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## Ways to improve communication and support in healthcare centres according to people with aphasia and their relatives: a Dutch perspective

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### ABSTRACT

**Background:** There is an increasing amount of research that investigates the needs and wishes of people with aphasia and their relatives with regards to improving the accessibility of communication with healthcare professionals (HCP). An important way to improve this is by training HCP to use supportive conversation techniques and tools.

**Objectives:** This study aimed to inform the development of such a training, by adding to previous findings in the literature regarding the experiences, needs and wishes of people with aphasia and their relatives. We were interested in their experiences with the accessibility of communication and support from HCP and how they believed this can be improved.

**Methods:** An exploratory qualitative research design was chosen. Data was collected through qualitative semi-structured interviews with 20 people with aphasia and 12 relatives. The time post stroke ranged from 3 months to 41 years.

**Results:** Four themes described the data. According to people with aphasia and relatives (1) information transfer in healthcare settings and (2) the use of supported conversation techniques by HCP are inadequate, (3) there is a lack of shared decision-making in healthcare settings, and (4) support, guidance, counseling and education is mainly targeted at the person with aphasia.

**Conclusions:** People with aphasia and relatives reported a variety of positive and negative experiences in all themes. Even though guidelines and interventions have been developed to improve healthcare for people with aphasia and their relatives, we found that people still encounter substantial challenges in access to- and

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provision of information, shared decision-making, support and communication with HCP. The findings in this study provide some important recommendations for improvement, including the improvement of transfer of information, shared decision-making and individual support for the relatives.

## Introduction

Aphasia as a consequence of stroke is associated with having a large negative impact on quality of life (Cruice et al., 2003; Flowers et al., 2016; Hilari, 2011; Lam & Wodchis, 2010). Social isolation, depression, loneliness, reduced autonomy are likely secondary impacts of aphasia (Bakas et al., 2006). Relatives of people with aphasia also report their own emotional consequences of aphasia such as irritation, stress and anxiety (Brown et al., 2011; Grawburg et al., 2014) and even third-party disabilities, including physical, emotional and mental health problems, limiting their own functioning (Cruice et al., 2006).

Even though communication difficulties can limit conversations in daily life, people with aphasia and their relatives may also be faced with a range of difficulties in healthcare settings. An important problem that people with aphasia report is the inaccessibility of communication with their healthcare professionals (HCP) (Manning et al., 2019). This is often due to the HCPs' lack of knowledge of aphasia, lack of skills and self-perceived competency in communicating with people with aphasia (Bartlett et al., 2008; Brown et al., 2013; Clancy et al., 2020). Successful communication between people with aphasia and their HCP is extremely important as it leads to shared understanding, increased social participation and support, positive health outcomes, patient safety and patient satisfaction (Blackstone, 2016; Street et al., 2009). A recent systematic review evaluating the perspectives of people with aphasia towards living with aphasia shows that inaccessible communication with their HCP leaves them feeling frustrated, disappointed and irritated (Manning et al., 2019). In addition to the detrimental effects of inaccessible communication on emotional well-being, inaccessible communication also makes it difficult for people with aphasia to communicate their basic needs, making them more vulnerable to adverse events in hospital and rehabilitation settings (Hemsley et al., 2013). They are less likely to be discharged home from inpatient settings (Bersano et al., 2009) and less likely to return to work than stroke survivors without aphasia (Graham et al., 2011).

An important difficulty that relatives of people with aphasia report is the lack of support from HCP in healthcare settings. As research studies have shown, aphasia affects relationships (Grawburg et al., 2014; Hilton et al., 2014). Relatives often experience inadequate service provision, including the lack of information provision, a discouraging manner in which information is provided, or a lack of support for the relatives to cope with communication difficulties and changed lives (Brown et al., 2011).

There is an increasing amount of research aimed at creating a better understanding of the needs and wishes of people with aphasia and their relatives towards 1) improving the accessibility of communication with HCP and 2) HCP's support for relatives. Most of these studies have analysed the views and perspectives from participants who were discharged from a healthcare setting a (long) while back. For people with aphasia, needs and wishes include the ability to communicate not only their basic needs, but also their worries and

