

## EMPIRICAL RESEARCH QUALITATIVE OPEN ACCESS

# Need for Human Interaction and Acknowledging Communication—An Interview Study With Patients With Aphasia Following Stroke

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## ABSTRACT

**Aim:** To explore stroke patients' experiences of the communicative practice during their hospitalisation and describe strategies and supporting communication techniques applied by patients and nursing staff from the patient's perspective.

**Design:** A qualitative descriptive study was undertaken.

**Methods:** A qualitative approach was chosen; through a purposeful sample strategy, 13 semi-structured interviews with 12 patients who had aphasia following stroke, and one patient had dysarthria. The interviews were video-recorded and partially transcribed. Data were analysed according to Graneheim and Lundman's content analysis. Interview data were collected in 2022.

**Results:** The analysis generated one overarching theme; Being acknowledged as an equal human being as it appeared to be a pervasive and underlying trait across the four categories; Waking up to a new communicative reality, A task-oriented communicative agenda, Misunderstandings as a communicative dead end and Establishing a communication-friendly environment: peace, patience and supporting techniques, describing the immediate and descriptive level. The patients did not seem to encounter a systematic approach to communication. They perceived the health care staff's communication as primarily task and purpose-oriented, lacking deeper conversations, which seemed to leave several with unmet emotional and psychological needs. Emotional, relational and existential aspects seemed interwoven in communication.

**Conclusion:** These findings contribute by illuminating an important patient perspective and ultimately, raising the point that from the perspective of patients the nursing staff's communication was primarily task and purpose oriented, and they lacked deeper conversations. Hence also raises the point that the use of supportive communication strategies alone will allow nursing staff to meet the existential needs of patients with aphasia. Supported communication needs to address compassionate and acknowledging aspects of communication.

No Patient or Public Contribution in this paper.

## 1 | Introduction

Stroke is the second leading cause of death worldwide and a leading cause of disability (Katan and Luft 2018). Annually

approximately 12,000 people suffer a stroke in Denmark (RKKP 2023). Some stroke survivors require rehabilitation following hospital discharge. Depending on the severity of the stroke, the patient may have various physical, cognitive

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## Summary

- Impact
  - Successful communication is critical in stroke rehabilitation. Healthcare professionals find it difficult to communicate with people with aphasia in their clinical practice, which can negatively influence patient safety and quality of care. For healthcare professionals to be caring communication partners, knowledge of the insider human experiences is vital, hence findings from this study can therefore be utilised to enhance practice by focusing on the importance of communicative interactions between nurses and individuals with aphasia. Likewise, knowledge from this study can support policy development and implementation strategies for supportive communication.
- Reporting method
  - Study design and conduct are reported in line with the consolidated criteria for reporting qualitative studies COREQ guidelines.
- What does this paper contribute to the wider global clinical community?
  - This study provides patient experiences with aphasia and communication difficulties and its impact on inpatient nurse—patient communication following stroke.
  - Patients with aphasia experience nurses' communication as primarily task oriented and lacking deeper conversations even though methods supporting conversation exist.
  - Methods implemented to support conversation between nurses and patients need to address compassionate and acknowledging aspects of communication.

or communicative difficulties such as aphasia or dysarthria (Danish Health Authority 2011; US Department of Health and Human Services 2022). Aphasia is a communication disability, due to an acquired brain injury such as stroke, impacting language modalities and affecting life participation of the person with aphasia as well as their family and friends (Papathanasiou, Coppens, and Davidson 2017). Understanding the experience of communicative practice during patients' hospitalisation and the role of healthcare professionals in supporting people with aphasia is the focus of this study.

## 2 | Background

Post-stroke aphasia affect up to 34% of patients in an inpatient rehabilitation setting (Flowers et al. 2016). Aphasia occurs predominantly following an injury to the left side of the brain and it may manifest differently depending on severity and location of the brain damage (Lahiri et al. 2021). People with aphasia (PWA) experience word-finding difficulties, but other language characteristics may differ. The language modalities affected are the ability to find words and produce comprehensible sentences, perceive and understand language, reading and writing (Papathanasiou, Coppens, and Davidson 2017).

