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‘But I have a cat, I have to talk to her now’: a qualitative study on reasons for not participating in guideline-based aphasia therapy from the perspective of patients in German-speaking countries

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ABSTRACT

Objectives Clinical guidelines recommend high-frequency speech therapy for people with aphasia. Little is known about the experiences of people with aphasia with high-frequency speech therapy, why they do not receive it, what they expect from it and their general wishes and requirements for therapy. The aim of this qualitative study was to investigate the reasons for refusing high-frequency speech therapy and therapy preferences of patients with aphasia.

Design An interview study with people with aphasia.

Setting Interviewees were recruited via snowball sampling in different settings of healthcare system (eg, speech and language practices, self-help groups, clinics of neurorehabilitation).

Participants Twenty-one people with aphasia and one relative participated in semi-structured interviews.

Results We identified five categories of not using high-frequency speech therapy: patient-related factors, health system-related factors, disease-related factors, social-economic factors and organisational factors. Most reasons for non-utilisation are within the domain of the healthcare system and are partly attributable to personnel shortages in care provision and knowledge deficits among healthcare practitioners. Patient therapy preferences notably pertain to the enhancement of speech therapy services, encompassing sessions both inclusive and exclusive of family members as well as the facilitation of information dissemination.

Conclusions As expected, there were indications of a lack of staff, poor care in rural areas and the influence of being affected by aphasia for a longer period on utilisation behaviour. These factors in the healthcare system and organisational factors are not unknown to those with practical experience, and some of them must and could be changed quickly. This would require a change from the established face-to-face setting in presence to sufficient digital therapy adjuvants. The results of patient-related factors could be a further reason to reflect on speech therapy and its settings and to view and treat people with aphasia in a more holistic, less language-focused way.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A purposive sampling method was used in the study to ensure the inclusion of participants with varying levels of aphasia severity.

⇒ Semistructured interviews were conducted, which allowed for an in-depth exploration of participants’ experiences while maintaining flexibility in data collection.

⇒ The analysis followed a structured qualitative content analysis approach that combined both inductive and deductive coding techniques.

⇒ Potential limitations include the reliance on verbal communication, which may have affected the accuracy of the data collected from individuals with severe aphasia.

⇒ The study was limited to a relatively small sample, which may limit the transferability of the results.

BACKGROUND

Cats are typically not a component of the rehabilitation process for aphasia, but instead speech therapy can positively influence aphasia and its effects on communicative participation. In contrast to many other areas of speech therapy, the evidence base for aphasia treatment is increasingly robust. These results have been demonstrated in numerous studies with high evidence values and are now part of the recommendations for action and guidelines.

When the chronic stage poststroke is reached and no more processes of spontaneous remission lead to improvements in speech and communication,[1] only therapy-induced changes in speech can be observed.[2 3]

Many factors influencing the effectiveness of speech therapy have been and continue to be discussed, but a clear predictive value for the outcome of therapy appears to result only from the extent of therapy and, above all, from the frequency of therapy.[3–6]

Based on a literature analysis, it was found that a therapy frequency of 8–10 therapy hours per week leads to significant linguistic and communicative improvements in the chronic stage,[7–9] and the feasibility and effectiveness of such high-frequency therapy were demonstrated for the German healthcare system.[5]

The comparison of this frequency recommendation with the reality of care is unfortunately less well known. An analysis of 17 571 health insurance data records in 2012 revealed a dramatic deficit in the implementation of guideline recommendation for speech therapy: Korsukewitz *et al*[10] found that therapy frequency was 28 min per week on average (± 23 min, median 23), including high-frequency acute care. The drama of this undersupply is not the subject of much research but is well known to clinically active speech therapists, so the resort to inadequate forms of communication such as speaking to pets is, therefore less surprising.

There seems to be a discrepancy between guideline-based speech therapy and the reality of the uptake of those recommendations. Some studies locate underlying reasons for non-guideline speech therapy in the healthcare system. There seems to be a shortage of speech therapists in the intramural as well as the extramural sector[11] and concerns about sanctions due to the regulations of the German healthcare system. Another analysis of insurance data indicates a deficit in the implementation of guideline recommendations on stroke aftercare. 44.1% of patients with speech impairments after stroke received outpatient speech and language therapy aftercare.[12]

Trebilcock and colleagues[13] used expert interviews to identify barriers and facilitators to implementing high-intensity aphasia therapy. Four overarching themes supported the identification and explanation of the key barriers and facilitators, according to professionals in the five English-speaking countries: (1) collaboration, joint initiatives and partnerships, (2) advocacy, promoting aphasia services and evidence-based practice, (3) innovation, problem-solving ability and (4) culture, the influence of underlying values. The concepts of ‘selling’ or ‘flying the flag’ for aphasia services were highlighted as a key outcome in the context of advocacy. However, this study did not include the perspective of people with aphasia. This is important, however, because even existing high-frequency therapy programmes that have already been implemented are not necessarily taken up.

Another survey of professionals[14] shows a discrepancy between speech and language therapists’ understanding of therapy intensity and clinical guidelines/research results. Although a wide range of therapies are offered, certain aphasia therapies are used more frequently. Awareness of Intensive Comprehensive Aphasia Programs is relatively high, but few therapists have experience of this model or consider it feasible in their context. There would be a need for new initiatives to move away from a low-dose or incomplete care model. At the same time, it is suggested that pragmatic research should be conducted to determine which treatments are effective in a low-frequency model, since this model is prevalent in the UK. Monelly collected client-related factors necessary for participation in high-frequency therapy, as assessed by therapists: motivation was the highest voted criterion, along with time commitment, clear goals and potential improvement. Factors such as impact of aphasia on people with aphasia (PWA) and emotional stability were required less frequently. Necessary conditions from the client’s point of view were family/carer support and transport options. The reasons for professionals to refrain from high-frequency therapy were knowledge, skills and capacity. However, the item generation did not take place via mixed methods, which raises the question of the extent to which the items could validly reflect the reasons for prevention in their entirety. Reasons for prevention from the patient’s point of view were not surveyed.

