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# ‘Everything is different’: the impact of acquiring aphasia on information seeking

Birgit Kvikne and Gerd Berget

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## Abstract

**Introduction.** Aphasia is a language impairment that can lead to significant changes in all aspects of life, including information-seeking behaviour. This paper presents findings from a qualitative study exploring how acquiring aphasia impacts information seeking. The study also assesses the applicability of the information behaviour theory of transitions as a framework to explore and understand this life change in the context of information-seeking behaviour.

**Method.** Data were collected through semi-structured interviews and observation of search behaviour of 20 people diagnosed with aphasia.

**Analysis.** Interviews were recorded, transcribed, anonymised and imported into NVivo. The data were examined using thematic analysis.

**Results.** The study found that acquiring aphasia entails significant changes, necessitating the development of new information-seeking behaviour. The findings suggest that creating more inclusive information systems for people with aphasia is possible, with features such as support for word mobilisation and tolerance for spelling errors.

**Conclusions.** Acquiring aphasia led to significant changes in information seeking behaviour. The information behaviour theory of transitions proved useful in identifying information seeking barriers for people with aphasia, as well as providing knowledge on how to support information-seeking behaviour for this cohort.

## Introduction

People go through many types of events during a lifetime, but some are more life-changing than others. In cases of dramatic life events, for example related to health, people can experience a life before and a life after which results in new and reconstructed information seeking strategies. According to Ruthven (2022, p. 130) 'living with an illness or the risk of illness often means changing our information behaviours, being alert to new information and developing interpretative skills over our own bodies'. Acquiring aphasia is an example where people experience noteworthy changes in all aspects of life, including information seeking skills and strategies for information searching (Kvikne and Berget, 2024).

Aphasia is an acquired language impairment caused by damage to the brain, such as stroke, head injury or brain tumour. This condition affects the ability to produce language, both verbally and in writing. Moreover, aphasia impacts reading skills and people have been reported to experience social isolation, stigmatisation, and a loss of independence because of the communication challenges associated with the condition (Spaccaveto *et al.*, 2014; Raymer and Gonzalez Rothi, 2018). This paper reports the findings from a qualitative study of 20 people with aphasia. The paper explores the following research question:

RQ<sub>1</sub>: How does a life event such as acquiring aphasia affect information seeking behaviour?

An overwhelming number of models and frameworks have been developed to describe information seeking and searching from various perspectives and contexts. Previous research, however, has indicated that general models do

not always work to describe the behaviour of people with cognitive or functional variations (Berget *et al.*, 2021). This study will apply the recent framework developed by Ruthven (2022) entitled the *information behaviour theory of transitions* and explore the following research question:

RQ<sub>2</sub>: To what degree can the information behaviour theory of transitions be applied to describe the information seeking behaviour of people with aphasia?

The paper is structured as follows. The background presents the information behaviour theory of transitions, aphasia, language abilities and information seeking. The methodology is then introduced, before the findings are presented and discussed according to the main components of the information behaviour theory of transitions (life before, event, transition process and life after). Finally, there is a short discussion of the implications of this research and answers to the research questions are provided.

## Background

### The information behaviour theory of transitions

In the *information behaviour theory of transitions*, Ruthven (2022) presents a model addressing how people deal with change and how information behaviour is an important part of the transition. In short, 'Information Sculpting describes how we become different to what we were before' (Ruthven, 2022, p. 5). In the information behaviour theory of transitions there is a series of processes between *life before* and *life after* divided into three phases (*understanding*, *negotiating* and *resolving*) and four processes (*event*, *engaging*, *enacting* and *establishing*) of transition (see figure 1).



Figure 1. Excerpt from the information behaviour theory of transitions (Ruthven, 2022, p. 42), printed with permission

The model starts with *life before* which refers to a person's way of life before an event occurs. The event can comprise many different types of transitions, such as puberty, retirement, illness, or be caused by realisation of personal dissatisfaction (Ruthven, 2022). Although not all events will result in transition, acquiring aphasia might be regarded as a change in health that affects all aspects of life, including information seeking and searching (Kvikne and Berget, 2024).

After the event has occurred, the phase *understanding* starts, which involves emotions. The person has to '*understand a new situation and its implications*' (Ruthven, 2022, p. 44) In the *eEngaging* process, the person must accept the transition process and figure out how to handle the change. The *negotiating* phase comprises learning and trying out new information behaviour strategies. *Enacting* is the process where people '*start to act with a changed identity*' (Ruthven, 2022, p. 47) and involves, among others, risk-taking and self-protection. However, lack of resolution and '*chronic uncertainty, denial and no routes forward*' (Ruthven, 2022, p. 47) can be the result, if the *negotiation* phase has been unsuccessful. The last phase, *resolving*, includes reconstructions of personal narratives and the development of skills required to seek information in the new way of living. The final process is *establishing*, where people commit to the new strategies and behaviour. Finally, *life after* refers to '*the new state of normality*' (Ruthven, 2022, p. 49), comprising reconstructed information behaviour, practices and information landscapes, to name a few. In summary, the *information behaviour theory of transitions* could potentially serve as a useful theoretical lens for understanding how a life change, such as acquiring aphasia, might impact information-seeking behaviour.