Depending on severity aphasia profoundly affects the person's psychological and emotional health and is associated with a high risk of depression (Zanella et al. 2023), loneliness and isolation (Northcott et al. 2015). Furthermore, aphasia affects the PWA's ability to engage in social activities (Northcott et al. 2015) and their overall quality of life (Hilari, Needle, and Harrison 2012). As the incidence of stroke rises with age, most stroke survivors are elderly people, often suffering from pre-existing communicative disorders such as hearing or visual disabilities. An Australian study found that 88% of patients admitted to an acute care stroke ward had some sort of mild–severe communication-related impairment, new or old (O'Halloran, Worrall, and Hickson 2009). Among these patients, 55% reported difficulties communicating their healthcare needs. The more severe communication impairment, such as aphasia, the more severe difficulties communicating healthcare needs (O'Halloran, Worrall, and Hickson 2012). On top of other communication-related impairments, aphasia can be a serious barrier to usual care. PWA and their families risk less involvement in healthcare decisions than other patient groups (Carragher et al. 2024). PWA further experience poorer rehabilitation outcomes (Boehme et al. 2016; Gialanella et al. 2011), and longer admissions (Boehme et al. 2016; Gialanella and Prometti 2009), are twice as likely to fall (Sullivan and Harding 2019), and experience a three-fold increased risk of preventable adverse events than other stroke patients impairing patient safety (Bartlett et al. 2008), which can be severely distressing for both patients and their relatives (Hemsley, Werninck, and Worrall 2013). Additionally, PWA have reported to experience inaccessible information, negative staff attitudes and inadequate communication skills on the part of the healthcare professionals (Horton, Lane, and Shiggins 2016).

Stroke survivors with aphasia and healthcare professionals alike have recognised that successful communication is critical to effective stroke rehabilitation (Clancy, Povey, and Rodham 2020). However, healthcare professionals reported how they lack both the resources and the knowledge to skilfully and confidently communicate with patients suffering from aphasia. They further experience that caring for PWA is time-consuming, which tends to limit interactions with these patients (Gialanella et al. 2011; Loft, Volck, and Jensen 2022).

Communication partner training is internationally recommended as an integrated part of stroke rehabilitation and is considered necessary to improve communication partner skills and techniques (Simmons-Mackie, Raymer, and Cherney 2016). Although previous studies have reported an effect on communication partner training programmes when imparted to healthcare professionals (Horton, Lane, and Shiggins 2016; Jensen et al. 2015; McGilton et al. 2011), experience from both research (Loft, Volck, and Jensen 2022) and clinical practice indicates a gap between what we know as best practice when communicating with PWA in the clinic and what is being done in real-life daily clinical practice.

In Denmark, the communication partner-training method Supported Conversation for Adults with Aphasia (SCA) method is recommended by the health authorities as part of best practice in stroke rehabilitation (Danish Health Authority 2017).

SCA have previously served as inspiration for communication partner training programmes directed at nurses working in stroke wards (Jensen et al. 2015; McGilton et al. 2011). In a Danish context, Jensen et al. (2015) reported on the successful implementation of SCA at Glostrup Hospital right after its implementation but also emphasised that continued education and monitoring were necessary to maintain an effect (Jensen et al. 2015). However, a recently conducted study on the long-term implementation of SCA indicated a challenge in relation to nursing staff's use of SCA strategies in daily clinical practice (Loft, Volck, and Jensen 2022). This study (Loft, Volck, and Jensen 2022) points to further exploration of the communicative practice in a stroke unit where communication partner training has been sought implemented to qualify future implementation of communication partner training and specific strategies in daily practice to create a PWA friendly environment.

Consequently, the present study aimed to explore stroke patients' experiences of the communicative practice during their hospitalisation and identify and describe the strategies and supporting communication techniques applied by patients themselves and the nursing staff from the patients' perspective.

### 3 | Materials and Methods

#### 3.1 | Design and Approach

In this study, we conducted a qualitative descriptive design, based on 12 semi-structured interviews (Kvale and Brinkmann 2009). Data were collected in 2022. The interviews were analysed through qualitative content analysis with an inductive approach, characterised by searching for patterns, moving from the concrete and specific to the abstract and general (Graneheim, Lindgren, and Lundman 2017; Graneheim and Lundman 2004).

#### 3.2 | Participants and Setting

The study was conducted at an inpatient stroke rehabilitation unit in a university hospital in the capital region of Denmark. Patients are admitted to the unit after having suffered a stroke if in need of further inpatient rehabilitation, after first being admitted to an acute stroke unit for 3–4 days. A purposeful sample strategy was subjected with the aim of obtaining in-depth and detailed information about the patients' experience and communicative practice. Hence, the sampling enabled the identification and selection of information-rich participants relevant to this study (Polit and Beck 2017). Participants were chosen in collaboration with speech and language therapists (SLTs), and patients with disorders affecting their communication were included. As part of their daily practice at the stroke wards the SLTs screen and diagnose patients for aphasia and other communication difficulties. During this process, participants were identified by the SLTs' and then referred to the authors. Maximum variation was sought by including a wide variety of severities of both stroke and aphasia and a mix of age, gender and stroke aetiology to give a

broad perspective on the subject. We chose to include patients who were in the very last part of their admission so that they have had some experience with their new communicative difficulties. The participants also had to be physically and emotionally stable and willing to participate. All patients asked to participate agreed.

