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Digital participation and communication disorders across the lifespan

Edited by
Petra Jaecks, Hendrike Frieg and Kristina Jonas

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Digital participation and communication disorders across the lifespan

Topic editors
Petra Jaecks — Bielefeld University, Germany
Hendrike Frieg — University of Applied Sciences and Arts Hildesheim, Germany
Kristina Jonas — University of Paderborn, Germany

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Table of contents

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Xiaolin Zhou,
Peking University, China

*CORRESPONDENCE
Petra Jaecks
✉ petra.jaecks@uni-bielefeld.de

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Editorial: Digital participation and communication disorders across the lifespan

Hendrike Frieg[1], Petra Jaecks[2]* and Kristina Jonas[3]

[1]University of Applied Sciences and Arts Hildesheim/Holzminden/Göttingen, Faculty of Social Work and Health, Hildesheim, Germany, [2]Bielefeld University, Faculty of Linguistics and Literary Studies, Bielefeld, Germany, [3]Paderborn University, Institute for German Language and Comparative Literature, Paderborn, Germany

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Editorial on the Research Topic
Digital participation and communication disorders across the lifespan

According to the UN Convention on Rights of Persons with Disabilities (see Articles 29, 30), participation is a human right. In this sense, participation in family, work and cultural life, recreation, leisure, sport, and political and public life must be the primary goal when empowering people with speech and communication impairments. As a consequence, improving all types of participation is the central goal of speech and language therapy. One major challenge of increasing and rapid digitization is ensuring digital participation for people with a variety of life situations and preconditions. While the original definitions of digital participation come from pedagogy and educational science, we see the need to further develop these specifications from the perspective of those affected by speech, language, and communication disorders. To date, the literature typically describes three main aspects of digital participation (Bosse, 2016; Bosse and Sponholz, 2023): (a) participation IN digital technologies, having access to and the ability to competently use digital devices, (b) participation THROUGH digital technologies, which entails participation through alternative access options, and (c) participation WITHIN the digital world, which means actively contributing to social networks, digital services, and media. In our view, this differentiation of digital participation seems inappropriate for the heterogeneous field of speech, language, and communication disorders and the people affected. Impairments in speech, language, and communication may occur across the lifespan at any age due to various etiologies. The commonality among such impairments is their impact on a person's ability to function with regard to speech, language, and communication, thereby affecting their activities and social participation. Thus, from our point of view, it seems worthwhile to use WHO's International Classification of Functioning, Disability and Health (ICF, World Health Organization, 2001) as a basis to clarify the different components involved.

The ICF serves as an international standard for framing, describing, and measuring functioning and disability. The individual characterization of the ICF components (body structures and functions, activities, and participation) covers all impacts of an existing health condition and should be accompanied by considerations of environmental and personal factors.

With respect to speech, language, and communication disorders, mental functions serve as the underlying basis, in the ICF coding especially those classed under b167 (*mental functions of language: reception, expression, and integrative language* *functions*). Furthermore, communication depends on *voice and speech functions* (b310–b340). These functions can be disturbed by many different health conditions, for e.g., congenital disabilities (such as autism spectrum disorder), developmental disorders, and neurological impairments (such as traumatic brain injury, stroke, or degenerative diseases). Furthermore, impairment to body structures in the brain (s110), mouth, tongue, throat, or ear (s310-s340; s240-260) might result in speech, language, and communication disorders.

Activities in the ICF framework refer to tasks or actions individuals perform that describe their general ability or competence in performing a specific task (in contrast to performing that specific task in everyday life). In the context of speech, language, and communication disorders, this means that activities linked to any form of communication are burdened.

Participation, considered the most important ICF component, analyzes how individuals live their life and incorporate their abilities into performing activities in daily living. The distinction between activities and participation is crucial because even if individuals are able to perform a task, they might feel too burdened or disabled by environmental or societal factors to perform the activity in their life as they wish to, although it is meaningful to them. Environmental or personal factors can then be examined separately to describe facilitators and barriers to performing activities in daily life, which impact individuals' participation. Considering communication disorders (ICF coding d3), disturbances are experienced when "communicating by [oral] language, signs and symbols, including receiving and producing messages, carrying on conversations, and using communication devices and techniques" (World Health Organization, 2001, p. 133). Products or technology for communication (e125) can facilitate communication, but access to alternative communication software and computer proficiency are considered critical factors.

As we move toward digitization, the scope of activities linked to (analog) communication is expanding. For example, when communicating with colleagues becomes difficult due to neurological speech impairment (dysarthria) which makes it impossible to use the telephone effectively, messaging services will represent a digital option that enables this activity, as reading and writing are unimpaired. Another example is the digital read-aloud function of many internet browsers, which allows individuals with a reading disorder (dyslexia) to engage in the activity of understanding online texts without reading.

At this point, it is important to stress that digitization has brought new forms of communication and correspondingly new activities to perform, for example, the activity of *forming relationships* (ICF code: d7200), which has always been dependent on language functions and communicative activities. Thanks to digitization, people experience new ways of forming relationships: they exchange information through internet forums or social media, maintain their relationships via messaging services or get to know each other using dating apps. *Forming relationships* has thus become a digital activity and must be considered a part of (digital) participation when dealing with individuals with speech, language, and communication disorders. Depending on the exact form of impairment, this expansion of participation can represent an opportunity (compensating for previous limitations and enabling participation) or a challenge (adding to the burden of severe limitations in participation).

Until recently, it did not seem necessary to differentiate between digital and analog aspects of participation, as the analog world was usually more important to many people. However, the digital world is increasingly gaining significance that has resulted in a separate type of participation known as digital participation.

Nevertheless, digital participation often remains a side issue. For example, digital participation is not coded in the ICF, although there are so many digitized areas of life. Therefore, when we look at the ICF from a therapeutic perspective, we should consider not only which activities beyond communication could be impaired due to the linguistic-communicative limitations of our clients but also whether these activities belong to the digital or analog world, or both (see Figure 1).

As shown in Figure 1, the activities overlap: using dating apps might lead to forming social connections, which in turn may result in engagement and participation in the analog world. However, this usage may also lead to digital interactions, leading to activities and participation in the digital world.

In our view, merely having access to technical devices, the internet, or a therapy app does not constitute digital participation for people with communication impairments. We prefer to speak of digital participation when people can perform activities relevant to them in the digital world, with all its social and technical possibilities, in the way and to the extent they wish to.

In this Research Topic, we see a wide range of activities that are relevant to digital participation. The ICF categorizes activities into nine major chapters: learning and applying knowledge (d1), general tasks and demands (d2), communication (d3), mobility (d4), self-care (d5), domestic life (d6), interpersonal interactions and relationships (d7), major life areas (d8), and community, social and civic life (d9). Analog and digital activities in all categories are important to people with speech, language, and communication disorders. Accordingly, activities from these categories can also be found in this Research Topic's articles.

Barthel et al. focus on activities in the d1 category by looking at decision-making in video-based telepractice as part of a qualitative analysis (d177 making decisions).

Both Wahl and Weiland, in their review of augmentative and alternative communication, and Keeley and Bernasconi, in their analysis paper, look at basic activities such as purposeful sensory experiences (d110-d129) as well as communication in particular, for example, producing non-verbal messages (d335).