## Aphasia

Aphasia is an acquired language disorder resulting from brain damage, such as stroke, head injury, brain tumour, infection, or neurodegenerative diseases such as Alzheimer's. When the primary symptom of a neurodegenerative disease is language impairment, the condition is referred to as

primary progressive aphasia (PPA) (Bekkhuis-Wetterberg *et al.*, 2022; Raymer and Gonzalez Rothi, 2018). Any, or all, modalities of language can be affected by aphasia, including speaking, comprehension, reading and writing. Although aphasia is associated with wide variation, challenges with word mobilisation are common in all forms. Further, while aphasia impacts a person's ability to communicate and understand language, it does not affect intellectual abilities, motor function, sensation or mental health (Hallowell and Chapey, 2008). However, the condition may be accompanied by other impairments, such as muscle weakness, paralysis or impaired vision, depending on the brain damage. Aphasia is a life-changing event and can significantly impact a person's ability to maintain employment and social connections, independence and participation. Consequently, aphasia often leads to feelings of frustration, isolation and worthlessness (Hallowell and Chapey, 2008; Souchon *et al.*, 2020). Aphasia has a huge impact on a person's ability to communicate, but there is a research gap in understanding how the diagnosis impacts the information-seeking behaviour (Berget and MacFarlane, 2019).

## Language, information seeking and searching

Previous research has explored the relationship between language skills and information seeking and searching for different user groups. For example, some studies have investigated spelling and reading skills in studies of people with dyslexia, *e.g.*, (Berget and Sandnes, 2015, 2016; Cole *et al.*, 2016) or intellectual disability (Hanson-Baldauf, 2013; Sitbon *et al.*, 2014). Traditional search systems have been criticised for being built '*on the same assumptions about the users' cognitive abilities and motor skills*' (Sitbon *et al.*, 2014). Artificial intelligence-based tools have been used in assistive technologies, but there is less emphasis on the potential benefits of search engine access. Further, artificial intelligence-based tools tend to develop at a faster pace than assistive technologies and are seldom designed considering inclusion and diversity (Sitbon *et al.*, 2024).

In the context of challenges in remembering words for query formulation, researchers have addressed information searching for items where the searcher cannot recall the identifier, or term, needed for a precise query. This phenomenon has been referred to as *tip of the tongue known item retrieval* (Arguello et al., 2021). Others have addressed support when people encounter memory problems, such as forgetting names, words or spelling, see for example Elweiler et al. (2007) and how rapid automatised naming skills affect the time spent formulating a query (Berget and Sandnes, 2019).

Recalling words have been less studied in context of impaired naming skills, such as having aphasia. A pilot study (Kvikne and Berget, 2022) found that aphasia had significantly affected the information seeking behaviour of the participants, for example by having to rely on others to solve information needs. Moreover, information searching typically involved strategies to mobilise words. Images and synonyms were frequently applied to identify suitable search terms. Also, browsing was favoured over direct searching because it did not require word expression. Furthermore, some information needs were left unaddressed because of the perceived strenuousness of searching.

Sitbon et al. (2024) explored the potential of artificial intelligence-based tools to understand the intent behind searches, particularly in the context of image search. They proposed that each interaction with an image, such as selecting, ignoring, or rejecting, can indicate a user's intent. Therefore, by analysing how users interact with collections of images and respond to recommendations, artificial intelligence-based tools can be applied to understand a searcher's intent. The potential of artificial intelligence-based tools to support information-seeking for people with aphasia represents an important area for exploration.

## Methods

### Procedure

The main goal of the study was to ensure that all aspects were addressed with sensitivity and respect for every participant, whilst acquiring high-quality data. It has been reported that

people with aphasia have often been excluded from qualitative research because of the demands of language abilities these methods typically require (Bronken and Kirkevold, 2013). Speech therapists and interest organisations were therefore consulted for advice and recommendations on how to facilitate communication.