#### 3.3 | Data Collection

Through a period of 2 months, the interviews were conducted by the first and last authors in collaboration but with the last author as the main interviewer and the first author as support. The interviewers: male and female are both skilled in doing interviews and qualitative research as well as skilled in communication with people with communicative difficulties. The interviewers, respectively, speech and language therapist/research assistant and a nurse/research manager were not part of daily clinical practice but were employed in the same overall department as the interviewees. We aimed to conduct the interview in a respectful, inclusive and humble manner, acknowledging the patient's communicative difficulties, and the fact that they had just survived a traumatising experience and that they were still, some more than others, suffering from physical and mental consequences of the stroke. The interviews were conducted in a meeting room at the hospital or in the patients' room depending on the patients' needs as some patients experienced sequelae following the stroke such as increased fatigue or physical disabilities. Hence, it was not always possible to transport the patients from the stroke ward to the nearby office. In these cases, the interview was held in the patient's room.

The sample size was determined based on the concept of data saturation, where we aimed for in-depth and comprehensive descriptions (Polit and Beck 2017). Data saturation was reached when no new information or insights emerged from the last few interviews. Each participant was interviewed only once, and data saturation occurred after 10 interviews. Subsequently, we continued until 13 interviews were completed.

A semi-structured interview guide to support the interview was developed by the first and last author based on the research team's prior knowledge and literature on PWA, communication and stroke rehabilitation. The guide was reviewed by each member of the research team and discussed for content and clarity with fellow colleagues. During the interviews, communication was supported by using SCA techniques as relevant. Some participants needed more support than others, hence some questions could be asked more openly than others. As recommended in the SCA method, gestures and other visual aids were used in some interviews. The interviews were therefore video-recorded to allow for a thorough analysis. However, one interview was audio-recorded because the patient did not wish to be recorded on video.

Verbatim transcription of the entire data material was initiated but subsequently deemed too time-consuming because of the complexity associated with transcribing both audio and visuals in the videos. Hence, it was determined that a partial transcription of sequences of significant importance would be

in accordance with the methodical framework and that this procedure was adequate in relation to conveying the participants' opinions, attitudes and feelings.

### 3.4 | Data Analysis

The interviews were analysed according to Graneheim and Lundman's reading of content analysis (Graneheim and Lundman 2004). Content analysis is a method of analysing written, verbal or visual communication in a systematic way (Krippendorff 2019). Qualitative content analysis is a structured but non-linear process and requires researchers to move back and forth between the original text and parts of the text during the analytical process (Graneheim, Lindgren, and Lundman 2017). The analysis was conducted as a joint effort of the authors. Initially, the interviews were watched through several times, with the authors noting their immediate thoughts and building a sense of the overall meaning. To analyse the data, the recordings were marked to identify meaning units that corresponded with the study aim. These meaning units were then transcribed. Following this, the meaning units were condensed and coded into descriptive labels for their content. The codes were then abstracted, interpreted and further compared for differences and similarities and sorted into tentative sub-categories (for example of the analysis see Table 1). Then the authors jointly reflected on and discussed the content and headings of the categories and in this course of the analysis, a total of four main categories emerged from this inductive process representing the manifest level. Quotations were carefully chosen and translated into English, preserving as much meaning as possible and aiming to exemplify and clarify the contents of each category. Finally, to achieve a deeper understanding of the meanings represented at the manifest level, we took a more interpretive approach to the meaning structure of the texts, then asking the text what is this all about. On this basis, we formulated one theme illustrating the underlying meaning at a latent level.

### 3.5 | Rigour

Qualitative rigour refers to approaches and procedures performed to establish authentic and trustworthy meanings from the research findings with the aim of establishing trust in the findings of a research study. Credibility was sought via reflexivity as an ongoing approach where we as researchers constantly reflected on personal, interpersonal, methodological and contextual issues. Hence, transparency was sought to visualise choices and decisions to strengthen dependability. Also, member checking was applied and integrated throughout the interviews as part of validating the initial analysis and interpretation. Interviewing people with communicative difficulties entails a risk of over or under-interpretation of the interviews, hence, the researchers constantly discussed the interpretation while drawing on both pre-existing experiences and knowledge but also remained open to new knowledge and perspectives in an inductive process. To strengthen this, a peer examination of the analysis and draft of the article was applied. We also made an effort in staying close to the participants' words and voices in the reporting at the manifest level. In the analysis,

reflexive discussions were held with inspiration from the two-dimensional model developed by Graneheim et al. (Graneheim, Lindgren, and Lundman 2017).