Babbitt *et al*[15] conducted 12 interviews with aphasia patients about their experiences with high-frequency therapy. The interviewees emphasised that intensive therapy, together with the social environment, formed a holistic ‘therapy package’ that led to improved outcomes. They reported not only progress in speech and conversation skills but also increased participation in daily life, better psychosocial health and physical improvements. Participants associated more intensive therapy and stronger social interactions with better outcomes, such as more word and sentence production, more fluent conversations, and improved mood and self-confidence. These findings are of great importance for the architecture of new therapeutic approaches, but they say little about how to optimise high-frequency therapy when it is used.

One factor that has been discussed rather casually so far is the motivation of patients and the psychosocial effects of speech therapy: in the much-cited Rotterdam study,[16] the most common reason for not participating in high-frequency therapy is a lack of motivation.

An explanation could give the self-determination theory, postulated by Ryan and Deci.[17] This theory formulates three cross-cultural and permanent basic psychological needs and their satisfaction to create optimal learning environments: experiencing competence, autonomy and social embedding.

The required intensity with more than 2 hours of therapy every working day demands a high degree of frustration tolerance, as it is always confronted with deficits also when using therapy methods such as vanishing cues and errorless learning.[18] By their very nature, patients’ autonomy is often restricted in speech therapy: even with participatively developed therapy goals, the level of detailed goal planning such as the choice of items, the didactic embedding, the evaluation of patient reactions and the number of repetitions are just as much the responsibility of the therapist as organisational circumstances such as scheduling. Aphasia impedes processes of shared decision-making by restricting communication and interrupts the stringent implementation of person-centred care.[19 20]

The willingness not to work autonomously on one's own deficits can be reduced, it is simply not pleasant. It has not yet been investigated whether speech therapy settings are specific in their situational and relational structure and whether this has a possible influence on motivation and terms of utilisation. Under certain circumstances, empathic, therapeutic behaviour in general can contrast with an approach that clearly reports and confronts errors, resulting in a stressful situation because it is ambiguous: the interpretation of ambiguous situations can lead to uncertainty and intolerance and can even be detected in cardiovascular response.[21 22]

This assessment coincides with a survey conducted in 2013[23]: 65% of the 257 speech therapy practices surveyed had the potential to use high-frequency therapy. In the cases where indicated high frequent therapy was not conducted, the reasons also lay in the responsibility of the patients themselves. Unfortunately, possible reasons for this were not investigated.

So far, only a few studies have focused on people with aphasia and not on their linguistic rehabilitation. One study asked participants with aphasia about their goals in an open-ended way. Nine categories emerged inductively from the answers: a significant goal was to return to life before the stroke and communicate beyond the narrowly defined limits of basic needs, including being able to express opinions. Other goals, some of which also corresponded to wishes, were more speech therapy and more autonomy, in addition to a general return to health.[24] This study in particular shows the ambivalence of the situation: the perceived negative restriction of autonomy, which is not explicitly related to the therapy but to restriction of independent living, is mentioned as well as the desire for maximum language rehabilitation.

This study focuses on the established and highly evidenced classic speech therapy. Even though initial studies show promising approaches to including chemical or physical therapy adjuvants[25–27] or the inclusion of digital home training options[28–31] to achieve a high-frequency therapy, further evidence is needed to implement it in routine care. However, in theory, conventional speech therapy is available to patients in Germany and Austria, as the legal framework is unambiguous. This study, therefore, focuses on the question of why aphasics do not (cannot) take advantage of this option.

This raises the question of what prevents the utilisation of high frequency and therefore effective therapy, even if it was available? What determines usage behaviour, what are the needs and requirements of people with aphasia?

METHODS

The described data collection is part of the AWARE project, which aims to identify the reasons for the prevention of guideline-based treatment, predictors of utilisation and the wishes of PWA. In order to systematically and differentiatedly identify the needs of those affected and at the same time involve them in the planning and implementation of activities to improve care, qualitative data access is initially selected. The methodology thus follows a preliminary study or generalisation design (exploratory sequential design), in which the implementation and evaluation of a qualitative preliminary study and its results are used to develop a quantitative study.[32]

In order to acquire data about how people affected by aphasia access speech and language therapy and the challenges they face, a qualitative approach to data collection and analysis was used.[33] The intention was to gain a global understanding of everyday care and the associated challenges and to systematise them accordingly.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting or dissemination plans of our research.

Participants

The study was conducted in Germany and Austria, where a significant shortage of healthcare professionals, particularly speech and language therapists, is a well-documented issue.[34] In 2023, there was not a single federal state in Germany where there was no shortage of speech therapists. On the contrary, this seems to be particularly pronounced everywhere, as the shortage indicators reach very high values.[35] In Germany, patients can choose their speech therapist and the therapist bills the health insurance company directly. As a rule, 90% of the therapy costs are covered by health insurance companies, with the patient having to pay the remaining 10% themselves. In Austria, patients can either opt for a private speech therapist, where they initially bear the costs themselves and are later reimbursed by the health insurance company (as a rule, 50% of the therapy costs are covered by health insurance company), or choose a contract therapist, where the therapist settles the full amount directly with the health insurance company.

Participants were selected using purposive sampling,[36] specifically using criteria aimed at including patients who have aphasia. Further inclusion criteria were age ≥18, native German speaker, participation in speech therapy in the past and willingness to participate in the study. The purposeful sampling of participants for this study was based on several specific criteria to ensure a diverse and representative sample. First, participants were selected based on the severity of their aphasia, which ranged from mild to severe. This was done to capture a wide range of experiences and challenges related to speech therapy at different levels of impairment. Second, time since onset of aphasia was considered, with participants representing different stages of aphasia recovery, from individuals with recent onset of aphasia to those in the chronic phase. In addition, geographical distribution was taken into account by selecting participants from different regions of the German-speaking world. All participants had previous experience with speech therapy, so they were familiar with the topic and could provide knowledgeable information about the factors influencing their participation or non-participation in high-frequency therapy. Finally, only people who agreed to participate independently or with the help of a caregiver were included in the study. If a person was very severely affected, it had to be ensured that a relative was present during the interview and could expand on the answers if necessary.