Núñez Macías et al. analyzed the use and acceptance of voice assistants among people with aphasia, focusing on activities of communication through the use of telecommunication devices (d3600). Similarly, Azevedo et al. interviewed people with aphasia and their relatives on the use of communication aids (d360), relating to activities of communication (d3) and interpersonal relationships (d7).

The articles by Weiss et al., Büttner-Kunert et al., Ivarsson et al., Leinweber et al., and Heide et al. deal with activities of self-care, i.e.,. maintaining one's health (d5702). They focus on what digital speech, language, and communication therapy and diagnostics can look like and how they contribute to digital participation.

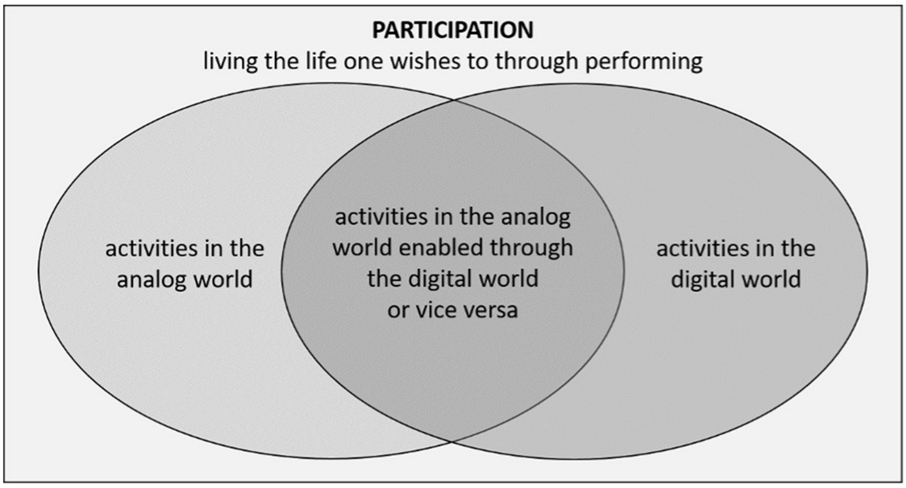

FIGURE 1
Digital activities in participation.

Kurfess et al. focused on peer-to-peer support through digital networking in individuals with aphasia, including activities such as engaging in social or community associations (d9100), while Pliska et al. and Schäfer and Miles present results on digital participation among individuals with autism spectrum disorder or those who are deaf or hard of hearing. Their studies also explore activities related to recreation and leisure (d920) as well as socializing activities (d9205).

Finally, Säuberli et al. involved people with intellectual disabilities in research, enabling them to actively exercise their right to autonomy and self-determination, thereby engaging them in activities concerning human rights (d940).

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EDITED BY
Petra Jaecks,
Bielefeld University, Germany

REVIEWED BY
Britta Dawal nee Gebhard,
South Westphalia University of Applied Sciences, Germany
Stephanie Riehemann,
University of Cologne, Germany

*CORRESPONDENCE
Magnus Ivarsson
✉ magnus.ivarsson@liu.se

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Self-rating via video communication in children with disability – a feasibility study

Magnus Ivarsson[1]*, Anna Karin Andersson[2,3] and Lena Almqvist[3,4]

[1]Department of Behavioural Sciences and Learning, Linköping University, Linköping, Sweden, [2]Division of Physiotherapy, School of Health, Care and Social Welfare, Mälardalen University, Västerås, Sweden, [3]CHILD, Jönköping University, Jönköping, Sweden, [4]Division of Psychology, School of Health, Care and Social Welfare, Mälardalen University, Västerås, Sweden

Background: Different barriers may hinder children with developmental disabilities (DD) from having a voice in research and clinical interventions concerning fundamentally subjective phenomena, such as participation. It is not well-investigated if video communication tools have the potential to reduce these barriers.

Aim: This study investigated the feasibility of administering a self-rating instrument measuring participation, Picture My Participation (PmP), via a video communication tool (Zoom), to children with DD.

Materials and methods: PmP was administered to 17 children with DD (mean age 13 years). The pictorial representations of activities and response options in PmP were displayed in a shared PowerPoint presentation, enabling nonverbal responses with the annotate function in Zoom. Child and interviewer perceptions of the interview were measured through questionnaires developed for the purpose.

Results: All the children completed the interview. Most PmP questions were answered, and no adverse events were registered. Technical issues could generally be solved. No special training or expensive equipment was needed for the interviews.

Conclusion: Interviewer-guided self-ratings of participation and related constructs through video communication may be a feasible procedure to use with children with DD from age 11.

Significance: Offering video communication may increase children's chances to contribute subjective experiences in research and clinical practice.

KEYWORDS

cognitive accessibility, developmental disability, interview, NDD, Picture My Participation, participation, Talking Mats, video application

Introduction

Children with developmental disabilities (DD) face different barriers hindering them from having their voices heard in in-real-life (IRL) interviews in both research and clinical practice (Varghese et al., 2015; Adugna et al., 2020; Doherty et al., 2020). Video communication-based procedures have an intuitive appeal as a way of reducing some of these barriers and thereby increasing participation. However, examining the feasibility of such procedures before applying them on a larger scale is important. The current study aims at exploring the feasibility of administering a self-rating instrument via a video communication tool to children with DD.

In the present study, the term DD refers to a set of conditions characterized by persistent physical and/or mental impairments affecting multiple major life activity areas, with an onset during the developmental period (in line with the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 2000). Beyond the neurodevelopmental disorders listed separately in the International Classification of Diseases and Related Health Problems (11th ed.; ICD-11; World Health Organization, 2022), such as disorders of intellectual development or developmental language disorder, the term DD also tends to include diagnoses from other parts of the ICD-11 such as cerebral palsy and spina bifida. Language impairments are common in DD, sometimes as a characteristic feature (e.g., pragmatic language impairments in autism spectrum disorder; World Health Organization, 2022), and in other cases as a condition co-occurring with another disability, such as attention deficit hyperactivity disorder (Mueller and Tomblin, 2012), autism spectrum disorder (Kjellmer et al., 2018), and cerebral palsy (Mei et al., 2016). Accordingly, in a sample of children with different DD, it would be reasonable to expect impairments in different aspects of communication, including pragmatic, receptive, and expressive language.

There are strong reasons for including the perspective of the child in research and health services targeting important everyday life aspects, such as participation and mental health (Nilsson et al., 2015). By using the term children in this study we refer to people 0 to 18 years of age. A fundamental ethical principle reflected by article 12 in the United Nations Convention on the Rights of the Child (1989), states that all children capable of forming views should be assured the right to express those views in matters affecting them. There is also a methodological argument to be made. Few studies show acceptable agreement between child and parent or teacher ratings (Achenbach et al., 1987; De Los Reyes et al., 2015; Huus et al., 2015; Dada et al., 2020), indicating that the omission of the child's subjective experience could lead to an incomplete understanding of the phenomena studied. Still, the subjective perceptions and experiences of children with DD are often neglected (see for example van Steensel et al., 2011; Downs et al., 2018).