### 3.6 | Ethical Considerations

The study was approved by the Danish Data Protection Agency (J. No. VD-2019-02) and conducted in accordance with the principles of the Declaration of Helsinki. In an aphasia friendly and supportive way, written and verbal information was given, and consent was obtained prior to the interview and again at the beginning of each interview. All participants were informed that they could withdraw their consent to participate in the study at any time with no consequences for their future treatment or care.

## 4 | Results

### 4.1 | Characteristics of Participants

In this study, we conducted 13 semi-structured interviews with 12 patients who had aphasia following stroke, and one patient who had dysarthria. The patients had mild-to-severe aphasia. Please see Table 2 for further patient characteristics.

### 4.2 | Findings

The analysis generated one overarching theme; *Being acknowledged as an equal human being* as it appeared to be a pervasive and underlying trait across the four categories; *Waking up to a new communicative reality*, *A task-oriented communicative agenda*, *Misunderstandings as a communicative dead end* and *Establishing a communication-friendly environment: peace, patience and supporting techniques*, describing the immediate and descriptive levels.

### 4.3 | The Overarching Theme: Being Acknowledged as an Equal Human Being

At the latent level of analysis, it became evident that the need for acknowledgement as an equal individual permeated through the manifest categories. Acknowledgement was perceived as crucial both communicatively and relationally, as essential for human interaction. What constituted the experience of an acknowledging behaviour appeared to depend on individual factors. By delving into the narratives of the interviewees, it appeared that, in addition to professional competencies, compassionate humane competencies were fundamental to how they perceived their interactions with the healthcare professionals, their admission experience and their ability to navigate their new life situation with communicative difficulties. It became evident that regardless of the degree of communication difficulties, being met with both compassion and professionalism could serve as a facilitator for positive experiences despite the circumstances. When this did not occur, frustration arose along with feelings of exclusion or being looked down upon.

**TABLE 1** | Example of the transcription and analysis.

Verbal transcription	Visual notes, participant	Visual notes, interviewer	Condensed	Code	Category
19.06 I: So, you're saying they walk with the rover, they walk with that thing.  Pt: But, [it has?] but he doesn't have it anymore.  I: They don't have it anymore?  Pt: They have it (but) they just, [indistinct] [hurry?] on [indistinct]  I: ('They have it)  I: Okay, so they just move on?  P: Yes.	Pretends he is writing something down in front of himself, then waves his hand in front of himself.          Nods yes.	Imitates the movement P made earlier, pretends to hold rover in left hand and enters with the right hand.          Enters on the imaginary rover.	Would like the staff to talk with him when they are in his room with medication instead of focusing on the robot.	Focus on the task	A task-oriented communicative agenda
I: They enter something (on an electronic device) and move on?  P: Yes  I: Do they talk with you?  P: No  I: No... Would you like them to talk with you?  P: Yes  I: That was a clear and distinct yes.	Shakes his head, no.          Nods yes.  Nods yes.  Nods yes.	Gesticulates towards P.          Gesticulates towards P.			

**TABLE 2** | Patients' characteristics.

Participant n	Age	Gender	Diagnosis	Speech and language therapist' description of aphasia
1	69	Male	Stroke	Moderate-to-severe non-fluent aphasia
2	64	Male	Stroke	Mild-to-moderate aphasia. Affected language production and reading/writing/spelling function
3	71	Male	Stroke	Severe aphasia
4	78	Male	Stroke	Moderate aphasia + tendency to dysarthria
5	66	Male	Stroke	Severe dysarthria
6	68	Male	Stroke	Severe aphasia
7	74	Female	Stroke	Mild-to-moderate aphasia affecting production/ comprehension and reading/spelling function
8	51	Male	Stroke	Moderate aphasia affecting language production and writing/spelling function
9	69	Male	Stroke	Moderate aphasia affecting language production/ comprehension and reading/spelling function
10	67	Female	Stroke	Moderate-to-severe language difficulties affecting production/comprehension
11	87	Female	Stroke	Moderate-to-severe aphasia
12	89	Female	Stroke	Mild aphasia
13	56	Male	Stroke	Moderate aphasia and dysarthria

Interpersonal aspects were often brought up as a primary concern; it was articulated that nursing staff should acknowledge patients' competence, listen to them, and treat them with respect. Conversely, healthcare professionals perceived as possessing sufficient and accommodating communication skills, who were pleasant to interact with, often insisted on maintaining a semblance of normality in their interactions. They treated individuals with aphasia as normal human beings, behaving as normally as possible while considering the patient's difficulties. This restoration of a sense of autonomy was noted by participants. Staff members who employed humour and persisted despite communication breakdowns were found to be pleasant and were reported as competent.