Patients were recruited via snowball sampling. Recruitment was based on the recruitment procedures described.[37] The recruitment process for this study followed a structured approach. Participants were primarily recruited through established networks within the healthcare system, including speech and language therapy practices, self-help groups and neurorehabilitation clinics. These institutions were contacted by the research team, who provided them with detailed information about the study. The institutions then helped in identifying individuals who met the study's inclusion criteria and reached out to these potential participants. Initial contact with potential participants was made by healthcare professionals, such as speech therapists or self-help group coordinators, who were already familiar with the individuals. The research team introduced the study and assessed the participants' interest. Once potential participants expressed a willingness to be involved, their contact information was shared with the research team. The research team then followed up with these individuals to explain the study in detail, answer any questions they had and schedule interviews. Before any interviews were conducted, informed consent was obtained from all participants. They were fully briefed about the study's purpose, the procedures involved, and their rights as participants. In order to minimise recruitment artefacts in the results and to obtain meaningful results from the three German-speaking countries, Austria, Switzerland and Germany, recruitment was carried out by telephone, post and digitally. Participants were selected over a period of 6 months, consistent with available resources. The participants received 50€ for their participation.

Data collection

A preliminary semistructured interview guide was drafted by a multiprofessional team (SM, FM, RD). The semistructured interview guide consisted of open-ended questions that explored the current therapy situation regarding therapy setting, frequency of therapies, content of speech therapy, challenges and wishes. In addition, sociodemographic data were collected, including gender, age, population figures and the underlying disease. To ensure clarity and relevance of the questions, the interview guide was piloted and adapted during the first five interviews. Some questions were adjusted in the process (please find the final interview guide in online supplemental material 1 interview guide). Interviews were conducted in person or by video call from May 2023 to October 2023 by two different researchers (LP, SM). The interviewers had no previous relationship with participants. Participants were given the opportunity to ask questions before being asked to give verbal informed consent. After the interview, participants were thanked for their time and given the opportunity to ask any further questions. The interview was then transcribed verbatim and anonymised. The transcript was imported into the software MAXQDA to record field notes and facilitate data analysis. Transcripts were not returned to participants for comment or correction.

Data analysis

Qualitative analysis of the interviews was performed iteratively by the study team (SM, FM) based on Kuckartz's structured qualitative content analysis[33] using MAXQDA Analytics Pro 2022, Release V.22.1.0, Verbi GmbH (Berlin, Germany).

In the qualitative analysis, we followed a deductive-inductive approach based on the adherence of long-term therapy model.[38] The main categories—health system-related factors, patient-related factors, disease-related factors, socioeconomic factors and organisational factors—were predetermined and reflect the main barriers to accessing speech and language therapy. The subcategories were partly determined inductively through a detailed analysis of the interview transcripts. The analysis began with a review of the interview transcripts, followed by coding the interviews. Relevant text passages in the interview material were coded using a combination of deductive and inductive methods. Main categories and subcategories emerged through an inductive process based on these codes. Consensus discussions within the research group continued until a shared understanding of all emerging categories was reached. In addition, some categories were developed deductively based on the research questions and then integrated into the coding framework. Data collection had already been completed at this stage. Two researchers (SM, FM) independently applied the established category system to analyse the entire dataset, ensuring transparency and reproducibility. To present the findings, significant excerpts from the transcriptions were selected as representative quotes. These quotes were translated into English and incorporated into the manuscript. The manuscript follows the guidelines of the Consolidated Criteria for Reporting Qualitative Research[39] (please see online supplemental material 2).

Ethical considerations

To begin, both verbal and written consent were integral parts of the process. Verbal consent was obtained first to ensure that participants clearly understood the study's purpose, procedures and their rights, using simple and clear language. This initial verbal consent was crucial, especially during the first contact. Following this, participants were provided with a written consent form, designed in plain language and, where necessary, large print to assist those with reading difficulties. Participants were given ample time to review the document, ask questions and discuss the information with a relative or caregiver if needed before signing. For individuals with

Table 1 Characteristics of the interviewees

Participant	Age (years)	Gender	Presence of relatives during the interview	Years poststroke	Underlying disease	Classification of population figures
TN01	60s	Male	no	4	Stroke	Big city
TN 02	70s	Female	yes	6	Stroke	Big city
TN 03	50s	Female	yes	4	Stroke	Big city
TN 04	60s	Male	yes	10	Stroke	Country town
TN 05	40s	Female	yes	11	Stroke	Big city
TN 06	40s	Female	no	20	Stroke	Big city
TN 07	50s	Female	yes	12	Stroke	Big city
TN 08	70s	Male	no	6	Stroke	Medium-sized town
TN 09	60s	Male	no	6	Stroke	Big city
TN 10	60s	Female	no	14	Stroke	Country town
TN 11	30s	Male	Interview with relative	6	Traumatic brain injury	Big city
TN 12	70s	Male	yes	14	Stroke	Village
TN 13	60s	Male	no	2	Stroke	Big city
TN 14	70s	Male	yes	2	Stroke	Big city
TN 15	30s	Female	yes	2	Stroke	Small town
TN 16	60s	Female	yes	0,8	Stroke	Village
TN 17	70s	Female	no	40	Stroke	Big city
TN 18	60s	Female	no	33	Traumatic brain injury	Big city
TN 19	60s	Female	no	35	Stroke	Big city
TN 20	50s	Female	no	31	Stroke	Big city
TN 21	60s	Male	no	2	Stroke	Big city
TN 22	60s	Female	no	32	Stroke	Big city

more severe aphasia, a relative or caregiver was present during the consent process to help explain the study and ensure comprehension. This involvement was an essential support mechanism, providing participants with the reassurance that they fully understood their participation. The recorded interviews were pseudonymised after transcription. The coding list is stored separately from the other study documents at Center for Health Services Research of Brandenburg Medical School Theodor Fontane. Access to the coding list is restricted to the study lead. Personal data were anonymised in the transcripts.

RESULTS

Twenty-one interviews were conducted and analysed until theoretical saturation was reached. Nine interviews were conducted with relatives and one interview was only conducted with a relative because the patient was so severely affected that he was unable to answer. Mean duration of the interviews (n=22) was 50,48 (27 –84,17) minutes. The mean age of the participants (n=21) was 61.7 (range: 34–97) years. Most participants were women (13/21; 62%) (for detailed characteristics of the interviewees, please see table 1).

The analysis followed a deductive-inductive approach. The main categories were defined in the course of the qualitative content analysis, reflecting distinct barriers to speech therapy access: patient-related factors, health system-related factors, disease-related factors, social-economic factors and organisational factors (please see figure 1).