One possible reason why the voices of these children are often excluded in this field of research is that many children with DD entail deficits in the cognitive and communicative abilities involved in self-assessment and self-rating (Beddow, 2012; Fujiura and RRTC Expert Panel on Health Measurement, 2012). For example, self-rating scales, in general, presuppose that the respondent can comprehend a certain level of written or spoken language and produce a verbal or manual response, i.e., abilities that may be impaired in developmental language disorder and many other DD. However, in the last decades, attention has shifted from the abilities of the respondent child to the properties of the materials and procedures used in assessment (Döring, 2010; Saywitz and Camparo, 2014). A cognitively accessible design (in self-rating questionnaires) anticipates respondent variability in cognitive abilities and reduces cognitive demands, i.e., the specific mental functions that a questionnaire implicitly assumes in a respondent (Kramer and Schwartz, 2017). It may also help respondents to interpret and respond to assessment items as intended. Thus, the accessibility of a self-rating questionnaire is related not only to the objective accessibility of the questionnaire but also to how the respondent perceives it (Maxwell et al., 2012).

This shift in focus, from body functions to contextual factors (World Health Organization, 2001), is demonstrated by the innovative attempts to support the self-rating of subjective experiences in children with DD through the use of different assistive aids, such as pictures or symbols (see for example Gullone et al., 1996; Scott et al., 2011; Boström et al., 2016; Arvidsson et al., 2021). The scale applied in the present study, Picture My Participation (PmP), is one example of a scale intended to be accessible to children with different levels of cognitive and communicative functioning. By using visual support and a relatively flexible procedure (within defined limits), PmP measures core aspects of participation (attendance and involvement) in everyday activities in children (Arvidsson et al., 2020, 2021). As such, PmP resonates with the definition of participation in the Family of Participation-Related Constructs (fPRC) framework, which identifies attendance (i.e., being there) and involvement (i.e., the experience of participation while attending) as the two essential components of participation (Imms et al., 2016, 2017).

However, cognitively and communicatively inaccessible materials and procedures are not the only factors hindering children with DD from participating in scientific studies. The COVID-19 pandemic has been the most recent example of a hinder to IRL interviews but other factors relating to the child or family, e.g., physical inaccessibility, lack of transportation, and lack of privacy, may also cause difficulty in including children in research and may hinder necessary health care interventions (Varghese et al., 2015; Adugna et al., 2020; Doherty et al., 2020). Such obstacles may have an impact on decisions on whether or not to include the children themselves in the assessment of mental health and participation-related constructs or to settle for proxy ratings.

For this reason, interviewing or data collection over a physical distance seems like an appealing solution. Video communication could have some potential advantages over the telephone, SMS, or chat interviewing since it allows the combination of spoken language with forms of augmented and alternative communication (e.g., body language, sign language), which may be necessary for successful communication with some children with DD (Kaiser et al., 2001; Stephenson and Limbrick, 2015). At the same time, the video communication tool applied, or the video format *per se* may contain cognitive and communicative barriers restricting participation in interviews for the same children. It is largely unknown how this change in the procedure may impact cognitive and communicative accessibility when collecting self-reported data on subjective phenomena such as participation. The video format and the associated digital environment may involve both elements that increase and decrease cognitive and communicative demands. Assistive aids, such as pictures or symbols, could be difficult to transfer to the digital environment. They are often reliant on IRL interviewing and can thus be dependent on situational and geographical conditions (Kramer et al., 2009). At the same time, it is also possible that the digital environment could enable new forms and uses of pictorial support. The direction of this effect may also be dependent on child factors. For example, it may be easier to combine a digital environment with different response formats (touch screen, eye control, etc.), enabling children with different levels of motor and communication impairments to respond to questions in various ways. Whether the administration of self-rating instruments by video communication increases or decreases the accessibility of children with DD needs to be further investigated.

As a first step, there is a need to evaluate the feasibility of administering self-rating instruments via video communication to children with DD before implementing the procedure in larger-scale studies. A feasibility study such as this makes it possible to foresee barriers and minimize negative consequences in later stages (Tickle-Degnen, 2013). The study aimed to investigate the feasibility of administering a self-rating instrument, PmP in this case, via a video communication tool (Zoom) for children with DD, including the subjective experiences of children and researchers in the process. By doing so, aspects of the children's participation (i.e., attendance and engagement) in the digital environment while being interviewed were identified and discussed.

Materials and methods

Based on a summary of the literature, Orsmond and Cohn (2015) have identified five main objectives for a feasibility study: (1) recruitment and sample characteristics, (2) procedures and measures, (3) study acceptability, (4) resources and ability to manage study, and (5) preliminary evaluation of participant responses. We used these five objectives as a structure for evaluating the feasibility of using a video communication tool for guiding self-ratings of PmP with children with DD.

Participants

Seventeen children with DD were recruited from the older cohort (born 2007–2009) of an ongoing longitudinal study of mental health and participation in children with DD in Sweden (CHILD-PMH). All families enlisted at the habilitation services in five regions in Sweden were invited to participate in CHILD-PMH via mail (see Figure 1 for a description of the flow of participants through the larger longitudinal study and the present study). The invitation mail was written in Swedish but contained information on how to access Arabic, English, or Somali translations. The habilitation services in Sweden serve children with DD who have substantial support needs, such as those with intellectual disability, autism (although this differs between regions), and cerebral palsy. Generally, they do not serve children with attention deficit hyperactivity disorder, developmental coordination disorder, specific learning disorders, etc. Children with the severest disabilities, e.g., children with substantial impairments in movement and intellectual functioning, are almost always enrolled in habilitation services. The level of enrollment varies more for children with milder levels of disability. For reasons of convenience, the sample of participants in the present study was drawn from three of the five participating regions in CHILD-PMH. During the initial contact with parents in the longitudinal study, they were asked if they believed that their child would be interested in participating in the current feasibility study and if data collection via video communication would be plausible for their child if adaptations were made. Exclusion criteria were (1) the parent not understanding the information about the study presented orally in plain Swedish or (2) the child having a type or degree of disability that would make it impossible to guide the child through the self-rating. Child consent was collected orally in connection with the interview. The CHILD-PMH project has been approved by the Swedish Ethical Review Authority (case number 2019-05028).

Material

Video-communication platform: Zoom technology

The choice of video communication platform was based on the following criteria: (a) using it was not associated with any costs for the child's family, (b) it could be run in commonly used web browsers on different types of devices, (c) it had a function that enabled both the host and guests to draw and make notes in the same document within the interview without having to open additional applications, (d) it was well known to the average internet user, and (e) it was intuitive and fairly accessible in cognitive terms (e.g., users do not have to go through a lot of text before launching the software). Microsoft Teams and Zoom were both considered with these criteria, and Zoom was chosen based on the criterion of allowing annotations in both the application and the web-based versions.

Picture My Participation

The self-rating instrument PmP (Arvidsson et al., 2020) is developed for children and youths aged from five to 21 years of age, to measure participation in 20 different home, community, and social activities. PmP is administered as a guided conversation, using pictures from the aided Picture Communication Symbols (Fuller and Lloyd, 1997) illustrating the items and the different possible replies (Willis et al., 2015), and yield quantitative data on aspects of participation. During the interview, when performed IRL, the interviewer and the child sit side-by-side at a desk, looking and talking about the material placed in front of them. PmP helps children to identify participation from four aspects: frequency of attendance of activity, level of involvement when performing an activity, choice of three important activities determined independently, and evaluation of perceived barriers to and facilitators of participation. The frequency of attendance is rated on a four-point Likert scale visualized by baskets filled with apples, where a full basket corresponds to 'always,' three apples in the basket corresponds to 'sometimes,' one apple corresponds to 'seldom' and an empty basket corresponds to 'never.' Perceived involvement is rated on a three-point Likert scale visualized by three pictures showing a very (actively) involved child, a child observing peers who are active in a play (less involved), and a child who is not at all involved, respectively. Consequently, PmP is designed so that children with no or very limited ability to produce spoken language can respond to most items.