#### 4.4 | Waking up to a New Communicative Reality

Common for all participants was the fact that the experience of living with aphasia was new. The participants' experience with their new communicative reality with aphasia after stroke was described to span a continuum from having no significant importance to being overwhelming and highly frustrating. Most participants perceived aphasia as a burden, describing the specific implication it had on their language function such as loss of some or all words, being unable to read and write or not understanding the message fully during conversations.

The experience of aphasia seemed to be related to the severity of the communicative difficulties and to the ability to employ strategies when communicating. It seemed to be of considerable importance how patients perceived the environment and how

the healthcare staff approached and supported them—both mentally and practically; and their general psychical and emotional condition also seemed of great importance.

As the aphasic difficulties were different from patient to patient, so were the participants' reactions when facing issues communicating with the nursing staff. In such situations, the patient's reactions ranged from giving up, shrugging it away, choosing when to use energy on trying or deciding to keep trying to communicate despite the difficulties:

**I:** So, you have something you want to say, but it's hard for you to express?

**P:** Yes

**I:** How does that make you feel?

**P:** I don't know. It's just as I say...You become a little passive; you know? (Patient 13)

The participants often worried about how they would communicate once they had been discharged and how communicating with family members and friends would be. During the short time that had passed since their admission, some patients had experienced a remission of symptoms for which they were grateful.

#### 4.5 | A Task-Oriented Communicative Agenda

The interviews revealed that patients experienced communication with nursing staff as almost exclusively task- or

purpose-oriented. The participants did express an understanding of this, and they tended to excuse the nursing staff for their lack of deeper conversations and for not stretching beyond task-oriented interaction and basic pleasantries. Most participants explicitly acknowledged that nurses and nurse assistants were busy and did what they could, given the available time.

Overall, the participants described the nursing staff as pleasant and accommodating. For some patients, the fact that nurses and nurse assistants were available when participants had questions was all they expected from nursing staff. Furthermore, this seemed to satisfy their immediate expectations and need for care for the vast majority. The purpose-oriented communication allowed nurses and nurse assistants to solve care-related tasks such as making sure the patient received food, medicine or the necessary help to meet other basic needs:

Well, it's like: Would you like a glass of juice? Right? Do you want something to eat? Right? It's no more than that. It's not like they say: Now, Stephen, listen... I hear you have some problems with this and that... and I'd like to help you... It's not like that at all, you know. Not at all...

(Patient 2)

By enquiring about further psychosocial, psychological and communicative matters, deeper conversational needs emerged even though the participants initially did not identify such needs. For some, the needs appeared to be unmet and unresolved; and not being engaged in deeper conversations would increase feelings of frustration and loneliness. A large proportion of the participants had only limited physical disabilities but were particularly affected cognitively and communicatively. They described how they felt left alone by the friendly nursing staff who were busy taking care of other patients with more severe physical disabilities whose care needs seemed more tangible.

Some patients even experienced that the nursing staff avoided communication and thought it was because it was too difficult or because they perceived that the patient was unable to understand and make decisions:

I: Okay, so they just move on?  
P: Yes.  
I: They enter something (on an electronic device) and move on?  
P: Yes  
I: Do they talk with you?  
P: No  
I: No... Would you like them to talk with you?  
P: Yes  
I: That was a clear and distinct yes.(Patient 1)

Some participants with mild or discrete aphasic difficulties described limited general involvement unless they actively sought it themselves. The nurses and nurse assistants would happily answer questions if the patients could articulate them. This gave participants with mild aphasia a distinct advantage as they were both able to ask staff for information and actively seek information themselves in leaflets, the participant training overview or on the whiteboards in the stroke wards. Participants with moderate to severe aphasia, on the other hand, expressed difficulties initiating communication, posing all their questions regarding treatment and care. They expressed how exhausting it was to attempt to communicate, expressing how it took a toll on their resources. Patients with more severe communication difficulties were dependent on others to initiate and engage in conversations.