The aim was to develop a study in line with recommendations described by Bronken and Kirkevold (2013) and Luck and Rose (2007). People with aphasia often communicate more than words alone convey. For example, silence can indicate reflection, struggles with word retrieval, tiredness, or discomfort. Consequently, it was essential to be attentive to non-verbal cues such as body language, facial expressions, gestures and tone of voice during the interviews. Various strategies to facilitate communication were employed, e.g., rephrasing or repeating the question, providing examples, allowing for a pause, or moving on to a different topic. Printed sheets with icons and a time scale, writing materials and drawing paper were made available. Participants also had the opportunity to bring someone along to the interview, which one participant did. The participants were recruited through speech therapists who assessed potential participants based on specific inclusion criteria: a diagnosis of aphasia; sufficient language skills to participate in an interview; and capacity to give informed consent.

Data were obtained through semi-structured interviews and observing search behaviour from April 2023 to January 2024. The flexibility and contextual sensitivity of qualitative interviews was considered particularly valuable because of limited existing research on how aphasia impacts information seeking. Additionally, observation of search tasks provided valuable insights into actual search behaviour that may have been difficult to capture through interviews alone. Combined, these methods aimed to explore both the lived experiences and observable behaviours of people with aphasia, in the context of information seeking. The interview topics included changes in seeking behaviour, strategies for finding information and access to

information. Questions were prepared in various versions and formats, ranging from detailed interview guides to simple one-question cards. The priority of topics was based on what participants could discuss, or had relevant input on. Response alternatives were customised to meet the preferences and needs of participants.

Following the interviews, the participants were asked to conduct one or more search tasks. A set of 40 photographs depicting everyday items, or people, were used to present tasks, without providing potential query terms. When a photo of a known, but unrecalled item or person was found, the participant was asked to solve a search task connected to the photo. Both a laptop and a tablet were available. Alternatively, the participants could use their own smartphones. Ample time was given for the search task(s), and the participants could take breaks when needed.

## Participants

The sample consisted of 20 participants aged 29 to 71 years, including seven women and thirteen men. All participants had been diagnosed with aphasia between 2001 and 2021 due to stroke, except one with Primary Progressive Aphasia (PPA) and one with a brain tumour. The sample had a wide range of language abilities, owing to different forms and severity levels of aphasia. Similarly, there was considerable variety in education, professional background and technological experience. Among the participants: 16 were no longer professionally active; one had returned to full-time work; one was working part-time (50%); while two were involved in voluntary work to varying extents.

Speech therapists informed the interviewer about the language skills and digital literacy of each participant before the interviews. This information guided the categorisation of participants into two distinct groups. The division into two groups allowed for a comparison of potential impact of language abilities and digital literacy on information seeking behaviour.

Group 1 consisted of 15 participants and group 2 of 5. Participants in group 2 had largely regained their language abilities and were

either currently working (full or part-time), or had been working (full or part-time) prior to retirement. They were also relatively young at the time they got aphasia, with an average age of 35 years when diagnosed and 50.8 years at the time of the interviews. These participants provided relatively elaborate descriptions compared to group 1.

In contrast, the group 1 participants exhibited lower to normal levels of digital literacy, faced more challenges in language production, and were mostly unemployed or retired. The interviews with this group varied in terms of verbal production. Moreover, group 1 participants were older at the time of diagnosis with an average age of 59.3 years when diagnosed, and aged 65.3 years at the time of the interviews. The amount of time from being diagnosed to the interviews varied greatly between the groups. The group 2 participants averaged 15.8 years post-incident, while group 1 averaged 5.5 years. It is important to note, however, that the severity of brain damage was evenly distributed across the entire sample, regardless of these differences in functioning, time elapsed since the incident and age of diagnosis.

## Analysis

Interviews were recorded, transcribed, anonymised and imported into NVivo version 1.6.1. Notes taken during interviews, presentation of search tasks and observation of search behaviour were all integrated in the transcripts, along with information from speech therapists about how to facilitate communication. The speech therapists were not present during the interviews, and the interpretation of the data was done by the interviewer. The coding process was primarily deductive, inspired by thematic analysis (Braun and Clarke, 2021) and the data were coded based on the phases and processes in the information behaviour theory of transitions (Ruthven, 2022).

## Ethics

The project was approved by the institution's ethics committee (project number 186678). To ensure informed consent, information was provided to the participants in several

modalities, including a pre-recorded video, easy-to-read information letters and written information that was also communicated orally. Each participant gave signed consent and was informed of the right to discontinue the interview, or withdraw from the study, at any time without any consequences. The researcher had no personal or professional relationships with any of the participants.

## Findings

The findings are presented according to the main components of the information behaviour theory of transitions, namely *life before*, *event*, *transition process* and *life after*. When relevant, association with group 1 or 2 will be used to describe potential distinctions.

### Life before

Life before refers to the typical lifestyle prior to a transition. This *normal* way of life includes established information seeking behaviour and landscapes. The transition occurs against this backdrop of normality (Ruthven, 2022).