Translation to the video communication environment

An essential aspect of PmP is the use of a Talking Mats approach (Cameron and Murphy, 2002) with visual representations of activities and response options. In transferring the approach to the digital environment, simplicity was prioritized over exact resemblance to the

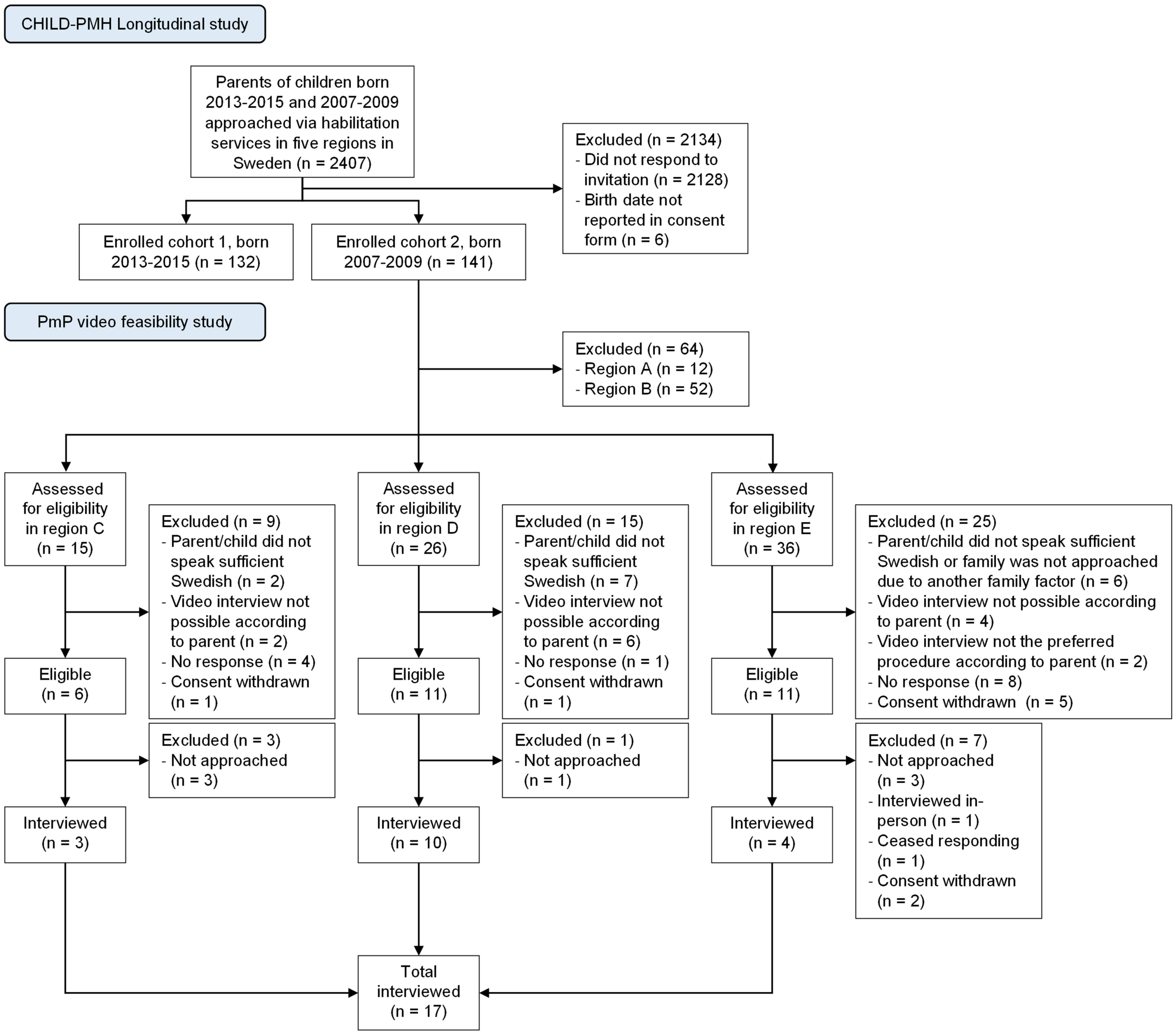

FIGURE 1
Recruitment strategy and flow of participants through the study.

non-digital version of Talking Mats, since it was deemed important that the participants did not have to switch between multiple applications during the interview or download additional applications. For this reason, all pictures were inserted into PowerPoint slides and arranged in a Talking Mats manner, meaning two slides per activity, one with the response options relating to attendance ('Never,' 'Not really,' 'Sometimes,' or 'Always') aligned above the activity and one with the involvement response options ('Not,' 'Somewhat,' or 'Very'). Examples of the attendance and involvement questions are displayed in Supplementary Figures S1, S2. One slide with 20 pictures representing all the activities was created for the part of the interview where the child has to choose the three most important activities. For the part concerned with barriers and facilitators, each activity was displayed on a separate slide with the barriers and facilitator template pictures aligned above it. Instead of having the children pick up, or drag, a picture and placing it under the favored response option, as when guiding children through self-ratings in PmP IRL, the children were instructed to mark the response of their choice using the annotate function within Zoom or if possible and if they preferred, they could just tell their response.

Ten Question screen

Ten Question screen (TQS, Durkin et al., 1991, 1995) is a parent-report screening tool developed to detect childhood disabilities in low and middle-income countries. In 10 closed binary questions the child's vision, hearing, movement, cognitive functions, and seizures are addressed. TQS was completed by the primary caregivers to describe the nature of their child's disabilities, either by telephone interview or questionnaire.

Registration form and feasibility questionnaire

To help the interviewer keep track of important aspects of feasibility during the interview, a short interviewer registration form was developed. The form included headings to note the duration of the interview, the number of breaks, technical disruptions, and adverse events.

The interviewers' perspective on the room for improvement of the material and procedure was measured with an eight-item questionnaire (see Figure 2), with a three-graded Likert-style scale ('No room for improvement,' 'Some room for improvement,' and 'Great room for improvement'), developed by the research team. The interviewers responded to the questionnaire immediately after having finished an interview and were instructed to contemplate to which degree they could see room for improvement across the domains. The scale also contained an open question about any need for changes in procedure and content. Further, a simple logbook was developed to keep track of changes made between interviews. All described scales and forms were developed to fit the aims and questions proposed by Orsmond and Cohn (2015).

To evaluate the children's attitude toward the interview in general, and the digital environment in particular, a scale was developed including five items (see Figure 3) with a three-graded Likert-style response scale ('Yes,' 'Partly,' and 'No') and two open-ended questions ('What would have been better/worse if I would have come to your home for the interview instead of conducting it via video?' and 'What can we improve if we are to interview more children via video in the future?'). The questionnaire was added to the same PowerPoint presentation as the PmP items, and the questions were displayed one at a time with response alternatives augmented with smiley-like faces in different colors.