Patient-related factors

Patient-related factors are the personal characteristics, attitudes and behaviours of affected individuals that influence decisions and actions related to health and medical treatment. These factors include health literacy, health beliefs, social and cultural influences, cognitive abilities, mental health, socioeconomic status, age, gender and personal motivation. They play a significant role in adherence to medical therapies and can lead to patients making different decisions about whether or not to follow recommended treatments. The following subcategories were identified:

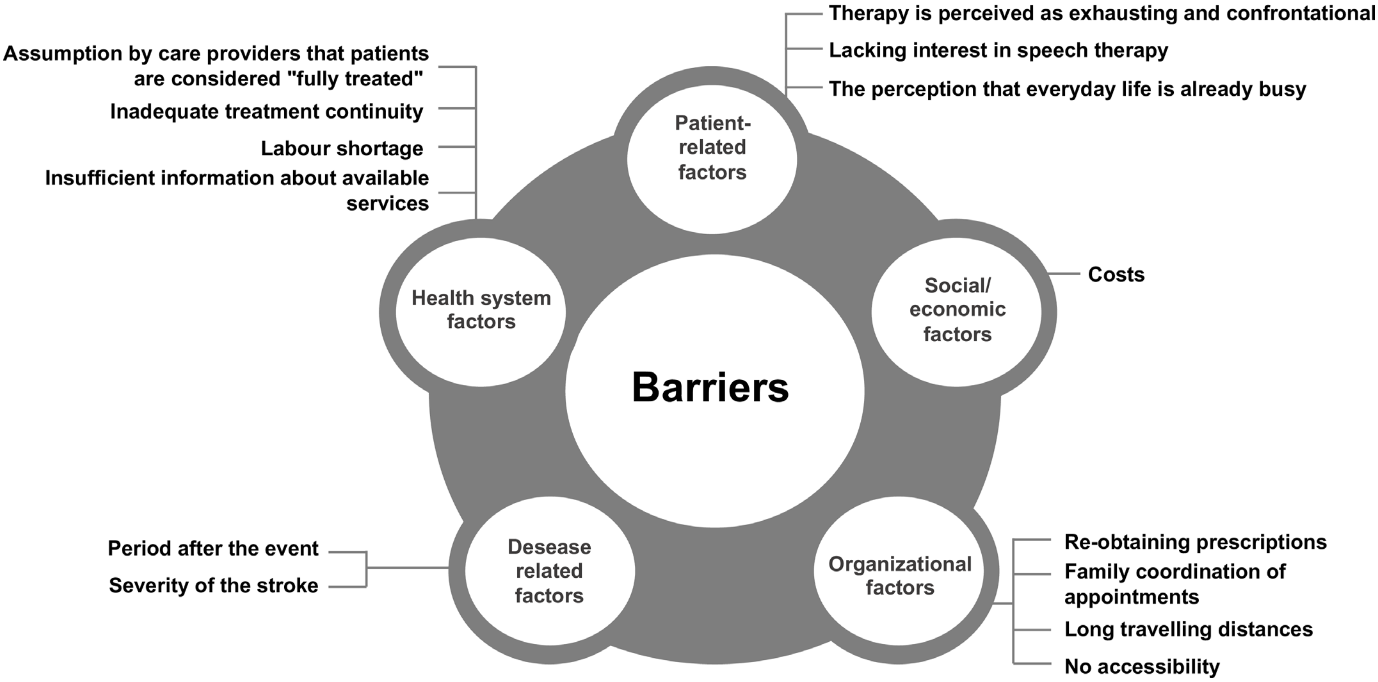

Figure 1 Systematisation of the reasons not participating in guideline-based speech therapy (coding tree).

Patients sometimes perceive speech therapy to be exhausting and confrontational, depending on the type of therapy and the therapist. These experiences have been described heterogeneously by the participants. Some therapy methods require active participation and intensive exercises, which can be perceived as strenuous. Patients must openly reveal and address their personal problems, fears or difficulties. This can be uncomfortable or confrontational for some people, as they have to confront their own weaknesses or psychological challenges. Therapy, especially rehabilitative therapies, often requires patience and perseverance, as progress is not always immediately visible. This can frustrate patients, and they might find the therapy strenuous if they do not quickly see the desired results.

> Thus, strenuous moments for me were when I had to work under time pressure. So, when somehow a click was made and the clock started ticking, and I had to, needed to say words for certain letters within a certain time. I didn't manage that, and I still can't do it today. That means, this pressure of time is very difficult for me, to get things in order. (Interview_09, 61 years, male, 6 years post stroke)

Another barrier for speech therapy is the lack of interest from the patients. Thus, therapy often requires intrinsic motivation, which can vary depending on the phase of the illness.

> A: And why are you not currently undergoing therapy?
>
> B: Because it… phew. Ah because I've lost interest. (Interview_02, 70 years, female, 6 years post stroke)

Another frequently reported barrier to speech therapy is the perception that daily life is already filled with other obligations and activities. A perceived lack of time can lead patients to hesitate to engage in therapy.

> A: Ah now… n… not anymore but… u… and ah… ah… ahm… ah… ah… month (whispers) Ye…Years or something… ah two or something and ah and… ah no… once, because because I can't manage it anymore, because ah Building ah ah… ah… driving and ah Physio and whatnot and ah… and then… ah… ah… stop and then ah year or so two or ah… ahm Speech therapy.
>
> B: It's just not possible because you also have enough to do otherwise?
>
> A: Exactly… and and… yes exactly. (Interview_01, 66 years, male, 4 years post stroke)

Social/economic factors

The cost factor is a common obstacle to accessing speech therapy. Therapy sessions can be associated with significant costs, especially if the health insurance/health fund/payer does not cover all or only part of the costs. This leads to many patients hesitating to undergo the necessary therapy.

> Because, ahm, it's all so expensive. Because ahm, physio, ah, so much more expensive and speech therapist, ah, speech therapist also expensive. Yes. And I have no more money. (Interview_15, 34 years, female, 2 years post stroke)

Health system-related factors

Health system-related factors are the characteristics, policies and processes of the health system that influence a patient's willingness and ability to follow medical therapies and recommendations. These factors include the quality of healthcare services, accessibility to medical care, efficiency of appointment scheduling, availability of medications and therapies, communication between patients and medical staff and the coordination of care. Health system-related factors can affect adherence by creating barriers or facilitators to following therapy recommendations.