The participants frequently referred to their life before aphasia, often in context of capabilities and proficiency. They often drew comparisons between life before and after the diagnosis, especially when discussing their professional life. P4 had high technological competence because of his previous work in IT support, but he was unable to continue working after being diagnosed with aphasia. He explained: 'Miss ... good at this ... [gestures typing] ... IT - helped people - job... [gestures that he is talking on the phone] Every year - all day'. P8 referred to exploring research papers as a previously appreciated activity: 'Research literature at work, a lot. But it is difficult with research literature now'. These comparisons could evoke emotions. P13 used to enjoy acquiring knowledge through reading, but expressed sadness as his access to academic literature had been hindered by aphasia '...academic literature.... [crying] ... it used to be literature. Now: not anymore'.

P16 looked back at her former career where information seeking was efficient and effortless: 'As an engineer, I had good search skills to begin with. I was a whiz at all that stuff, SQL, different interfaces, searches. Nothing was

foreign to me'. P10 described that he used to enjoy seeking information, he utilised Google widely and for various purposes: 'Everything, absolutely everything. I did many different things. I did an extreme amount. With words and with all sorts of things. I also read a lot'. P9 used to be a person others sought for advice: 'I am not [working anymore] ... before nine to five ... working on the computer... someone called, and I answered and helped others.'

P15 and P18 specifically highlighted the impact of aphasia on their former linguistic proficiency, which subsequently posed challenges when seeking information. P15 used to be fluent in multiple languages before he lost the ability to talk completely in the acute phase of aphasia: 'I used to speak English, German, French in addition to (native language anonymised)'. Another participant also talked about language: 'My language used to be rich. I had so many words both in speech and in writing' (P18), compared to the current situation where a less nuanced vocabulary made information searching strenuous.

Overall, the participants often reflected on their lifestyle before aphasia, including their capabilities and proficiency in information seeking. The comparison between life before and after the diagnosis evoked emotions, caused by limited access to activities they previously enjoyed.

### Event

The event in this context refers to the brain damage that led to aphasia. According to the information behaviour theory of transitions (Ruthven, 2022), the event can be perceived as a physical or psychological dissonance that triggers a transition from the previous state of normality.

All participants, despite varying causes and severity of aphasia, shared the profound life-altering experience of a condition that fundamentally disrupted normality. Acquiring aphasia was often described as a life-altering event that could be frightening, confusing and painful. The participants mentioned emotions like fear, anger, confusion and pain, along with an altered sense of self. Owing to impaired language, it could be difficult for the

participants to convey to their surroundings that overall, they remained the same person, despite some changes in communication and appearance.

All in all, acquiring aphasia, regardless of cause, disrupted normality and had a profound impact on the person's sense of self.

### Transition process

The transition process has three stages, each marked by three processes that signify shifts from one phase to another. The three stages and processes are *understanding* and *engaging*; *negotiation* and *enacting*; and *resolving* and *establishing*. According to Ruthven (2022), the transition develops from a general, vague situation with many possible outcomes, to a specific, concrete situation that results in new information behaviour and solutions.

#### Understanding and engaging

The initial stage of the transition process, known as *understanding*, involves creating a model of the required information-seeking solutions. The process of *engaging* represents the shift from understanding the situation, to working out how to approach it. At this stage, information behaviour aims to enhance understanding and may include seeking information for comparison, introspection and interaction with others (Ruthven, 2022).

This study found that communication difficulties, in addition to physical and psychological aspects related to the cause of the brain damage, could make this phase lengthy and strenuous. P1 emphasised how the inability to access words complicated the process of asking for help to seek information: *'it's almost impossible to ask for help if there's a lot to wonder about and I can't manage to explain it'*.

P7 described having language trapped inside, a language he was unable to express: *'I don't say that language'*. However, sessions with a speech therapist to develop communication skills also led to improved abilities to formulate information needs. Nonetheless, he acknowledged that aphasia made information searching a challenge, stating that aphasia *'isn't search'*.

The phase of *understanding* involves a process of *'making sense of a new situation and working out how we feel about the new situation'* (Ruthven, 2022, p. 44). This phase could be demanding. P16, representing group 2, reflected on this challenging phase:

*When searching, we might not understand what we need (...) it is difficult to get the insight you need to help yourself ... It is part of the diagnosis that you cannot understand what you really need ... you do not understand... and the insight into the disease comes so slowly for some.*

The ability to communicate was experienced as critical, and speech therapists represented considerable support:

*So, then I had several information needs that I could not solve because I did not have insight, or the ability to understand. I had to ask the speech therapist, then fortunately I came to (anonymised name), who is the best (P16).*

Likewise, P18, representing group 2, found this phase devastating because of the huge dissonance she experienced when comparing her current state to *'how things were before'*: *'But now, when I'm going to search for everyday things or things I'm wondering about, I misspell, or I can't find the word'*. She also elaborated on how typos impacted information searching: *'I had never used a spell checker before, just that... I used to enjoy writing; it was natural for me'*.