opinions (Worrall et al., 2011). People with aphasia wish to be treated with dignity and respect and to be engaged in healthcare activities and leisure (Wallace et al., 2017; Worrall et al., 2011). For the relatives of people with aphasia, needs and wishes towards HCPs' support include support in taking care of the person with aphasia, emotional support for dealing with the consequences of aphasia, psychosocial and financial support (Le Dorze & Signori, 2010). The relatives also report the need for timely information about aphasia, ongoing emotional guidance, inclusion in rehabilitation, ability to cope with new responsibilities, looking after their own emotional well-being and provision of occasional respite (Le Dorze & Signori, 2010; Hilton et al., 2014). Such findings were taken into consideration in the development of guidelines, such as the (revised) Dutch Guideline for Stroke (Limburg & Tuut, 2017) and the Dutch Guideline for Aphasia (Berns et al., 2015) that were developed to provide important recommendations for organizing healthcare for people with aphasia and their relatives. For example, the Dutch Guideline for Aphasia recommends that SLTs should focus on improving communication skills of HCP as soon as possible.

Communication between HCP and people with aphasia, and support for the relatives, can be greatly improved when HCP are trained to use supportive conversation techniques, such as using mimic, gestures or drawing, and engaging the relatives (Kagan, 1998). These training programs are commonly referred to as Communication Partner Training (CPT) interventions. CPT interventions aim to train HCP to use a more inclusive communication style so that the accessibility of communication for people with aphasia and support for relatives can be improved.

Although many CPT interventions have been developed worldwide, the vast majority of them are insufficiently described in terms of content and development. In order to increase the likelihood of successful implementation of an inclusive communication style in healthcare centres, it is essential that the development and content of CPT interventions meet the needs and wishes of the recipients (i.e., people with aphasia and their relatives) (Michie et al., 2011). The present study aims to analyze the experiences, needs and wishes of people with aphasia and relatives concerning the accessibility of communication and support in healthcare centres. The findings will inform the development of a CPT intervention for HCP. In this paper, the term "HCP" will be used to describe all staff working in healthcare settings that have a professional background in healthcare, e.g., speech-and language therapists (SLTs), physiotherapists, occupational therapists, nurses, nursing assistants, doctors, geriatricians, psychologists, etc.

The findings in this study will answer the following two research questions:

- (1) *How do people with aphasia and their relatives experience the accessibility of communication with HCP and how can this be improved according to them?*
- (2) *How do relatives experience support from HCP and how can this be improved according to them?*

This study provides a broad enquiry of feedback from people with aphasia and relatives. Although we focus on adding to previous findings in the literature, by analyzing the perspectives of people with aphasia and relatives in the Netherlands, we also aim to elaborate on the previous findings. Most studies that analyze experiences with communication and support in healthcare settings have a retrospective

design. They include people with aphasia and relatives who have been living in the community for a long period of time (Le Dorze & Signori, 2010; Hilton et al., 2014; Manning et al., 2019; Michallet et al., 2001). In contrast, we aim to include people with aphasia and their relatives currently admitted to a healthcare facility. The benefits of this are that people with aphasia and relatives provide accounts of their experiences in communicating with HCP at the present moment instead of reflecting on experiences from the past.

## **Materials and methods**

### ***Context and design***

This study was part of a large multicentre implementation study in the Netherlands and Belgium, in which an intervention aiming to improve communication between HCP and people with aphasia in healthcare centres was developed, implemented and evaluated. The development of the intervention was informed by identifying stakeholders' opinions about the problem, i.e., the experiences, needs and wishes of HCP (Van Rijssen et al., 2021), people with aphasia and relatives (the focus of this paper). An exploratory qualitative research design was chosen using semi-structured interviews.

### ***Participants***

A total of 20 people with aphasia and 12 relatives participated in this study. People with aphasia and relatives were selected by the SLTs working in three geriatric rehabilitation settings in the Netherlands. Selection of these settings was based on the following arguments. The management of these specific settings gave consent to participate in this study. Furthermore, they are some of the largest facilities in the region where stroke survivors receive (long-term) care. SLTs selected participants based on in- and exclusion criteria described below. Three people with aphasia and three relatives were still admitted to the healthcare facility, seven people with aphasia and seven relatives were recently discharged (2–6 months ago). Unfortunately, no ethical approval could be acquired from participating healthcare centres in Belgium to include people with aphasia and their relatives. Therefore, additional participants had to be recruited by a call via social media. Ten people with aphasia and two relatives responded to this request and were recruited for this study. Participants did not have to be a part of a participating dyad. Inclusion criteria for people with aphasia were that their language comprehension was adequate enough to be able to provide informed consent (determined by the SLT, based on a Dutch language comprehension test), they were aged over 18 years, had aphasia as a result of stroke and were receiving or had received care in healthcare centre(s) for an undefined period. Inclusion criteria for the relatives were that they were aged over 18 years and had contact with a person with aphasia at least once a week. People with aphasia and relatives were excluded if they had severe hearing problems, a history of psychiatric disease or no Dutch language proficiency. Mean age of people with aphasia was 59 years (range 46–93 years). Mean age of relatives was 67 years (range 39–96 years). The time post stroke ranged from 3 months to 41 years. Twenty percent of the participants were receiving inpatient care at the time of the study. Participant details can be found in [Table 1](#).