Some participants were capable of seeking communication elsewhere, and some engaged in communicative interactions with neighbouring patients or family members, expressing that this momentarily satisfied their conversational needs:

I: Do you miss having other conversations in here?  
P: Yes, yes... I'll have to do that with my family, I get... I get visits often... my daughter comes almost every day... (Patient 9)

Some patients voiced that they dealt with existential thoughts, worrying about the future or being a burden for their family and expressed a need to be accommodated by the staff in communication on this. One patient experienced how all his questions, feelings and worries would keep him awake at night when left alone. However, patients also described how conversations with acknowledging and competent nursing staff members could help them deal with or ease the burden associated with stroke-related changes in life and that conversations like these conveyed a feeling of security, hope, comfort and safety.

#### 4.6 | Misunderstandings as a Communicative Dead End

The participants described how misunderstandings occurred in all communication, disturbing the communicative practice and often leading to a dead end.

The cause of these misunderstandings was divided into misunderstandings due to communication difficulties, misunderstandings caused by an insufficient level of information and misunderstandings caused by other factors such as nursing staff workload. Some patients lacked basic information about what had caused their stroke in the first place. Others did not know the daily or longer-term plans, which could lead to misunderstandings regarding the continuity of care.

I: Do you feel you know what the plan is during the day?  
Pt: Eeehm  
I: Do you get informed about your plans?

- Pt:** No.
- I:** Do you need that (writes keywords)? Do you need that information?
- Pt:** Yes. And it is frightening. I mean. And. The information. Ehm. Clear enough.
- I:** Clear enough? Just to be sure I understand you correctly. Are the information clear enough?
- Pt:** Eeehm (pause)
- I:** (writes down “yes” and “no” to provide pt with possibilities to answer).
- Pt:** No.
- I:** No it is not clear enough (circles no).
- Pt:** No (confirms the answer is no). (Patient 6)

Misunderstandings and the perception of how big a problem these misunderstandings posed were often related to the severity of the patient's language disability. The misunderstandings were occasionally cleared, but this was not always the case.

Being misunderstood and unable to clear up the misunderstandings had negative emotional consequences for the participants. Some gave up, while others felt frustrated and belittled, making them withdraw from the conversation.

- I:** Do misunderstandings occur? (...) because of the language difficulties during conversation?
- Pt:** yeah (a bit hesitant while thinking).
- I:** Ok, what happens in those situations?
- Pt:** Yeah (pause) what happens is I, I roll over on my side and says (make a shushing sound and motion with finger).
- I:** And shuts down?
- Pt:** Yes.
- I:** Okay. (Patient 3)

In some cases, the misunderstandings seemed to have consequences not only for the level of information received and the patient's emotional well-being but also for the patient's treatment and care. Some patients had experienced not knowing what medicine they had been given or why. Some had even experienced being given medication they did not agree to. Some patients expressed their need for information and involvement regarding medical decisions. Still, they experienced that their communicative attempts to engage in a conversation on the matter were sometimes rejected by the nursing staff and that this could lead to misunderstandings on, for example, usual procedures regarding their own diabetes treatment:

Now I've had, for 8 years, I've had diabetes, and I've managed it myself every single day, and here it's been taken from me. It was frustrating, how they took it from me and said, no, no, this is how it should be. It's wrong, I know it in my head, but I couldn't get it out. (Patient 8)

#### 4.7 | Establishing a Communication-Friendly Environment: Peace, Patience and Supporting Techniques

The patients emphasised the importance of a quiet, calm and peaceful environment as opposed to communicating in a busy ward or a noisy patient room. Further, participants with more severe aphasia described how they needed additional time when communicating. The participants often felt that the staff members were neither focused on nor interested in giving the patient time to attempt to communicate as they appeared very busy. A slower paceduring interactions was described as helpful, whereas rushing and intensive guessing made participants feel tired and frustrated and could result in them giving up:

- I:** You know what you would like to say?
- P:** Yes.
- I:** It's in your head?
- P:** Yes.
- I:** But when it needs to come out of your mouth...
- P:** and tjebebetjeb (a “rushing” noise in Danish).
- I:** It must go faster?
- P:** And it, almost give up (rolls his eyes and shakes his head).
- I:** Yes.
- P:** Because the staff and others, ehm guessing competition (...).
- I:** Do you give up then?
- P:** Then I give up. (Patient 6)

Accessible nursing staff in a peaceful ward was described as valuable, as was also the availability of a patient room of their own. During the various stages of admission, some participants described how the need for patience and quietness was especially evident early in their admission. This stage was especially characterised by difficulty understanding what was occurring and difficulties voicing their needs. The descriptions showed that time and patience allowed the participants to follow instructions, receive information and express themselves. It was further helpful when staff took their time and focused on communicating clearly.

When asked how staff helped the participants express themselves despite difficulties, the participants described that staff would often tell them to repeat or would start guessing, sometimes successfully, other times not.