Procedure

A total of 28 of the 77 children assessed for eligibility met the inclusion criteria for the current study. Of these, 17 were asked to participate and agreed to a short 10–15-min preparatory meeting aiming to (a) test if the child was able to log on to a Zoom meeting, (b) if he/she could use the annotate function in Zoom to choose cards in a simple PowerPoint-based memory game, and (c) to collect informed consent to participate in the study directly from the child. The PmP interview was then scheduled at a separate time and day in all but one case. All interviews were conducted by the first author (a Ph.D. student and clinical psychologist with years of experience in interviewing adolescents with disabilities), the second author (a Ph.D. and physiotherapist with extensive clinical experience in interviewing children with disabilities), or a Ph.D. student working in the CHILD-PMH project. Parent participation in the interview was accepted but the interviewer made clear that it was the child's own opinion that was the focus of the interview, and this instruction was repeated during the interview if necessary. The feasibility questionnaire was administered in direct connection with the PmP assessment, while the interviewer filled out the interviewer questionnaire immediately afterwards.

Data analysis

The data were analyzed with descriptive statistics (i.e., counting of occurrences, and calculating means). All processing and analysis of data and visualizations were carried out in R (R Core Team, 2021) and RStudio (RStudio Team, 2020) with the *table1* (Rich, 2021), *ggplot2* (Wickham, 2016), and *patchwork* (Pedersen, 2020) packages (except Figure 1, which was made in Microsoft Word).

Results

The findings are presented according to the five feasibility objectives suggested by Orsmond and Cohn (2015).

Objective 1: evaluation of recruitment capability and resulting sample characteristics

The main question to ask to address this objective is: 'Can we recruit appropriate participants?' As expected, when recruiting participants from the habilitation services in Sweden where children with all levels and many different types of disabilities are enlisted, a substantial proportion of parents did not consider a video interview to be feasible for their child (see Figure 1). However, all children that were scheduled for an interview completed it according to plan, indicating that parents generally do not overrate their children's abilities in this area. This could mean that a proportion (36.3% based on our preliminary findings) of children aged 11–14 years

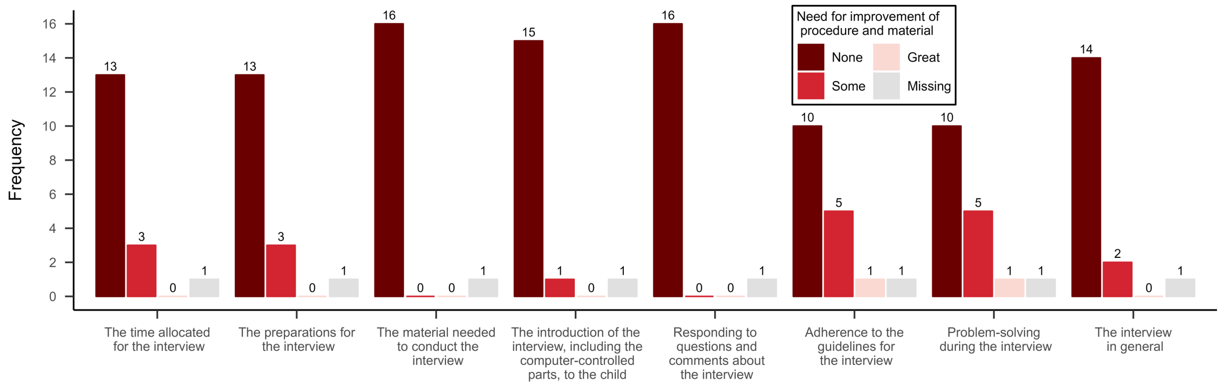

FIGURE 2
Interviewer rated need for improvement of procedure and material.

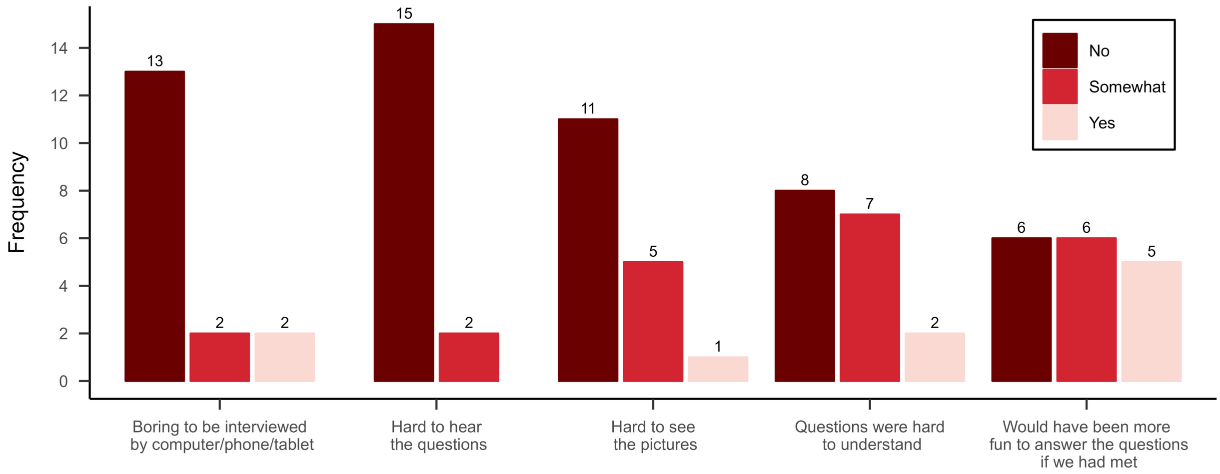

FIGURE 3
Participants attitudes toward the interview and the digital format.

with DD may be eligible for a video-based version of the PmP interview. The eligibility rate may be higher, depending on the prerequisites of the assessment process. There is a chance that some of the excluded children would have managed the interview after all. This could certainly be the case when it comes to parents with another ethnic background, where the children sometimes speak Swedish more fluently than their parents. As in all research involving children with foreign backgrounds, some families were excluded because the parent did not understand the study information, which precluded them from providing informed consent.

Distinctive for the children participating in the interviews was that they tended to have more difficulty relating to movement (see TQS-5 in Table 1) and slightly less relating to cognitive (TQS-10) and communicative skills (TQS-8 and TQS-9) than the rest of the children in the CHILD-PMH cohort. Still, several of the children participating in the present study were rated to have some degree of difficulty with comprehension by their parents and the group was similar to the larger CHILD-PMH cohort in terms of age and average disability rate (mean across all TQS items).

Objective 2: evaluation and refinement of data collection procedures and outcome

The main question to ask regarding this objective is, 'How appropriate is the data collection procedure for the intended population and aim of the study?' The children generally had no problems navigating the digital environment independently when the interview was in progress but almost all of them had some level of support from a parent when logging in for the first time. The children responded to the items and questions verbally, by drawing or inserting icons (e.g., a star) with the annotate function in the shared PowerPoint slides in Zoom. It was noted that drawing lines took effort for some of the children, in which case the icons were preferred. The extent to which children utilized the annotate function varied but most children demonstrated that they could use it in the preparatory memory game at least. Most children answered the questions. However, some children reported difficulty in seeing the pictures on the slide with all the activities when choosing their three most important activities.