**Table 1.** Participant demographic information.

Participant number	PWA or relationship with PWA	Sex	Age (years)	Educational background	Time post onset stroke		Receiving inpatient care at the time of the interview	Recruitment site
					(year)	(month)		
1	PWA	Female	63	Elementary education	0;4	Yes	Healthcare facility	
2	PWA	Female	56	Master degree	1;2	No	Healthcare facility	
3	PWA	Female	56	Associate degree	1;0	Yes	Healthcare facility	
4	PWA	Female	46	Elementary education	2;10	No	Healthcare facility	
5	PWA	Male	67	Associate degree	22;0	No	Healthcare facility	
6	PWA	Female	61	Elementary education	0;9	No	Healthcare facility	
7	PWA	Male	57	Bachelor degree	1;3	No	Healthcare facility	
8	PWA	Female	54	Associate degree	4;9	No	Healthcare facility	
9	PWA	Male	59	Associate degree	6;0	No	Healthcare facility	
10	PWA	Male	66	Associate degree	3;0	No	Healthcare facility	
11	PWA	Male	59	Unknown	10	No	Social media	
12	PWA	Female	47	Unknown	11	No	Social media	
13	PWA	Male	53	Unknown	0;3	Yes	Social media	
14	PWA	Female	65	Unknown	41	No	Social media	
15	PWA	Female	51	Unknown	9	No	Social media	
16	PWA	Male	63	Unknown	1	No	Social media	
17	PWA	Male	93	Unknown	0;10	No	Social media	
18	PWA	Male	51	Unknown	2;6	No	Social media	
19	PWA	Female	57	Unknown	25	No	Social media	
20	PWA	Female	53	Unknown	3	No	Social media	
21	Husband	Male	60	Bachelor degree	1;1	Yes	Healthcare facility	
22	Husband	Male	78	Elementary education	5;5	Yes	Healthcare facility	
23	Wife	Female	74	Associate degree	6;0	No	Healthcare facility	
24	Partner	Female	64	Master degree	1;3	No	Healthcare facility	
25	Husband	Male	66	Associate degree	0;9	No	Healthcare facility	
26	Wife	Female	78	Master degree	2;9	Yes	Healthcare facility	
27	Wife	Female	71	Associate degree	22;0	No	Healthcare facility	
28	Son	Male	39	Bachelor degree	2;0	No	Healthcare facility	
29	Husband	Male	96	Bachelor degree	31;0	No	Healthcare facility	
30	Wife	Female	68	Unknown	2;0	No	Healthcare facility	
31	Daughter	Female	47	Associate degree	6;0	No	Healthcare facility	
32	Wife	Female	65	Bachelor degree	5;0	No	Social media	

PWA = Person with aphasia

## Data collection

Six clinician-researchers conducted the semi-structured interviews with the participants. It was a deliberate choice to have six researchers involved throughout all phases of the project. The goal was to have a group of highly experienced SLTs involved in each step of the development of the intervention. Secondly, there were practical reasons; the spread of geographical locations of the healthcare settings meant more researchers were required to conduct the interviews within the allotted time for this phase of the study. The clinician-researchers were all experienced in either qualitative research and/or had a background as SLT. They were familiar with conducting interviews and talking to people with aphasia. All participants were unfamiliar to the interviewers.

The interviews took place between April and December 2018 in the participants' homes or in a healthcare setting. The participants with aphasia were given the choice to be supported by a relative during the interview. The interviews were conducted with open ended questions, avoiding interpretative comments. However, in order to include people with moderate to severe aphasia, the interviewer offered a choice of possible responses when needed. Interpretively rephrasing the responses of people with aphasia was sometimes needed to ensure understanding of what was said. Inspired by narrative enquiry, people with aphasia and relatives were asked to "tell their story" from the "start of the stroke". Moving on to a more phenomenological approach, further in-depth questions were guided by an interview guide that was based on the literature about the needs and wishes of people with aphasia and relatives (Bakas et al., 2006; Bartlett et al., 2008; Le Dorze & Signori, 2010; Michallet et al., 2001; Northcott & Hilari, 2018). The topics that were discussed can be found in Table 2.