P3 acknowledged a considerable change in information seeking behaviour after acquiring aphasia: *'yes, it is a change because I spend more time, and everything is different'*. P15 and P17 both stressed the time-consuming aspects of searching, because of *'reduced capacity and concentration'* (P17) and being *'slower than before'*(P15).

Overall, making sense of the new situation was experienced as strenuous and emotional, and the ability to *engage* was marked by realisation of the constraints caused by the aphasia, such as challenges expressing information needs and reduced capacity.

### Negotiation and enacting

The main activity in the negotiation phase is creating a model of response. This model is built through planning, adjusting, calibrating and learning about new information seeking behaviour and practices. This phase is highly experimental and in the form of approximations and characterised by 'more detailed sculpting activities' (Ruthven, 2022, p. 181).

The negotiation phase involved adapting to and dealing with a new situation following aphasia. Coming to terms with the changes did not necessarily entail valuing them, but understanding that they had to find a way to navigate the new circumstances in the context of information seeking. Group 2 participants P15, P19 and P20 all addressed this issue. P20 elaborated on this:

*It was kind of, okay, now I can't do much, so then I had to find ways because I wanted as much information as possible. So, it was kind of, like: 'I need that type of medicine' that I could point to [gestures pointing].*

Technological experience was mentioned as important in the phase of finding new ways of seeking information:

*I am slower, that's for sure. But what has helped me a lot is that I have worked quite a lot with digital platforms (...) so I am used to it. At [anonymised rehabilitation hospital] I noticed it. I used Outlook easily, but the others didn't. Times of the day and messages and so on went fine for me. It has helped me a lot that I have worked so much online. We started making websites when it all began, in the 90s, right at the beginning. Then we learned a lot (P15).*

The background of P18, as a scientist, contributed to her ability to effectively navigate and evaluate the reliability of sources:

*My field of expertise helps me a lot in searching and evaluating sources. It's also part of my education, and finding what is credible, and being able to read through the source and see if it holds up ... that's how it is with science*

Except for the group 2 participants, who preferred using computers, or had no specific preferences regarding digital devices, the remaining 15 preferred using touch screens. 'Not on computer [gesticulating typing on keyboard]', P19 claimed. Avoiding inputting queries and instead using touch screens to browse, or navigate, was valued. Participant P9 explained: 'I bring smart phone and find that thing with my fingertip [points to a digital newspaper app, and an online grocery shopping app, and display categories with different groceries]. This is good for me, it is a photo of a soap, for example'. P3 said: 'But I am pleased that I have some methods that help, and I... get a lot of enjoyment from my iPad and cell phone'. P5 was uncomfortable using a computer: 'I almost only search on the phone. I don't know why, it's what I feel most comfortable with. Not the PC, there's so much that can go wrong'. P14 also preferred using her own phone: 'Not that thing [points at laptop]. But phone [shows iPhone]'.

The outcome of the negotiating phase could also be influenced by the level of support from other people. 'Looking back, I can't understand how I got through it. Really. But it's due to a lot of support', P20 realised. In terms of information seeking, several participants reported relying more on others to retrieve information: 'I ask my wife or someone around me' (P3). Others expressed a strong desire to seek information without assistance: 'I always want to try myself, if it doesn't work, I don't need to [search]', P6 stated. P7 sought independence, declaring: 'I have my own search' (P7).

A part of the negotiation process was to identify acquired barriers, as described by P19: 'But language dissp ... dissarpr... disappear ... disappeared. I have to search and search for words that I ... [already] know'. Sometimes the hampered access to words did not result in any search activity: '... Safari ... no. Not Google, because writing is bad, and the words are gone' (P9). Despite adequate search skills, P14 struggled to find the specific information she needed: 'It is because... I know how [to search]. But it doesn't follow the plan I had'. P14 found YouTube to be an accessible platform to seek information, as long as she had managed to input a relevant search term:



*it's like I can't manage to ... yes, finding out more about, for example, topics, it's like ... I can't move forward ... stuck ... full stop. And searching, yes, it's a bit difficult. I'm interested in politics and everything that's happening now. YouTube has many suggestions, then I can watch one after another. But I have to search first with words.*

In the phase of testing new search strategies, the participants described different scenarios of how to respond to the barriers. *'I might try a little bit, and then I wait a little bit, and then I try*

*again. And at some point, it works'*, P15 explained. Common strategies entailed describing the appearance, function, or role, of the desired object or person. For instance, when P1 was presented with a photo of a traditional cake known as *kransekake*, renowned for its distinctive cone-shaped stack of almond cake rings (see figure 2), she incorporated these physical attributes, namely *rings and tower*, with the keyword *cake* in her query. By browsing through images, she eventually succeeded in finding the desired word.