The assumption by therapists or healthcare providers that patients are considered 'fully treated' can lead to patients not receiving further therapy sessions.

> Ah, the speech therapist said there's no point anymore, she's out of therapy, she doesn't need it anymore. (Interview_02, 70 years, female, 6 years post stroke)

Inadequate treatment continuity may occur when there are restrictions in ensuring regular and consistent therapy sessions. Reasons for this are, for example, when therapists retire or go on maternity leave. A replacement is often not automatically available.

> A: I had [speech therapy]. The speech therapist retired.
>
> B: When was that?
>
> A: It was a year ago
>
> B: A year ago, yes. And you haven't had any speech therapy since then?
>
> A: Yes. But I have a cat, I have to talk to him now. (Interview_10, 69 years, female, 14 years post stroke)

The labour shortage in the healthcare system, including speech therapists, can limit the availability of therapy options. Long waiting times for therapy places are common.

> A: Yes, the problem is in our area, we don't have any speech therapists.
>
> B: Okay, so the lack of speech therapists.
>
> A: Yes, it's really bad for us, because ah, we practically drive an hour to the speech therapist. (Interview_04, 67 years, male, 10 years post stroke)

Another obstacle is the lack of information about available speech therapy services. Patients and their relatives may not be sufficiently informed about how to access therapy or what options are available.

> And you would also need the information. Who is there so that you don't have to look for it yourself? Where can you go. You would need that and whether the therapist is responsible for it or does it, or perhaps more than one. (Interview_14, 72 years, male, 2 years post stroke)

Organisational factors

Organisational factors are the characteristics and aspects of the medical treatment or therapy that influence a patient's willingness and ability to comply with the recommended medical measures. These factors include the complexity of the therapy, the type of therapies prescribed, the duration of treatment, the availability of aids or support in carrying out the therapy and possible side effects or discomfort. Organisational factors can influence adherence by either facilitating or complicating treatment.

A common barrier to accessing speech therapy is the need to reobtain prescriptions from doctors. This bureaucratic process can be time-consuming and frustrating leading to patients being reluctant to attend therapy sessions.

> Yes, it is. It's easier without a prescription. Because as soon as I say I need a prescription, the next one comes and says she needs one, I have to call again. (Interview_10, 69 years, female, 14 years post stroke)

Sometimes family members of patients have therapy needs at the same time, whether in the same specialty or in other areas. Coordinating therapy sessions for multiple family members can be a logistical challenge and can lead to delays in accessing therapy.

> A (person with aphasia): Not at the moment, because my husband is at therapy now
>
> B (husband): Yes, those are the appointments that overlap. Then mine are simply postponed or cancelled. (Interview_16, 69 years, female, 0,8 years post stroke)

Another organisational obstacle is long distances to therapy facilities. In rural areas in particular, the distance to therapists can lead to patients not taking advantage of therapy due to the inconvenience or time required.

> One hour a week, because I have to drive there and back again. That's exhausting for me. Once a week is enough. (Interview_10, 69 years, female, 14 years post stroke)

The lack of accessibility in therapy facilities can prevent patients with mobility impairments from accessing therapy. A lack of accessibility can create not only physical but also psychological barriers.

> If you are there and have to climb three steps, but if you can't walk or are in a wheelchair and there are no facilities there, then you can only cancel the speech therapy because it doesn't work. (Interview_03, 57 years, female, 4 years post stroke)

Disease-related factors

Disease-related factors are the characteristics and effects of a medical condition or state of health that influence a patient's willingness and ability to comply with recommended medical treatment or therapy. These include, for example, the severity of the illness, the symptoms, the course of the illness and other related health aspects. These factors can influence the patient's perception of

Table 2 Representation the code frequencies of reasons for not participating in speech and language therapy

	n	%
Health system factors		
Assumption by care providers that patients are considered 'fully treated'	5	23%
Inadequate treatment continuity	3	14%
Labour shortage	7	32%
Insufficient information about available services	1	5%
Patient-related factors		
Therapy is perceived as exhausting and confrontational	15	68%
Lacking interest in speech therapy	2	9%
The perception that everyday life is already busy	1	5%
Organisational factors		
Reobtaining prescriptions	5	23%
Family coordination of appointments	1	5%
Long travelling distances	2	9%
No accessibility	1	5%
Social/economic factors		
Costs	10	45%
Disease-related factors		
Period after the event	1	5%
Severity of the stroke	1	5%

the need for treatment and the assessment of the risks and benefits of therapy.

Utilisation of speech therapy services can vary in the different phases following the acute event. Depending on which comorbidities are present, the patient's focus is sometimes not on speech therapy.

> A: Did you have speech therapy during that time?
>
> B: Yes, enough.
>
> A: When was the last time you had therapy?
>
> B: Ten years. (Interview_17, 79 years, female, 40 years post stroke)

The severity of a stroke can influence the willingness to use speech therapy.

> But they will help you get to the most fundamental things, let's put it this way. I can read, I can discuss, but that's not enough. You can't get any further, so you can't work. So you can't work as a salesman, as a representative, as a businessman. You simply no longer have the language. And you can, you probably need much, much, much longer and much, much more intensive training. And you don't have that. (Interview_08, 70 years, male, 6 years post stroke)

The table 2 presents the frequency of codes related to barriers affecting speech therapy participation. Among health system factors, the most significant issue is a labour shortage (32%), followed by care providers assuming patients are 'fully treated' (23%). Patient-related factors show that therapy being perceived as exhausting dominates (68%). Organisational challenges include reobtaining prescriptions (23%). Cost was the most prominent socioeconomic factor (45%). Disease-related factors, such as the severity of the stroke, were mentioned but less frequently (5%).

Wishes and needs

The following wishes and needs were identified in the interviews and categorised into the corresponding categories that were previously identified.

Participants want therapy to focus not only on improving language skills but also on understanding and supporting individual needs and goals. They want to be more involved in the therapy process, have a say in which goals they want to pursue and be included in the design of therapy plans.