The interviewers identified a need for improvement concerning compliance with the interview guidelines, the ability to solve problems during the interview, the preparations, and the allocated time (see Figure 2). Changes were made to the interview guide between the first and second (e.g., adaptations of wording to better fit the digital format) and the sixth and seventh interviews (e.g., the interviewer's use of the annotate function when giving instructions on the learning tasks was emphasized). The interviewers' notes concerning the need for improvement included (1) during the interview to repeatedly confirm verbally that the digital environment is working as intended for the child (in one case the child could not see any of the pictures in the slides for several minutes, but did not mention it), (2) to set aside more time (one-hour minimum) per interview in case of technical problems, and (3) to increase knowledge about the Zoom interface on different types of hardware (mobile phone, tablet, and computer).

Objective 3: evaluation of acceptability and suitability of the study

The main question to address this objective is, 'Are the study procedures suitable for and acceptable to participants?' The participants generally adhered to the planned interview procedure. Interviews were completed in 35.3 min on average (range 22–60), excluding the time used for administering the feasibility questionnaire and the short, separately scheduled, preparatory meeting. Even though the children were instructed that they could ask for a pause whenever they felt they needed one, this never occurred. One of the children chose to participate with the camera turned off and by answering exclusively through the annotate function, i.e., with no verbal responses to questions. Child involvement in the interview was generally perceived as high by the interviewer and only two of the participants said that the interview was boring (see Figure 3). There were no serious unexpected adverse events (e.g., signs of discomfort) and few technical issues during the actual PmP interviews. In two cases, short interruptions in the interviews were caused by the child

TABLE 1 Characteristics of the participants in the current study and the rest of the children in the older cohort of the CHILD-PMH longitudinal study.

	CHILD-PMH (N=68)	Current study (N=17)
Gender		
Girl	23 (33.8%)	6 (35.3%)
Boy	45 (66.2%)	10 (58.8%)
Other	0 (0%)	1 (5.88%)
Birth year		
2007	20 (29.4%)	5 (29.4%)
2008	20 (29.4%)	7 (41.2%)
2009	28 (41.2%)	5 (29.4%)
Serious delay in sitting, standing, or walking (TQS-1)		
No	50 (74.6%)	12 (70.6%)
Yes	17 (25.4%)	5 (29.4%)
Missing	1 (1.5%)	0 (0%)
Difficulties seeing, either in the daytime or at night (TQS-2)		
No	59 (88.1%)	14 (82.4%)
Yes	8 (11.9%)	3 (17.6%)
Missing	1 (1.5%)	0 (0%)
Difficulties hearing (TQS-3)		
No	59 (88.1%)	15 (88.2%)
Yes	8 (11.9%)	2 (11.8%)
Missing	1 (1.5%)	0 (0%)
Child comprehends when parent asks the child to do something (TQS-4)		
No	8 (12.1%)	1 (6.25%)
Yes	58 (87.9%)	15 (93.8%)
Missing	2 (2.9%)	1 (5.9%)
Difficulty walking or moving arms or is weak or rigid in arms or legs (TQS-5)		
No	55 (82.1%)	9 (56.3%)
Yes	12 (17.9%)	7 (43.8%)
Missing	1 (1.5%)	1 (5.9%)
Sometimes has seizures becomes rigid or loses consciousness (TQS-6)		
No	56 (83.6%)	16 (94.1%)
Yes	11 (16.4%)	1 (5.88%)
Missing	1 (1.5%)	0 (0%)
Has learned to do things that other same-aged children do (TQS-7)		
No	31 (49.2%)	7 (41.2%)
Yes	32 (50.8%)	10 (58.8%)
Missing	5 (7.4%)	0 (0%)
Speak at all (TQS-8)		
No	10 (15.2%)	0 (0%)
Yes	56 (84.8%)	16 (100%)
Missing	2 (2.9%)	1 (5.9%)
Mentions at least one thing (TQS-9)		
No	9 (13.6%)	0 (0%)
Yes	57 (86.4%)	17 (100%)
Missing	2 (2.9%)	0 (0%)
Seems to have difficulty comprehending or is slow (TQS-10)		
No	24 (36.9%)	8 (47.1%)
Yes	41 (63.1%)	9 (52.9%)
Missing	3 (4.4%)	0 (0%)
Average disability score (mean TQS score)		
Mean (SD)	0.234 (0.197)	0.200 (0.169)
Median [Min, Max]	0.200 [0, 0.800]	0.200 [0, 0.600]

Abbrevations used in table: Ten Questions Screen (TQS).

or parent receiving a telephone call on the same device they were using for the PmP interview. The other technical challenges were identified and dealt with during the preparatory meeting. For one family, there was an issue with a microphone malfunctioning, which was solved by replacing it for the actual interview. At least seven children struggled to find the annotate function in Zoom and three of them had to switch devices to get it working (from computer to computer and from computer to smartphone). All parent–child dyads were able to solve the problems that arose somehow but, for the interviewer, it was not always clear exactly what had caused the problem and how it was solved.

Objective 4: evaluation of resources needed for managing the study

The main questions to ask to address this study objective are ‘Does the research team have the resources and ability to manage the study?’ and ‘What are the ethical implications and necessary considerations of the study?’ The video interviews combined with the preparatory meetings (10–15 min) took somewhat longer than the 30-min approximation of the time needed for the interview mentioned in the PmP manual. Still, there is no reason to believe that a partial transfer to a video-based procedure would increase the time and resources needed for the data collection process as a whole since video-based interviews should lead to less time spent on traveling to data collection sites (participants’ homes, schools, or habilitation services in the CHILD-PMH project). Since data in many projects are collected over large geographical areas, traveling to sites could require a substantial amount of time throughout the projects.

The software applied in the interviews was chosen for its simplicity and familiarity with most academics, and as indicated by the interviews, to many children. Not all children had used Zoom before, but all of them had experience with some form of video communication. The COVID-19 pandemic and the resulting increase in digital meetings have probably contributed to a general increase in relevant skills within this field for many academics. The interviewers in the study were not chosen because of their level of expertise in IT and digital communication. Rather, their skills and experience in the field were in line with academics in general. It is thus unlikely that extensive training would be required to provide data collectors working with PmP or other self-rating instruments in a video format with the fundamental technical skills needed to administer the interview. However, the difficulties in assisting the children with some of the technical issues indicated that some skills and knowledge about the digital environment may be needed to facilitate technical problem-solving during the interview. Thus, one could consider letting data collectors who are more skilled in video communication do all the video-based interviews rather than dividing them among all data collectors in a project. It is also advised that all data collectors that are scheduled for video interviews first try out and practice the procedure, ideally on all possible forms of devices (smartphone, tablet, laptop, etc.) that may be used by participants.

Furthermore, some of the children demonstrated a high degree of familiarity with the digital environment and responded swiftly to the questions, which put further demands on the interviewers’ capability to navigate the digital environment. Apart from the potential effects on costs/savings related to time, partly switching to the described procedure is not expected to lead to additional costs in terms of technical equipment, since both software and hardware are part of the standard equipment of most academics. Of course, video interviewing presupposes that the child has access to a device capable of running the necessary application. In the current study, 13 children (76.5%) used a computer, three (17.6%) a mobile phone, and one (5.9%) a combination of both (due to problems accessing the annotate function on one of the devices).