**Figure 2.** *Kransekake*

All participants in group 1 reported that they frequently delayed, or completely avoided, seeking information. Challenges with word retrieval made them dependent on assistance from others: *'If I can't find the words, I can explain in other ways to people who know what I mean'*, P2 said. P13 realised that online searching mostly belonged to the past: *'I rather ask someone around me ... or ... I want ... but I do want the internet but ...not anymore'*. When asked whether he preferred to search for information by himself or ask someone, P19 expressed a preference for the latter: *'I'm more dependent on help after this [aphasia]*'. P8, however, acknowledged that searching had become a non-activity: *'I prefer Google, but I rather don't search at all. I don't like asking for help either'*. He found that certain information needs could not be met through digital sources or consulting others, but by reflection: *'Search? No, I must rather think than search, it doesn't work'*.

The *negotiation* phase involved sculpting an information-seeking solution with the challenges posed by aphasia, by testing and acting on various options for information-

seeking tools and methods. However, the solution developed often involved elements of uncertainty, struggle and a sense of incompleteness.

### **Resolving and establishing**

The *resolving* phase represents the development of a new model of being, involving the process of meaning-making and developing narratives about identity, in relation to a new health status (Ruthven, 2022). This phase also includes the development of new information behaviour. The *establishing* process refers to the maintenance and commitment, where new information solutions become integrated and familiar.

While one might expect the *resolving* and *establishing* phase to be characterised by participants becoming more proficient in their information-seeking strategies, this phase focused more on coping with language related challenges, rather than expert use and becoming more proficient. The *negotiation* phase appeared to be less successful, particularly for participants in group 1, and resulted in a resolving phase that was primarily

characterised by the recognition of limitations. Among these limitations were challenges with word mobilisation, which led to a preference for browsing over searching, although searching could potentially provide more precise results and involved less reading. Browsing was frequently characterised as a method of information retrieval that did not require typing words. P13 explained: 'Ipad or iphone ... um ... not write ... um ... Yes, I must select here and there but not write'. Other limitations involved avoiding searching and relying on asking someone, or not seeking for information altogether. Some participants had become accustomed to their new situation. P19 elaborated:

*I don't search because it doesn't work without a name or a word for this and that. I've gotten used to it. Not to search. I might talk to people or read newspapers if they write about it.*

New information seeking strategies, preferences and habits had been established within the limits caused by aphasia. P1 appreciated the simplification in Google's results list, referring to the *people also ask* section containing related questions to their query and provided quick answers: 'like that sometimes a kind of short version of answers to questions appears in the Google results, maybe just three sentences. I like that. Less reading. Searching had become a more time-consuming activity for many participants. P2 said: 'it is ok, but it can be many searches. It is not recalling words. I think and think' while P5 stated: 'must have much time. What I write will not end up so stupid ... [if]... I have time to plan sentences.'

In situations characterised by hampered word mobilisation and spelling challenges, images were often reported to be helpful when searching. When presented with a photo of Karsten Warholm (a hurdle athlete who recently won a gold medal at Bislett stadium), P7 inputted a query containing related words hoping to retrieve relevant images:

*This is how it is.... I will do a search, I start with.... This one I use [his own iphone]. I can just take it now, because this is recent, then I will try the news, because he*

*recently won the gold medal. Or I search 'sport sport..ee' and then 'Bis...lett' and then I write like this 'hurd ...hurdle' [tries different spellings, ends up with the query: sport bis lett hurd]... Like this, but I must find an image of him but there isn't [browses through results]. Karsten is his name, suddenly it appeared, I can write Karsten, too. You know, I always have to try several times each time! Difficult to get this one, it takes time, too [selects an image of Karsten Warholm, with name displayed in cutline]. I wrote a few words to get an image of the boy, and then the name of the boy appeared. One, two, three times. Many attempts. I tried several times.*

Several participants brought a memory notebook they occasionally consulted and displayed during the interviews. The notebooks served various purposes and consisted of, e.g., contact information with photos, lists with important facts, such as addresses and directions, essential words and sentences, upcoming appointments and events. Moreover, the notebook was used for information seeking purposes. P10 explained that he rarely used digital devices for information seeking, because: 'the part [language] is broken (...) I might check my phone if I have an appointment with (speech therapist anonymised) ... I don't search on that thing [phone]'. However, a memory notebook was a very useful tool: 'I exercise [speech] all the time, you know, I have this book [shows a notebook containing lists of words, pictures of people and their names, and more] ... I must look at it all the time. I have a notebook because I can't do that [points to a phone], because of the part of me [aphasia]'

P19 used his notebook for instructions on how to navigate on a web page where he could donate money and buy symbolic donation gifts:

*I use this sketch book, or this book, this one I have [finds his notebook]. There are things here that I have to look at. Look, here are the numbers [payment details] for (anonymised foundation web page), so I can donate to them. I can go to the website if I'm going to buy gifts. Under the purple line, press online store, where there is a picture of a circle with a goat inside.*

Choose a gift. [demonstrates handwritten instructions: under purple line – ring with goat – choose a gift. The purple line is a part of the web page design].