The patients had met a speech and language therapist during hospitalisation, but they described that information from the therapeutic professionals did not seem to reach the nursing staff and they did not experience that all nursing staff had the specific tools necessary to secure involvement. Consequently, participants would occasionally choose and prefer specific nurses or nurse assistants whom they found better qualified for supporting a conversation.

The participants did not describe many specific support techniques used by the staff members in conversations. However, one prominent support tool that was mentioned in the interviews was the use of a dialogue notebook. The perceived functionality of the dialogue notebook varied from patient to patient. Some described how it was a help in the communication or when trying to remember things. Others did not find the dialogue notebook helpful at all. Some patients were unaware of its existence even though they had one. The patients who found that the book useful knew its purpose and acknowledged its importance for communication. The participants described how the nursing staff—although with some exceptions—did not use the dialogue notebook to the same extent as other professionals.

The use of gestures and body language, expressive facial expressions, sounds and so forth as part of the communication was also addressed during the interviews. The participants did not report that the nursing staff used gestures, but they themselves used this technique along with body language and other alternative means to try and help communication flow or make themselves understood.

## 5 | Discussion

The aim of this study was to investigate stroke patients' experiences of communicative practice during their hospitalisation and to identify and describe the strategies and supported communication techniques applied by the patients themselves or the nursing staff as seen from the patient's perspective.

At a latent level, we interpreted the participants expected the nursing staff to acknowledge their competence by meeting them as equal human beings while accommodating their need to be heard, involved, and treated with respect. However, patients did not consistently experience this in daily clinical practice. Feeling recognised as an equal human being was vital, and the patients' descriptions underscored the importance of the nursing staff members' ability to accommodate the need for humanisation of the communicative interactions. The analysis underlined the fact that emotional, relational and existential aspects are interwoven in communication and are important for the participants' perception of treatment and care. Hence, these findings underscore the point that training the staff in the use of supportive communicative strategies and techniques alone—even if well implemented—will not necessarily allow nursing staff to meet the existential needs of PWA as suggested in a study by Pound and Jensen (2018) as well (Pound and Jensen 2018).

The manifest analysis illustrated how the participants experienced waking up to a new communicative reality and were just beginning to learn how to cope with this life-changing event. Most participants described aphasia as a burden and stressed the importance of how they were met and supported by the environment and the nursing staff. Pound and Jensen (2018) describe how a number of studies have reported interactions with healthcare professionals that reinforce feelings of comfort or discomfort in PWA (Pound and Jensen 2018). Yet, hope remains as a positive influence may be achievable if the staff prioritises values such as those presented in the Humanisation Values Framework as, for instance, *embodiment* in which a nurse

responds to human dignity by acknowledging the PWA in their social, cultural and familial context; or *togetherness* in which an emphatic bond develops between a healthcare worker, a patient and their family (Pound and Jensen 2018; Todres, Galvin, and Holloway 2009).

Although the staff members were perceived as friendly and accommodating to the patients' basic needs, their communication seemed to mainly revolve around these. The participants therefore perceived the nursing staff's communication as primarily task- and purpose-oriented, and they lacked deeper conversations. This is in line with previous studies describing that communication between nurses and stroke patients with or without aphasia is often task-oriented and only to a limited extent conversation-oriented and patient-driven (Gordon, Ellis-Hill, and Ashburn 2009; Heard, Anderson, and Horsted 2022) (+Own references). According to Todres, Galvin, and Holloway (2009), evidence confirms how human dimensions of care are often suppressed by a technological and specialised focus. Although a technological and specialised focus may be an absolute necessity in some cases, we risk dehumanising care if these technical strategies take over (Todres, Galvin, and Holloway 2009).

The patients primarily attributed the task-oriented agenda to a lack of time on the nursing staff's behalf. However, this practice seemed to leave several participants with unmet emotional and psychological needs. Baker et al. (2021) also described that because they need help to communicate and understand, PWA may have psychological and emotional needs that are often not addressed (Baker et al. 2021). A help that is not provided. This influences patient safety and quality of care alike (Mandal, Seethalakshmi, and Rajendrababu 2020). Moreover, since nursing staff have a unique opportunity to prevent distressing emotional responses like depression during hospitalisation (Baker et al. 2021), a focus on this aspect may help improve care in the future. Rehabilitation that fails to address the basic emotional and psychological consequences of aphasia is inadequate from a patient's perspective (Worrall et al. 2011).