There are however a few ethical considerations that need to be addressed. For example, moving to a digital environment may lead to new challenges in controlling and protecting confidentiality. This question relates to what sort of information is being collected by the companies providing the video service, but also to who may be listening in on the interview without being visible through the participating child's web camera. In some of the interviews, a parent's presence in the room was only indicated by the child's gaze or when technical issues emerged, and the parent assisted the child with solving them. The presence of a parent may affect how a child responds to certain questions, and if the parent is not visible in the webcam frame, there is a risk that such problems may pass unnoticed.

Objective 5: preliminary evaluation of the children's responses

The main question to address this objective is: 'Does the study show promise of being successful with the intended population?' A visual inspection of the PmP responses (see Figure 4) did not reveal any distinct problematic patterns. There was a general skewness toward more positive responses, but all response options were utilized across items. The highest summed ratings were seen in 'School' for attendance and 'Celebrations' for involvement, and the lowest for 'Spiritual activities' (for both). In most activities, high involvement accompanied high attendance and vice versa, but there were a few exceptions, such as 'Trips and visits' where response distributions differed. Most difficulties that arose during the interview were related to the PmP instrument rather than the video format *per se*. The amount of missingness was relatively low (6.5%) and originated from four participants' inability to respond to involvement items. For two of the participants, the interviewer chose not to administer the items from the involvement dimension in PmP, since it was clear that they would be too cognitively demanding for the child. The remaining missing data was derived from two interviews where the participating children found specific questions illogical or not possible to answer correctly. There was no missing data in the attendance subscale. Nine of the children indicated that the questions were hard to understand to some degree (see Figure 3). Primarily, this concerned the barriers and facilitators part of the interview, which demands high cognitive capacity due to its level of abstraction.

Discussion

In this study, we aimed to investigate the feasibility of administering the self-rating instrument PmP via a video communication tool for children with DD. We chose to use Zoom as a video communication platform and PmP as an example of a self-rating instrument developed to measure children's participation. By conducting this study, we gained further knowledge in how to use video communication to facilitate children's self-rating of subjective experiences such as participation in research and/or clinical practice, when situational or geographical conditions may hinder IRL data collection. We learned that guiding self-ratings through video communication may be a feasible option when assessing participation in everyday activities in a non-negligible proportion of children with DD aged 11–14. A considerable share of children approached agreed to participate and went through with the interview. The applied procedure and application were well tolerated by the children and did not lead to problematic levels of attrition or any adverse events. A few technical issues appeared but were generally solved by parents and children before the actual interviews. No special training or expensive equipment was needed to conduct the interviews.

The study touches on the core components of participation identified in the fPRC framework (attendance and involvement; Imms et al., 2016, 2017) of children with DD across three layers: (1) the research process, (2) the digital environment where the assessments were conducted, and (3) the everyday activity domains assessed with PmP. While the study did not investigate the general feasibility of self-rating procedures for children with communicative and cognitive impairments, it aimed to identify specific cognitive and communicative barriers inherent to the digital format. The results revealed that a video-based interview procedure could facilitate attendance in research for some children with DD, most clearly indicated by the participant who chose to answer the questions via the chat function within the video application. This child would have refused participation in an IRL interview. However, relying solely on video interviews when collecting data on participation for children with DD could risk introducing bias in the results, as evidenced by differences in TQS profiles among the children in the study. To reduce this bias, guided self-rating through video communication could be offered as an option, rather than the sole method for data collection. It is important to note that the procedure may be less feasible for children with individualized pictorial support systems. In this study, we relied on the pictorial support included in PmP, which was transferred to the digital format in advance. However, parents of children who require more specific accommodations may have declined participation. It is also worth noting that children with DD such as dyslexia or developmental coordination disorder, with less severe cognitive and communicative impairments, were excluded since participants were recruited through clinics that do not provide services for children with such disabilities. It is reasonable to assume that video interviewing could be a feasible option for an even higher proportion of children with less pervasive diagnoses.

The level of child involvement in the video interviews was high, according to the interviewers. This impression was partially supported by the children rejecting the notion of the interviews as "boring." Barriers to participation in the interviews were often related to aspects of PmP rather than the digital environment, as demonstrated by some children not comprehending the involvement items. However, the technical problems that occurred during some of the interviews highlighted a feature of the digital environment that may increase implicit demands on expressive language ability. In Zoom and other similar video communication platforms, the environment is only partially shared. The interviewer cannot directly perceive the same things as the child or control all parts of the environment. For

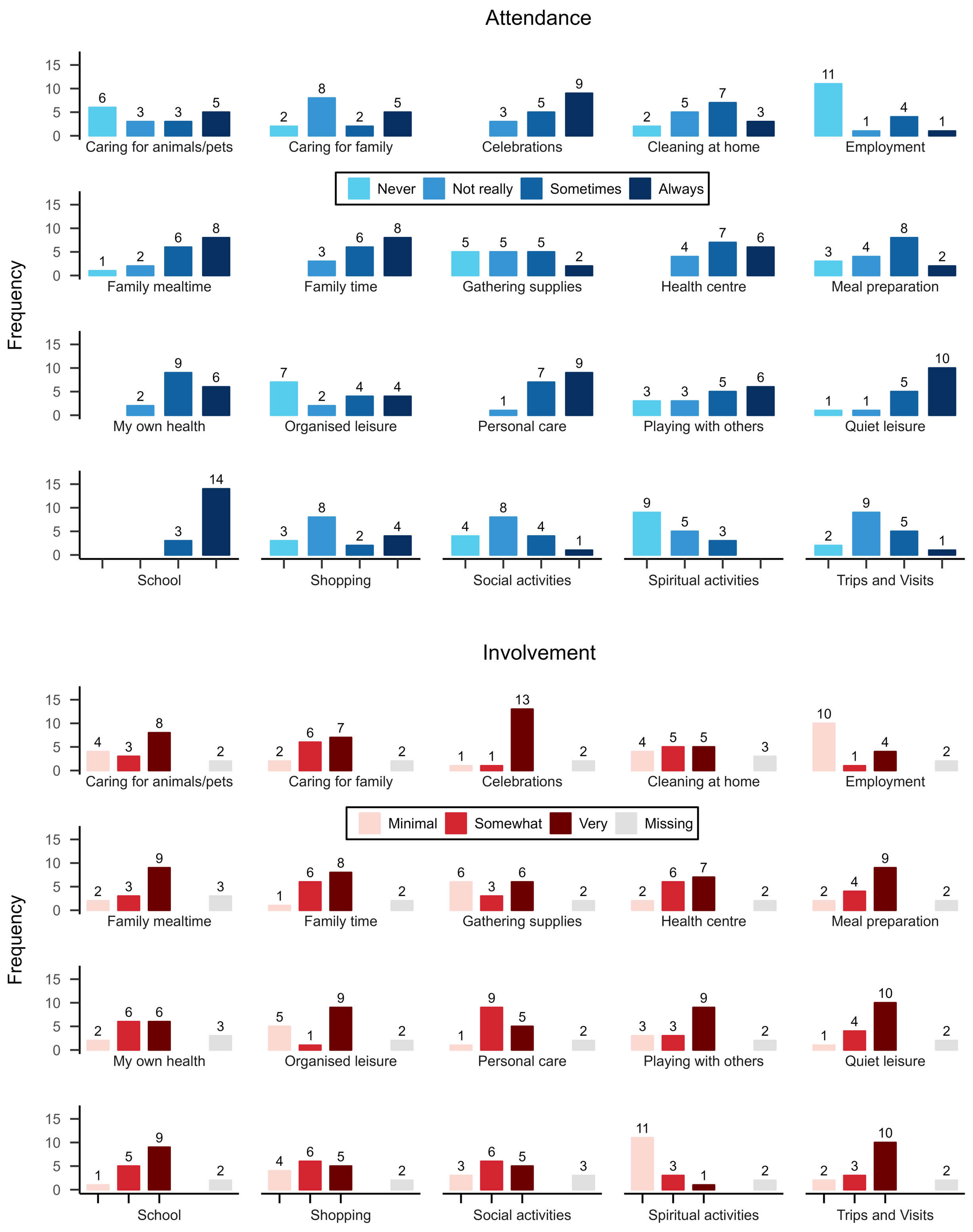

FIGURE 4
Picture my participation: attendance and involvement in activities.