> "A (interviewer): So it would also be an important point to move a bit away from the curriculum and //.
>
> B (person with aphasia): Mhm.
>
> C (husband): Really look at what the patient needs.
>
> A (interviewer): Exactly, exactly.
>
> C (husband): Or the affected person. (Interview_04, 67 years, male, 10 years post stroke)

In group therapy sessions, people with aphasia have the opportunity to talk to other people with aphasia, learn from their experiences and support each other. An expansion of group therapy services would enable more people to benefit from the advantages of group therapy and build a supportive network.

> If there could also be group therapies. That's also because simply being in a group with like-minded individuals, let's say, feels good. You also notice, ah, that it simply makes a big difference for the people and those affected. (Interview_03, 57 years, female, 4 years post stroke)

Intensive therapy programmes offer the opportunity for concentrated and targeted treatment over a limited period of time, often leading to faster improvements. Expanding these services would, in the view of people with aphasia, give more patients access to this important form of treatment and increase the chances of a successful recovery.

> And, it can be said right away, it would also be great if it ah… could go therapeutically, that one could make it more condensed. An offer where you have it every day ah for fourteen days, right? And that is also still very rarely offered. (Interview_03, 57 years, female, 4 years post stroke))

Self-help groups and organisations offer not only practical advice and information but also emotional support and the opportunity to talk to others who have had similar experiences. Expanding these self-help services would enable more people to find support and encouragement outside the clinical environment and lead active and fulfilling lives despite their speech disorder.

> The main thing is to do something. What is clearly missing, we have in ***, I believe in Austria in general, as far as I know… there are no organized self-help groups for people with aphasia here. There are none. It's missing globally because you can't find the people together. And then again, the techniques are missing, whether it's digital or analog. (Interview_08, 70 years, male, 6 years post stroke)

Those affected would also like to see the establishment of an aphasia network that organises educational and information events to educate people with aphasia and their families about the disease, highlight treatment options and provide coping strategies. On the other hand, the network should promote opportunities for peer support by giving people with aphasia the opportunity to support and encourage each other.

> Two problems again. Underfunded, yes, and no networks available. Networks, that's easy to do. Find information, set up a homepage that works reasonably well, and a bit of communication with the right people so they know what it's about, who has what, where can I refer them. That's relatively cheap and quick to do. (Interview_08, 70 years, male, 6 years post stroke)

People with aphasia often experience a variety of challenges that can vary from day to day. It is, therefore, important that the therapy services are flexible and can be adapted to the individual needs and daily form of those affected.

> Well, it depends on the family. If things are good in the family, ahm, and the people simply also have the time to do something with me, that's good. If it naturally turns out that I'm getting better and better and better, I find it difficult. That's why you have to just see how the, how the, ahm, people are feeling. (Interview_09, 61 years, male, 6 years post stroke)

Involving family members in therapy for people with aphasia is crucial and was frequently mentioned by interviewees as they play an important role in the recovery process and have a unique insight into the needs and challenges of the person with aphasia. Relatives should be involved at an early stage.

> "A:Should they be involved in the therapy and also in the self-help group?
>
> B: Definitely. As early as possible. If they want. Probably many don't want to again, but definitely try and explain to them what it's about because they also don't know anything. (Interview_08, 70 years, male, 6 years post stroke)

A fundamental desire is, therefore, to create a common goal between therapists and patients. They want to actively participate in the therapy process and feel that their goals and wishes are heard and respected. By setting common goals, they feel empowered and motivated to play an active role in their recovery.

> Okay, but the goals should indeed be set together. 23:14 A: I could imagine that, yes, but as to the problem, we can't judge. Is something doable, is nothing doable, is something possible? Then the speech therapist has to say. Yes okay, let's do that or nonsense, it's not possible. Which I also don't believe would go that far. (Interview_02, 70 years, female, 6 years post stroke)

Another wish expressed by interviewees is the desire for more knowledge about the effects of therapy procedures and, associated with this, a deeper understanding of how therapies work and what results they can expect, which can help to strengthen the self-efficacy and self-confidence of those affected.

> In my opinion, first of all, know that probably, if one trains, trains intensively… it helps, one makes progress, right? (Interview_08, 70 years, male, 6 years post stroke)

Another wish expressed by interviewees is for close collaboration between therapists in different settings to ensure that the patient's therapy process is seamless and effective, regardless of the different settings in which it takes place.

> It would be an advantage if the speech therapists could exchange a bit among themselves, in case there comes a change, maternity leave comes. That happens more often in this field. That one simply says

Table 3 Representing the code frequencies of the theme wishes and needs

	n	%
Expansion of group therapy	15	68%
Expansion of intensive therapy offers	3	14%
Expansion of self-help	2	9%
Aphasia network	2	9%
Patient-centeredness	3	14%
Flexible adjustment of frequency, setting, content—according to daily form	1	5%
Inclusion of relatives	14	64%
Common goal setting	13	59%
More knowledge about effects	1	5%
Cross-setting communication	2	9%

> briefly, okay, the patients, this is the status now, this is how one could proceed, this is also important to the patients for example, that the relationship then also works well, the transfer. (Interview_14, 72 years, male, 2 years post stroke) (please see table 3)

DISCUSSION

In this qualitative study, we explored the reasons preventing the utilisation of high-frequency aphasia therapy and the resulting needs and wishes for appropriate aphasia therapy from the perspective of aphasia patients.

Principal findings

We were able to identify a variety of reasons for the prevention of high frequency and, therefore, effective therapy, which are based on various aspects. The main categories consisting of patient-related factors, socioeconomic factors, organisational factors, disease-related factors and health system factors, are comparable to the adherence of long-term therapy model postulated by Sabaté.[38] Sabaté identified five dimensions of adherence: Health system/HCT–factors, social/economic factors, therapy-related factors, patient-related factors and condition-related factors.

Subcategories for all five main categories were identified. In regard of patient-related factors, which can be described as factors regarding personal characteristics, attitudes and behaviours, dimensions such as the perceived level of confrontation in therapy settings, as well as the experience of exhaustion, lack of interest and lack of time due to the amount of daily activities are factors prohibiting guideline-based therapy. While the effect of increasing or decreasing cueing on word retrieval, semantic, phonological or word type-specific cueing is not understood but well discussed,[40–42] the effect on the person performing the task has not yet been discussed beyond the linguistic level: the present results make it clear that the methodological tools of speech therapy and sufficient intervention planning must also include the assessment of possible effects on the patient. Even the contrast between a drill-based and a conversation-based therapy application was conducted at the level of the linguistic, not the motivational outcome,[43] the effects of task difficulty were researched at the level of cortical activation,[44] not hollistically. These results are necessary and valuable, but the dominance of the linguistic and imaging-specific view of aphasia should be supplemented by a motivational one or perhaps even combined to form a holistic one.