P3 treasured his notebook greatly:

*I have to go through the notes regularly, I have everything there. My memory is not what it used to be, and the notes are worth their weight in gold. Before this meeting, for example, I wrote down things I had to remember to mention to you.*

He further described that he used the notebook as a tool when seeking information. He described a recent information need that was very specific, but he could not recall the name of an observed item (see figure 3):

*If I can't remember a word, and I realise in advance that I'm not going to get there, it can wait... Then I use my book, you know. Here I write words or draw something so I can search later, maybe I have to wait until I feel better or until I have found a place to search. Then I don't forget to search. I drew a sweater because I was going to search for the name of the nice sweater, it's called a Marius sweater, and I wondered why is it called that? I was going to search but couldn't remember the word [knew it was a personal name but couldn't recall 'Marius'] so I drew it and wrote that it was knitted. Sorry for the poor drawing [shows drawing]. Plus [name anonymised], who has the sweater. I gather information so I can figure it out later.*



**Figure 3.** Drawing of a sweater with recognisable pattern, the text *knitted* and a redacted personal name. The image to the right displays an actual Marius sweater for comparison.

The five participants allocated to group 2 had managed to reconstruct their information seeking strategies quite well. In addition, they were still able to utilise their former and familiar search strategies. They also demonstrated higher self-esteem when discussing information seeking. P15 encouraged others to be more confident and less inhibited: *'Many are afraid of making mistakes when they are online. You don't always need to be that'*.

The *resolving* phase was characterised by the incorporation of new information-seeking solutions. However, despite the development of

new search strategies and patterns, the process of solving information needs often remained challenging, time-consuming and unestablished. Overall, the transition process involved *understanding* and *engaging*, *negotiation* and *enacting*, and *resolving* and *establishing* new ways to seek information. Participants found these phases both strenuous and lengthy, marked by communication difficulties and emotional challenges. Various coping mechanisms were developed, such as searching images and relying on others. Despite these strategies, many participants delayed, or

avoided seeking information because of the barriers posed by aphasia.

### Life after

According to the information behaviour theory of transitions, *life after* is characterised by a new state of normality (Ruthven, 2022). The transition may not be over, but rather incorporated into, a reconstructed information solution (*sculpture*). In this study, all participants reported significant life changes after acquiring aphasia. Consequently, their information seeking behaviour was similarly affected. The familiar information landscapes they used to navigate became less accessible, and their former search strategies less effective or futile. The result was often only partial recovery, or a life where the crisis was never fully resolved. The new normal was mostly about finding new ways to access information and accepting limitations.

The findings of this study highlight the major impact of aphasia on information seeking behaviour. *Life before* aphasia was characterised by proficiency in seeking information, which was disrupted by the event of brain damage leading to aphasia. The transition process involved *understanding* and *engaging*, *negotiation* and *enacting*, and *resolving* and *establishing* new ways to seek information, often marked by communication difficulties and emotional challenges. Ultimately, *life after* aphasia involved a new state of normality where the person had to find new ways to access information and accept limitations imposed by the condition. However, despite these adaptations, the participants never fully recovered and developed effective information seeking coping strategies.

### Discussion

It has been reported that people with cognitive, or functional variations, can experience reduced access to information caused by barriers and shortcomings in information systems (Berget and MacFarlane, 2019). Information seeking barriers are often met by coping strategies developed over time, to compensate for these obstacles. RQ<sub>1</sub> aimed to explore how a life event, such as acquiring aphasia, affects information seeking behaviour.

This study found that previous and familiar information seeking strategies applied before acquiring aphasia were of less or no use. For example, challenges with word mobilisation made query formulation time consuming, troublesome and sometimes impossible. Consequently, new information seeking strategies had to be learned, explored and established in the process of recovering and adjusting to a new normality. However, this new normality was characterised by unresolved, inefficient, or non-existent information seeking strategies.