## Data analysis

The transcripts of people with aphasia and relatives were analyzed using the six steps of Braun and Clarke for thematic analysis (Braun & Clarke, 2006). The qualitative data analysis software Atlas.ti 8 Windows™ (ATLAS.ti Scientific Software Development GmbH) was used to manage the data. The interviews were coded by two researchers. An iterative approach was used, where researchers checked the themes against earlier transcripts and keywords.

**Table 2.** Topics in interview guide.

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**Topics discussed with people with aphasia**

General experiences with receiving healthcare

Experiences with communicating with HCP

Factors that may help to improve afore-mentioned negative experiences

**Topics discussed with the relatives of people with aphasia**

General experiences with receiving support in healthcare centres

Experiences with the frequency and nature of support from HCP

Factors that may help to improve afore-mentioned negative experiences

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## **Rigor**

Before conducting the interviews, the researchers met for one calibration session to discuss the interview guide and one calibration session to practice the interview. After the interviews, member checks were conducted with three people with aphasia and three relatives to verify data and interpretations, which included sending a summary of the interview back to the respondent to check the validity of the data. No participants requested any changes. During coding, analysis and interpretation, two researchers discussed decisions to ensure investigator triangulation. Representative quotes were translated from Dutch to English, and double checked by a translator with excellent knowledge and understanding of Dutch and English.

## **Ethical issues**

This study was approved by the Medical Ethical Committee of the University Medical Centre Utrecht (number: 18–159/C) and performed in accordance with the Helsinki Declaration and the EU General Data Protection Regulation. The researchers provided thorough written and verbal information to participants and informed consent forms were signed. Aphasia-friendly informed consent forms were provided to participants with moderate to severe aphasia. Pseudonymity was preserved by assigning a number to each participant. Only the first author had access to disclosed data.

## **Findings**

Four themes were identified to describe the experiences, needs, and wishes of people with aphasia and relatives with the accessibility of communication in healthcare settings and the experiences, needs, and wishes of relatives for supporting them in healthcare settings. Findings will be represented for both research questions separately.

**Research question 1) How do people with aphasia and their relatives experience the accessibility of communication with HCP and how can this be improved according to them?**

### ***Theme 1: inadequate information transfer in healthcare settings***

Information transfer was a prominent theme for people with aphasia and relatives. This theme highlighted the importance of providing people with aphasia and relatives with accessible information in the early stages of recovery and repeating information throughout subsequent phases. The majority of participants were dissatisfied about the way that HCP provided information. Most information was provided by written text, such as folders, presentations or through websites, and



supported by spoken information. People with aphasia commented that written information was often inaccessible or too generic for their situation, as the following quote illustrates:

*Person with aphasia (1 year post-onset): It started on my first day at the healthcare facility ... Some sort of ... welcome. That was strange. The woman ... nurse. she had four pages with text. There you go. But I said ... I said I can't read. Then she said: the most important thing to know is that you can't smoke. We laughed ... a joke ... But it did leave me feeling ... What am I missing? So I asked my wife to read it. It made me feel so stupid.*

Written information should be made accessible according to people with aphasia. Suggestions that they made included using more pictures, underlining words, using a bigger font size and shorter sentences, and always supporting written information with spoken information.

*Person with aphasia (22 years post-onset): Make written information easier to read. Shorter sentences. Use pictures.*

Opinions about the accessibility of spoken information were particularly evident in relatives' comments, which revealed that HCP used "difficult terminology", making information inaccessible to them and their family member with aphasia:

*Relative (1;1 year post-onset): [...] and I'm staring at this folder, with all kinds of medical terms. I told them that. Write and speak in terms that are accessible from a lay perspective and for people with aphasia.*

Relatives also commented that every piece of information, whether it was written or spoken information, should be repeated. Opinions about how often HCP should repeat information in each stage after stroke varied. The following relative commented that she wished information was repeated every three days:

*Relative (1;1 year post-onset): Brochures, folder, books. All with good intentions, but please dose it more carefully, or wait. Come back after three days, and explain again page by page.*

## **Theme 2: inadequate use of supportive conversation techniques by HCP**

According to people with aphasia, communication with HCP improved when HCP took more time for conversations and used supportive techniques to provide structure, non-verbal support and written support. Some people with aphasia were satisfied about the supportive conversation techniques that HCP used to communicate. Others, particularly the people receiving inpatient care at the time of the interview, experienced a complete absence or insufficient use of relevant techniques by HCP. The following quotes provides an example:

*Person with aphasia (1;3 years post-onset): I ... that doctor, who, yeah, who came to visit me regularly ... and that ... situation I was in, OK, that was ... aphasia ... yes. She told me I had been lucky. Well, great. And I couldn't ... I thought, let her talk. I don't understand ... couldn't. She kept talking and talking. So I just let her.*

The use of supportive conversation techniques by any conversation partner made people with aphasia feel like that person was genuinely interested in their lives and their needs; a crucial component for people with aphasia to feel they could successfully live with aphasia. The following quote provides an example of suggestions made by a participant with aphasia:

*Person with aphasia (10 years post-onset): HCP should make more effort to understand what I have to say. Try to listen between the lines. It's like when I'm reading my e-mails. I have difficulty reading because I can't see the left side properly. I really have to make an effort to read. That's what HCP should do. Make an effort to write down their words or use other ways to communicate.*

Most relatives expressed their desire that HCP acted as role models, showing them techniques that were beneficial to communicate with the person with aphasia. People with aphasia and relatives also suggested to invite experts by experience (people with aphasia and relatives in the chronic phase) to share their stories with HCP. Some relatives hypothesized that inviting experts by experience to talk about aphasia and their experiences would improve empathy from HCP. This relative had once seen a person with aphasia share her experiences during lectures:

*Relative (6 years post-onset): She (person with aphasia) gave lectures about aphasia and how to deal with it. She gave these lectures at healthcare settings and schools. Everyone went quiet after her talk. I think it is very important that healthcare professionals know the impact of aphasia.*

### **Theme 3: lack of shared decision-making in healthcare settings**

For many people with aphasia, the theme of shared decision-making was mainly associated with decisions made around follow-up care. Many people with aphasia and relatives indicated that those decisions were made by the HCP and/or the relatives. One third of the people with aphasia preferred it this way, as illustrated by the following quote:

*Person with aphasia (4 months post-onset): My husband decided which rehabilitation centre I would go to, because I had no idea. And I was happy with that.*

These participants with aphasia felt too scared or incapable to make these decisions, mainly due to their communication difficulties. They reported that they trusted HCP to make the right decisions and their loved ones to take their wishes into account. Others expressed their dismay at not being involved in decisions around follow-up care:

*Person with aphasia (11 years post-onset): I hated it when others made the decisions for me. Or when they completed my sentences. It was always my decision!*

Relatives recognized these frustrations in their family member with aphasia:

*Relative (2;9 years post-onset): My daughter came back from Aruba and heard that they were planning to transfer her father to a nursing home. She rejected that decision. I do understand that healthcare professionals have certain protocols they should stick to. But they could have at least discussed this with me and my husband.*

Overall, there was strong agreement that HCP should always provide people with aphasia the opportunity to make smaller decisions, such as what to eat or when to go to bed, themselves; a crucial component to feel valued and autonomous.

## Research question 2) How do relatives experience support from HCP and how can this be improved according to them?

### **Theme 4: support, guidance, counseling and education is mainly targeted at the person with aphasia**

A small subgroup of relatives expressed that they were satisfied with the amount and quality of support, guidance, counseling and education in healthcare settings. Involving them in therapy especially made them feel supported in coping with the communication difficulties and educated in the consequences of aphasia. However, guidance and support for relatives was insufficiently targeted at the emotional consequences of living with a family member with aphasia. Therefore, most relatives expressed negative experiences with support, guidance, counseling and education with regards to their own needs. The following quote illustrates this:

*Relative: (5;0 years post-onset): They never asked me how I am doing and if I need any help. As long as they acknowledge that you, as a relative, may need help as well.*

One relative shared that she had missed a HCP to share her sorrows and anxiety with. Another relative expressed that she believed that if she had been guided in how to look after herself, she would have been more capable to look after her husband. One relative noted that she felt deserted by the HCP, who focused only on her husband with aphasia and not on her own psychosocial wellbeing:

*Relative (31 years post-onset): I understand it's difficult, but I would have liked it if HCP had been accessible to me sometimes.*

Although some relatives asked for more emotional guidance of their own wellbeing, others expressed that the rehabilitation of the person with aphasia had priority and that they preferred to seek emotional guidance elsewhere:

*Relative (1;3 years post-onset): I have experienced that these sort of problems can lead to divorce and that is not what I want. My wife was doing so well in the rehabilitation centre, and I wanted her to continue improving, so I sought out help for myself elsewhere.*

Some relatives expressed that trivializing or reducing information about outcomes or expectations for the future felt disrespectful and would be counterproductive for positive relations:

*Relative (1;3 years post-onset): [...] not knowing what is happening and what possibilities we have. What do therapists expect for the future? Is anything changing or improving for the person with aphasia? Or not? Please be honest.*

## Discussion

The aim of this study was to inform the development of a training program for HCP, by analyzing the experiences, needs and wishes of people with aphasia and relatives. The findings show a large variety of positive and negative experiences within the themes. This

emphasizes not only the importance of recognising and capturing people's individual realities in healthcare research but also underlines the importance of providing personalized care.