The cost of speech therapy can be an obstacle to receiving sufficient therapy. This can be attributed to social factors. Financial burdens arise in the case of aphasia on the one hand due to the frequent withdrawal from the primary labour market, the frequently present and often pronounced comorbidity, possibly necessary assistance or care and the therapy resistance of aphasia, which must be countered by high-frequency therapy. If the costs of speech therapy are not covered by social insurance systems, a necessity becomes an expensive or unaffordable luxury: just 10 hours of therapy per week at €100/hour (comparative value for Styria) over a period of 1 month can far exceed available savings. While at the individual level, the costs associated with guideline-based treatment can quickly become a barrier to treatment, solutions at the systemic level show possibilities for improved care without a significant increase in costs. The potential of concomitant computerised therapy,[31 45] which shows improvements at the functional language level as well as in quality of life, chemical and physical therapy adjuvants can facilitate the effectiveness of established exercise therapy and its transfer into everyday communication,[25 26] the evaluation of high-frequency standardised exercise therapy shows high effectiveness at sometimes lower costs than with usual care.[46]

Characteristics, policies and processes of the health system can have an influence on following recommendations like therapy frequency. Certain aspects of the health system contribute to insufficient care, including assumptions made by care providers about a patient's progress, lack of continuity in treatment after a therapist retires or goes on maternity leave, labor shortages within the health system, and inadequate information about accessing services. In German-speaking countries, the profession of speech therapist is in short supply; even in conurbations, availability is not a matter of course. In Austria, therapy centres are centrally planned by the social security system and the number of primary qualifying study places is centrally planned, but current demand analyses do not exist, and central planning appears to be deficient. There is a lack of systems for designating free therapy places, regulations and frameworks for digital therapy. For aphasia, patient pathways have neither been mapped nor understood, nor has any attempt been made to systematise, design and develop them in accordance with all relevant components.

Limited resources could possibly already lead to triage: the statement by the treating speech therapists that aphasia can be fully treated and reach a level of rehabilitation where no further therapy is indicated does not correspond to the current state of science. On the one hand, it could be an artefact of non-guideline-based, low-frequency therapy in which progress is not made or is not measurable. On the other hand, it could also be a matter of triage: speech therapy investments in child language acquisition could show up as a priority over aphasia rehabilitation; economic calculations on this point of view already exist.[47]

Reobtainment of prescriptions, family coordination of appointments, travelling distances and no accessibility to therapy facilities can be organisational factors for not receiving guideline-based treatment. One aspect that arises in the nursing professions when work cannot be carried out in accordance with the actual intention is moral injury. Caregivers fall ill when the institution is unable to meet the caregivers' goal of caring for the patients entrusted to them and their rehabilitation process.[48] The impact on speech therapists when non-guideline-compliant treatment cannot take place due to external, systemic circumstances and patients may not be able to reach their maximum rehabilitation potential must also be considered and taken into account as an opportunity cost of a suboptimal system. In relation to the disease itself, the period after the event as well as the severity of the event can be seen as factors determining therapy frequency.

People with aphasia expressed many wishes regarding optimising care and treatment. A few had already clear visions for their ideal therapy concept, like duration and frequency, as well as therapy contents. Overall patient-centeredness, expansion of group therapy, intensive therapy offers and self-help, an aphasia network, flexibility concerning therapy sessions, as well as inclusion of relatives, common goals, knowledge about effects and cross-sectoral communication (intramural and extramural) were most frequently mentioned by those affected by aphasia. These wishes can be systematically attributed to the health system, patient-related factors, and organisational aspects. Regarding socioeconomic and disease-related factors, no needs were expressed. These findings demonstrate the importance of involving those affected by aphasia or other conditions in the decision-making process in relation to health policy and health research. Numerous studies looking at the NHS (national health service) confirm that patient involvement has an impact at a systemic level, for example, on the planning and development of services and the development and dissemination of information.[49] Impacts have also been reported for all stages of research, including the development of user-focused research objectives, the development of user-relevant research questions, the development of user-friendly information, questionnaires and interview schedules, more appropriate recruitment strategies for studies, consumer-focused interpretation of data and improved implementation and dissemination of study results.[50] Participation in these processes could in turn increase actual or perceived autonomy, resulting in increased intrinsic motivation to engage in the intervention.[17] Motivation is a factor related to treatment failure or improvement. Therefore, motivation must be considered when participating in health-related interventions.[51] This emphasises the fact that people with aphasia should be included in the decision-making process and in healthcare research.

Even if the localisation of the reasons for prevention clearly shows that systemic changes are necessary to enable more guideline-based treatment, the initial considerations regarding self-determination at the personal level cannot be dismissed. In the present study, too, the participants in the open-hypothesis interviews not only directly address a lack of motivation but also the possible causes for it, such as a lack of competence experience at the personal level due to lengthy and confrontational therapy, or full days in which externally prescribed therapy appointments can be disruptive. Even if the present results have to be validated by the subsequent quantitative survey, they could show that it is not unfounded intrinsic disinterest that prevents patients from participating, but rather modifiable characteristics in the content and implementation of therapy. All in all, a lack of motivation on the part of patients is thus an indication of care that is not patient-centred and should facilitate adaptations at the systemic level, and should by no means continue to exclude unmotivated patients from care.