Understanding how people with aphasia seek information is crucial to provide appropriate guidance and support during the transformation process. For example, information specialists, such as librarians, can play a significant role by assisting people during the *negotiation* phase, which entails developing and learning new information behaviour. Moreover, in the *resolving* phase, characterised by the recognition of limitations, an approach emphasising source trust over source criticism, can be beneficial. Source criticism, which involves assessing multiple sources, analysing conflicting information and evaluating potential bias can be demanding. Therefore, a helpful approach may be to work with source trust by limiting oneself to a few reliable sources. This can involve identifying trustworthy websites, such as certain news outlets, or knowledge institutions (Sundin, 2018).

Limited applicability of existing information seeking models in describing the information-seeking behaviour of people with cognitive or functional variations has been discussed by Berget *et al.* (2021). Building on this, RQ<sub>2</sub> examined the usefulness of the information behaviour theory of transitions as proposed by (Ruthven, 2022) in the case of aphasia. To understand how a life event such as acquiring aphasia affects information-seeking behaviour, the information behaviour theory of transitions (Ruthven, 2022) provides an applicable framework, by demonstrating transition phases and the development of new information solutions.

The findings from this study illustrate how acquiring aphasia can compel reconstruction

and adjustments that result in a spectrum of information behaviour. Examples of new strategies range from innovative and creative seeking strategies, such as using a memory notebook to support query construction and utilising images search to help mobilise desired search terms. In other cases, there is complete inactivity. Further, group 1 or 2 association seemed to influence how *life after* turned out in the context of information seeking and access. This study indicates that variables, such as age when diagnosed and digital literacy, can play a vital role in the transformation process.

The transition process and information seeking solutions described by the group 2 participants aligned well with Ruthven's model, resulting in a reconstructed information sculpture. However, the information sculpture by the group 1 participants appeared to still be under construction, in negotiation, filled with uncertainty, and less resolved and established. Nevertheless, the information behaviour theory of transitions can be useful for identifying various boundaries, barriers and opportunities in information behaviour in the phases following a life change experience by this group, as well.

In this study, the information behaviour theory proved effective in modelling a detailed understanding of the various ways people with aphasia adapt their information behaviour to new conditions, necessitating new information solutions. Current search systems fall short in supporting people with aphasia. These systems are typically based upon the same assumptions about users' cognitive and physical abilities (Sitbon, 2014), resulting in significantly reduced access to information for this user group, where many people had impairments or limitations in word mobilisation, reading and writing.

To create truly inclusive information systems, it is fundamental to reconsider how these systems are designed, to ensure they account for user diversity. The information behaviour theory of transitions can model a wide range of transition processes, providing insights into potential ways to support search behaviour at different stages. For example, during the negotiation phase, when users learn about and

test new information searching strategies, the assistance of information practitioners, through guidance, courses, and search support, can prove beneficial. Further, artificial intelligence-based tools could assist users in query construction by aiding word retrieval and might potentially enhance understanding of a user's search intent by analysing various interactions with images, as suggested by Sitbon (2024).

Understanding and identifying shortcomings in information systems are crucial for developing inclusive systems. This knowledge is most effectively obtained from the people who experience these challenges. User studies involving people who face difficulties using information systems are invaluable for gaining these insights. Therefore, future efforts should focus on refining research methods and elaborate models that can capture and address these issues.

## Conclusion

The findings of this study can provide a foundation for the development of more inclusive and accessible information systems for people with aphasia. Such improvements could, for example, include system support for word mobilisation and a higher tolerance for spelling errors. The study also suggests the potential use of artificial intelligence-based technology to assist people with aphasia in constructing search queries. Furthermore, it underscores the potential role of information specialists in providing tailored guidance and support to users with aphasia. This study shows that the information behaviour theory of transitions is an applicable framework to identify barriers in information seeking, experienced in the phases following an acquired language impairment, such as aphasia.

This study encourages researchers and practitioners to rethink how information systems are designed. This research also shows that involving people with aphasia in user studies is possible, provided that the data collection methods are considerate and adjusted to the participants' needs. Moreover, the study provides knowledge on how to design accessible and inclusive information systems.

However, more research is needed to deepen our understanding of acquired language impairments. Such knowledge can benefit a broad range of practitioners, including librarians and system developers in how to support information seeking for people with aphasia.

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## About the authors

**Birgit Kvikne** is a Ph.D. student at Department of Archivistics, Library and Information Science at Oslo Metropolitan University, Norway. She received her master's degree in 2021. Her research focuses on aphasia, interactive information retrieval, and universal design.

**Gerd Berget** is an associate professor at Department of Archivistics, Library and Information Science at Oslo Metropolitan University. She holds a master's degree in library and information science and a PhD in informatics. Her main research areas comprise universal design of search user interfaces, interactive information retrieval and cognitive variations. She has conducted several user studies involving people with dyslexia and intellectual disability.

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