Even though guidelines have been developed in order to improve healthcare for people with aphasia and relatives (Berns et al., 2015; Limburg & Tuut, 2017), based on the findings of our participants who shared their recent experiences, substantial challenges are still evident in this population regarding access to and provision of information, shared decision-making, support and communication with HCP. We can conclude that the organization of healthcare for people with aphasia and their relatives still requires improvement and the findings in this study provide some important areas that require attention.

According to people with aphasia and relatives, one important area of improvement is the transfer of information in healthcare settings. Spoken and written information should be made accessible to people with aphasia, by using short sentences, keywords and pictures in written information and supportive conversation techniques in spoken information. The relatives reported that they wish to be provided with "honest" information about the prognosis and expectations for the future. Providing an adequate prognosis for people with aphasia is challenging, as outcomes depend on many factors such as lesion site or aphasia severity at onset (el Hachoui et al., 2012). The results in this study advocate addressing this uncertainty directly in conversations with relatives instead of shying away from the topic, and communicating information sensitively and repeatedly (Northcott & Hilari, 2018).

Another important area of improvement is the use of supportive conversation techniques by HCP. One way to address this, is by inviting people with chronic aphasia and their relatives to share their stories and provide recommendations to HCP. Implementation science has shown that participation of experts by experience during skills training can be an important way to motivate HCP to use supportive conversation techniques, because it provides HCP with information about health and emotional consequences from credible sources (Michie et al., 2011) Therefore, patient involvement in healthcare education is becoming increasingly important (Sharma, 2017).

The third area that needs improvement concerns support for relatives. The finding that relatives want to be involved in the care pathway of their loved one is in line with previous findings (Clancy et al., 2020; Worrall et al., 2011). In fact, better outcomes are to be expected when stroke rehabilitation is organised as family-centred care (Visser-Meily et al., 2009), which family members describe as care that focuses on preparing for discharge (Camicia et al., 2019). However, after prompting, the relatives in this study advocate providing individual support for relatives alongside a family centred approach. Suggestions they gave were screening and monitoring their physical and mental health and providing them with emotional guidance. As relatives of survivors of stroke often experience third-party disabilities, such as anxiety and depression (Grawburg et al., 2014; Visser-Meily et al., 2009), it seems very reasonable to state that relatives should receive individual support.

In relation to study limitations, it is important to note that we aimed to include people with aphasia and relatives currently admitted to a healthcare facility. Unfortunately, we managed to recruit only six participants who met this criterion. Therefore, elements in this study include a prospective design and 20% of the findings (interviews with 3 people with aphasia and 3 relatives) are based on the experiences of communicating with HCP at that present moment. We did manage to include another six participants around 1-year post

stroke, who thus shared relatively recent experiences. Also, one may expect that the participants with longer post-onset periods still continuously communicate with HCP. Thus, these participants could also recall encounters with HCP outside rehabilitation settings.

Some people with aphasia chose to be supported by a relative during the interview. Data from people with aphasia was only analysed when two researchers- who were also qualified SLTs- independently judged these data to be the person with aphasia's own opinion. However, there remains a slight chance that some answers may not have been the person with aphasia's own opinion.

Starting the interviews with a narrative approach allowed further in-depth questions to be based truly on the participants' own experiences in healthcare settings. It is important to note that we conducted qualitative research to help us inform the development of a training program for HCP. The findings in this study therefore do not represent the overall opinions of people with aphasia and relatives throughout the Netherlands.

## Conclusion

This study aimed to inform the development of a training program for HCP, by analysing the experiences of people with aphasia and relatives with communicating with HCP and their needs and wishes for improvement. People with aphasia and relatives reported both positive and negative experiences with communication and support from HCP. The main areas that require attention in the organization of healthcare for people with aphasia include the transfer of information, individual support for the relatives, shared decision-making and communication between HCP and people with aphasia. The findings in this study provide some important recommendations in each area.

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