Strengths and weaknesses of the study

To the best of our knowledge, this is the first study in the German-speaking countries to ask people with aphasia about their wishes and needs with regard to health measures and healthcare. In addition, people with aphasia are familiar with the problems of the healthcare system from their own experience. Asking them about their experiences in the healthcare system can lead to new insights into which areas of care need to be adapted and geared towards the needs of people with aphasia. The representativeness and heterogeneity of the sample have several potential limitations. All participants were recruited through clinicians, speech therapists and self-help organisations. Therefore, the data may over-represent the views of people who are more likely to engage in positive self-management and use health-promoting behaviours and adaptive strategies. A selection bias cannot be ruled out at this point. It is characteristic of people with aphasia that communication is impaired. It, therefore, cannot be precluded that the aphasic person's utterances were not understood correctly and at the same time interpreted inadequately. This was minimised by the fact that the interviewers had a background in speech therapy and asked specific questions in the event of discrepancies. In addition, the large differences in the period after the acute event could limit knowledge about the reasons for prevention and treatment preferences in the different stages of aphasia. It can be assumed that people with aphasia in different stages of the disorder have a different status in coping with the illness and, depending on this, also have different treatment preferences. Another limitation of this study is the geographical distribution of the sample. Most participants come from large cities, fewer from smaller towns, villages or rural areas. Of the 22 participants, most lived in large cities, and only a few came from smaller towns or villages. This urban concentration may limit the generalisability of the results, as the experiences of those living in more rural or remote areas, where access to health services, including speech therapy, can vary greatly, may be overlooked. Differences in healthcare infrastructure, accessibility and regional differences in speech therapy services between urban and rural areas could influence both the experience and outcomes of therapy for people with aphasia. However, the aim of this study could not be to generate generalisable data at this stage; the qualitative and thus possibly confounded approach served the necessary exploration of a field of research that has hardly been systematically investigated to date. The present results are not less valuable due to methodological influences. They reflect the first, brief moments in which people with aphasia allowed an insight into their lifeworld and their view of care; naturally, this is coloured, influenced and highly subjective data. To develop implications not for individuals but at a systemic level, it is necessary to generalise these results, also to better understand how time and the other identified factors influence the use of speech therapy by people with aphasia. Therefore, at the time of writing this manuscript, a quantitative survey will be conducted based on the results presented here.

The great strength of the chosen multistep design lies in the derivation of the subsequent study content from the reactions of the PWA: the study presented here collected data-driven reasons for prevention, which will be collected in the subsequent, quantitative project stage with a large number of cases and compared with possible predictive factors, for example, from the sociodemographic area. This gave those involved the opportunity to directly influence the research into their illness.

Possible explanations and implications for clinicians and policymakers

In our view, four main implications for practice can be derived from the results on reasons for prevention and utilisation behaviour as well as the wishes and needs of those affected in comparison with the current care situation:

The future begins now. The sociodemographic development in most industrialised nations, including German-speaking countries, predicts a doubling of age-related diseases and thus also of aphasia according to CVA, accompanied by falling birth rates and the associated shortage of specialists. If we are already unable to provide guideline-based care today due to staff shortages and system problems, how will we be able to do so in the future? So far, speech therapy has been characterised by individual settings in the present; therapy-accompanying measures such as transcranial direct current stimulation are not established in practice. There is no way to identify non-responders to the usual practice-based intervention at an early stage and offer alternative care. Digital solutions are not established across the board. In order to be able to ensure care in the future, the course must now be set at the level of the external environment and the healthcare organisation.

Where are the people with aphasia? In contrast to indications such as cancer, no care pathway or systematic follow-up care has yet been established across the board in German-speaking countries. With discharge from the initial treatment of the disease-causing aphasia, the adequate treatment of aphasia is located at the individual level of the patient and their relatives. This means that needs analyses, access control, register studies and evaluations of the intervention are not possible. In the available data, there is usually a combination of several reasons for prevention, which can occur with varying degrees of intensity. Systemically anchored care pathways would make it possible in the first step to identify and understand the individual reasons for prevention and their interaction, patterns of occurrence and possible interventions. This would make it possible to develop an instrument that can predict which factor is currently/at the time of the survey decisive for non-guideline-compliant utilisation and which measures/interventions can be taken. The aim of this study is to validate the available results in the subsequent quantitative step and then to derive possible interventions in a focus group with stakeholders.

Our results demonstrate that a large number of PWA want to involve their relatives in the therapy not only in terms of organisation but also in terms of content. Making appointments, obtaining medical prescriptions and driving patients are not unusual activities for relatives. In terms of content, they are often assigned the role of therapists, who are supposed to increase the frequency of speech intervention by accompanying the exercises at home. On the other hand, they are supposed to facilitate the important transfer of the skills practised in therapy into everyday communication by providing linguistic and communicative support in everyday life. In everyday therapy, these roles are often transferred to relatives without reflection and taken for granted. It is rarely considered that a whole range of roles have to be taken on by relatives when a person with aphasia is ill. Relatives of aphasic stroke patients showed significantly more symptoms in a variety of quality of life parameters,[52] and a quarter had unspecified physical impairments. Relatives should, therefore, not have to compensate for a systemically caused, non-guideline-compliant treatment.

Speech therapy must be fun or at least the benefits must outweigh the effort. One result of this study is the confirmation that the therapeutic approach should not be too confrontational. The confrontation that accompanies the intervention should be carefully considered and tailored to meet the patient's individual needs and abilities. Too much confrontation can be counterproductive and impair the success of the therapy. It is, therefore, important that speech and language therapists find the right balance to encourage the patient's progress without overwhelming them. The therapeutic relationship plays a central role here and should be seen as an integral part of successful speech therapy.

CONCLUSION

The present results show opportunities for change at the individual level of people with aphasia. Wishes for more education, more information offers, patient empowerment could be implemented quickly. Wishes at the level of therapists and institutions for more flexible therapy design and framework conditions, inclusion of relatives, stronger networked communication among stakeholders could be crystallisation points for the development of a framework for aphasia therapy. This recommendation should not focus solely on the linguistic outcome and the evidence, it should rather be a guide to contextualise speech therapy and help therapists to shape their collaboration with the patient and their environment with aphasia.

It is important to evaluate aphasia therapy against the background of maximum speech-communicative rehabilitation. However, the present results show that this is only one component of speech therapy intervention. It is imperative to contextualise speech therapy and to specify it regarding the life and experience of those affected and their reference system. On the other hand, the type of awareness that leads us to no longer speak and write of aphasics but of people with aphasia must also be reflected in therapeutic action. It is not aphasia researchers who have the expertise on aphasia, but the people who live with aphasia daily and their relatives. Participatory approaches to the design of research, the identification of outcome parameters, the orientation of therapy and the decision as to whether a diagnostic instrument is valid can only succeed with the involvement of this expertise.

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