree are shared by other cohorts. Impaired spelling skills are for example also experienced by people with dyslexia. Challenges in retrieving the proper concepts to express an information need may also be shared by children, people learning a new language and possibly people with dementia. Consequently, it seems like better system support for expressing information needs and formulating queries may also be purposeful for other cohorts. This approach complies with the universal design mode of thought. It seems like there is a need for better system support for people with impaired language skills. Based on this study, a more extensive use of images in the search user interfaces as navigational support and in result lists might be purposeful for at least this cohort.

Browsing was reported to be more efficient than searching, especially when the participants had challenges with word retrieval. This is not surprising, since browsing typically entails less cognitive load than searching ([Borlund and Dreier, 2014](#); [Rosenfeld et al., 2015](#); [Xie, 2017](#)). Moreover, browsing is a suitable strategy when the user lacks index terms for a query ([Bates, 2007](#)). Browsing has also been reported as most efficient for muddy information needs ([Ingwersen, 2000](#)). The preference for browsing is also in accordance with the extensive use of apps reported by the participants. Consequently, there might be a need to consider whether information systems presented as browsable apps might be more purposeful than general web search engines for this cohort, at least for certain types of information needs.

This study revealed that many information needs were rejected due to the strenuous effort required to seek information. This finding is in accordance with the information seeking framework by Marchionini and White ([2007](#)), who emphasise that acceptance of information needs is related to time constraints and the usability of the system. This finding also complies with reports that people with aphasia have extensive, unsolved information needs ([Mangset et al., 2008](#)), meet barriers when using the Web ([Menger et al., 2017](#)) and challenges in expressing questions to librarians ([Muir et al., 2019](#)).

Marchionini and White ([2007](#)) emphasised in their framework that accepting and formulating information needs are phases with little system support. Based on the design of the information systems today, this still seems like a valid conclusion. Although systems may be useful in suggesting search terms, the user must input relevant content to get purposeful suggestions. The same applies for assistive technology. Although speech recognition can counteract challenges with spelling, the user must express the proper terms for this technology to be purposeful. Consequently, when designing search systems for people with



aphasia, there is a need to address the phases preceding query input, which are also more cognitive in nature ([Rosenfeld et al., 2015](#)). System developers must also consider ways to compensate for the anomia. The extensive use of image search and related synonyms may provide some direction to areas which might be interesting to explore further in search user interface design. It also seems like the basic human computer interaction principle stating that recognition is preferred over recall ([Norman, 2019](#)) may be especially valid for this cohort.

This study resulted in the following requirements for system support during information seeking for people with aphasia:

- An information architecture that facilitates browsing.
- Terms and concepts linked to meaningful images and synonyms, to support word retrieval and query formulation.
- Access to a thesaurus and/or subject index.
- Search system suggesting search terms.
- A high tolerance for spelling errors in all search systems.
- Multimodal presentation of results, to support result list assessment.

There are some limitations to this study. Due to the lack of research in this area, there was a need for a small-scale pre-study, to get a better understanding of the user group before designing a large-scale study. Although the number of participants is quite low, the findings in this study provide some direction to potential areas for future research. Although the participants wanted to be more self-reliant, they had relied on help from close family members. Consequently, many people depended on mediators with technical skills and information literacy. This mediated information searching may also be a potential topic for future research, in addition to more detailed user studies of actual searching behaviour.

## Conclusion

The findings from this study indicate that people with aphasia have a desire to be self-reliant and able to search for information themselves. The aphasia, however, has affected the information seeking behaviour which has become more time consuming, frustrating, and strenuous. These negative experiences may potentially be reduced through more supportive search user interface design, tailored for people with language impairments. Better system support for word retrieval would probably also benefit other cohorts. More research is needed to explore search user interface design further. It seems, however, likely that a more extensive use of images and systems that allow for more browsing would be beneficial. Finally, this study shows that qualitative studies with a cohort with severe language impairments is challenging but doable given that certain methodological considerations are taken.

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Note: A link from the title, or from "Internet Archive" is to an open access document. A link from the DOI is to the publisher's page for the document.

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