Misunderstandings seemed to occur relatively often in the communicative practice—even among participants without severe communication difficulties. Besides negative emotional consequences, misunderstandings meant that some patients missed vital information or were given medication to which they had not agreed. Hemsley, Werninck, and Worrall (2013) reported unfortunate events due to a lack of understanding in the communication between PWA and staff. They suggested involving family members more teaching hospital staff about aphasia and providing communicative strategies as a way to ease these barriers (Hemsley, Werninck, and Worrall 2013).

To improve the communicative practice, patients stressed the importance of creating a communication-friendly environment. This included peaceful surroundings, staff approaching communication with patience and information regarding supporting techniques provided by the speech and language therapist to nursing staff—techniques they would apply in their daily care. Studies have shown that health professionals were aware of the discrepancy between the communicational needs and the actual communication practice and expressed a need for support and help to enhance their communication with PWA (Carragher

et al. 2020). These changes must be addressed systematically at an organisational level (Burm et al. 2019).

Overall, patients did not seem to encounter a systematic approach to communication. The patients' perception of the nursing staff's communicative practice shows how the implementation of supported communication for nursing staff from this point forward needs to be addressing the emotional, relational and existential aspects of communicative interaction. Thus, it seems that we may need to explore ways to enrich approaches like SCA to allow nursing staff to address PWAs' fundamental needs as argued by Pound and Jensen (2018). They suggest leaning on Todres, Galvin, and Holloway's (2009) eight theoretically informed dimensions for humanising care (Pound and Jensen 2018), as it seems important that healthcare professionals are familiar with insider human experiences in order to be caring communication partners of PWA (Pound and Jensen 2018).

## 5.1 | Methodical Considerations

Interviewing people with communication disabilities in general and aphasia is—naturally—challenging due to the communication difficulties associated with this disorder. As expected, non-verbal communication and aphasic difficulties were prominent during the interviews. This may be considered a limitation because it leaves room for additional interpretation. According to Loft et al. (2019), a lack of studies exists that comprise interviews with patients with aphasia (Loft et al. 2019), and people with aphasia are generally neglected and left out of stroke research (Shiggins et al. 2022). Since one third of all stroke patients suffer from aphasia (Flowers et al. 2016), we find that our study is an important contribution to knowledge in this field. Taking into account, its potential limitations, the authors discussed and considered preconceptions and potential biases during the entirety of the study to secure the validity of the results.

The process was dynamic and demanded that the interviewer continuously reflected on their communicative practice and the participants' need for support while listening and remaining present during the interview. Discussing these preconceptions and reflecting upon them during the process allowed us to adopt a reflective approach during the interviews and the analysis of our data. As recommended by Shiggins et al. (2022) supportive communication techniques were used when necessary to give participants the best possible possibilities for contributing in-depth descriptions of their unique position, thus securing the quality of the interviews (Shiggins et al. 2022). Furthermore, patients were sampled aiming for maximum variation in terms of levels of aphasia in patients from different socio-economic backgrounds and who were diverse with respect to gender and age. This is a strength for the study as it allowed us to illuminate the experiences from various perspectives while also achieving data saturation, with PWA informants' narratives beginning to repeat. A quality indicator for qualitative research is achieving thick descriptions (Polit and Beck 2017). Interviewing PWAs can naturally challenge this, but by incorporating video recordings and recognising nonverbal communication as part of the thick descriptions, we believe our findings demonstrate that we achieved precisely that.

We found that despite obvious challenges, the method proved suitable as the interviews produced large amounts of data, allowing for a rich description of the patients' experiences of the communicative practice.

## 6 | Conclusion

In conclusion, the findings of this study contributed to knowledge about what aspects of the communicative interactions patients' value and do not value. The participants reported that the nursing staff's communication was primarily task- and purpose-oriented, and they lacked deeper conversations.

The patient's perception of the nursing staff's communicative practice shows that the implementation of supported communication techniques for use by the nursing staff at a stroke ward needs to address compassionate or acknowledging aspects of communication. These aspects are important to PWA during their early admission as are the basic communicative strategies that participants commonly reported, and which are typically relational. Even newly admitted people with communicative support needs, such as aphasia, may voice their preferences despite limited experience living with aphasia; unaware of any specific support techniques. They have needs and concerns that the nursing staff can accommodate. Involving people with communication disabilities is important to building a common understanding of which elements are essential to successful clinical communication targeting patients' care needs.

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### Author Contributions

All authors have agreed on the final version and have made substantial contributions to the conception and design, acquisition of data, analysis and interpretation of data, drafting of the article and revising it critically for important intellectual content.

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### Conflicts of Interest

The authors declare no conflicts of interest.

### Data Availability Statement

Author elects to not share data.

### Peer Review

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