example, the Zoom interface differed somewhat between devices, and finding the annotate function was not always straightforward. Further, one child failed to mention that the sharing of PowerPoint slides had stopped working for several minutes. This indicates that problem-solving and participation may be more dependent on the child's ability to verbally explain what they perceive and to understand instructions on how to navigate the environment in digital interviews. In an IRL interview, it is likely easier for the interviewer to use clues from the environment to identify and solve problems. For children with language impairments, such as those with developmental language disabilities, this aspect of the digital environment is more likely to cause participation restrictions than for children with typical language development. The effect is likely to be larger in less structured interview settings. To reduce this dependency, interviewers should be made aware of reoccurring problems and their typical causes in different digital environments.

Concerning the participation in everyday activities measured by PmP, results need to be interpreted with caution due to the low number of participants in the study. As when administering PmP in person to children with an intellectual disability (Arvidsson et al., 2020, 2021), the responses were positively skewed, which is likely to do with the PmP instrument as such rather than the digital format of the interview. However, in contrast to findings in earlier studies (Arvidsson et al., 2020, 2021), there was no missing data in the attendance subscale.

PmP does not differentiate between activities in a digital and non-digital environment but, notably, the level to which the activities can be performed in a digital context differs. Trips and visits to friends and family are likely to be much more difficult to transfer to a digital environment than quiet leisure, which may involve activities such as playing video games online. For this reason, it is interesting to compare the relatively low rate of attendance in organized leisure in the present study, which probably most often takes place IRL, to the higher rate in quiet leisure. Whether digitalization could play a role in enabling higher rates in certain activity domains than others needs to be further evaluated in future research.

The results of the study call attention to a few specific ethical challenges in projects including video interviewing. Firstly, additional measures are needed to reduce the risk of sensitive data leaking from the project. It may, for example, be necessary to communicate information that could be used to identify participants (e.g., social security number) separately from the video interview if the information is somehow transferred and/or stored in the hands of a third party or corporation. Secondly, measures need to be taken to get a picture of who is listening to the interview (e.g., family members off-screen). Equally important is giving the participating child a clear picture of the immediate surroundings of the interviewer.

Previous research has proved there are many obstacles to overcome for accessing necessary healthcare interventions for children with DD as well as participation in self-ratings and self-assessments of participation and related constructs (Varghese et al., 2015; Adugna et al., 2020; Doherty et al., 2020). Although tentative, the results from this study are promising since the use of video communication could increase the accessibility of research projects including self-ratings of participation in children with DD. It is reasonable to assume that the results would generalize to other outcome measures where the subjective experience is of key importance, such as mental health problems or well-being, as well as to older individuals with similar types and levels of disability. Before being applied in a larger project, it is recommended that the procedure and necessary applications are tested and practiced by all data collectors, on different types of devices. The results are also applicable in rehabilitation and habilitation services where participation is an important outcome, at least in environments where digital solutions are available. In a recent scoping review, professionals and service users reported several benefits of using digital meetings, i.e., teletherapy, as a complementary alternative to IRL meetings with professionals (Benz et al., 2022). Teletherapy was perceived as resourceful, increased the accessibility of service, and contributed to opportunities to connect with others. It could be presumed that children and youth with DD would similarly benefit from teletherapy. One finding from the present study, that may apply to teletherapy as well, is that unexpected events such as technical issues are likely to reveal demands on language abilities. The more familiar the interviewer is with the digital environment in the treatment, the more likely it is that he or she could assist the child, without having to rely on the child's expressive communicative abilities. In addition, in teletherapy, where the procedure may be less predictable than in the current study, a more flexible pictorial support system is likely to be needed.

Limitations

The major limitation of the present study is the relatively small sample and the sampling strategy. The communicative and cognitive functioning of the participants were not assessed in the study, contributing to the limitation in the generalizability of the findings. The study does not provide an answer to the question of exactly where to draw the line on which children can and cannot validly respond to, what are assumed to be, cognitively accessible questions on subjective phenomena like participation in a video format. It also does not answer how cognitively accessible the questions and procedure are, or whether the video format as such has an impact on how children respond to questions concerning participation and related constructs. Although further research is needed to answer these questions, there are some indications that self-ratings for children with DD actually can be facilitated through the use of different apps and different forms of video communication (Kaiser et al., 2001; Stephenson and Limbrick, 2015). Also, the results of this study give enough confidence in the feasibility of the approach to encourage future use of video communication to guide self-ratings of participation and related constructs in children with DD.

Data availability statement

The datasets presented in this article are not readily available because of commitments in the ethical approval. However, anonymized data without participant characteristics is available upon request. Requests to access the datasets should be directed to magnus.ivarsson@liu.se.

Ethics statement

The studies involving human participants were reviewed and approved by the Swedish Ethical Review Authority (case number 2019-05028). Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin. The individual(s) provided their written informed consent for the publication of any identifiable images or data presented in this article.

Author contributions

MI and AA: conceptualization, data curation, formal analysis, investigation, methodology, project administration, software, visualization, writing—original draft, writing—review and editing. LA: conceptualization, data curation, formal analysis, methodology, project administration, visualization, writing—original draft, writing—review and editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1130675/full#supplementary-material

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EDITED BY
Hendrike Frieg,
University of Applied Sciences and Arts
Hildesheim, Germany

REVIEWED BY
Bryan Abendschein,
Western Michigan University, United States
Barbara Schneider,
Osnabrück University of Applied Sciences,
Germany

*CORRESPONDENCE
Naizeth Núñez Macías
✉ naizeth23@ru.is
Martina Hielscher-Fastabend
✉ martina.hielscher@uni-bielefeld.de
Hendrik Buschmeier
✉ hbuschme@uni-bielefeld.de

†PRESENT ADDRESS
Naizeth Núñez Macías,
Department of Computer Science, Reykjavik
University, Reykjavik, Iceland

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Use and acceptance of voice assistants among people with aphasia in Germany

Naizeth Núñez Macías*†, Martina Hielscher-Fastabend* and
Hendrik Buschmeier*

Faculty of Linguistics and Literary Studies, Bielefeld University, Bielefeld, Germany

Aphasia is an acquired disorder that affects the ability to communicate. The increasing availability of voice assistants (such as Amazon Alexa or Google Assistant) provides new opportunities to support people with aphasia in a variety of tasks, from everyday communication to speech and language therapy exercises. To ensure accessibility and acceptance, it is important to involve people with aphasia in the development process. Using the Unified Theory of Acceptance and Use of Technology (UTAUT2) as a theoretical framework, this study examines their willingness to use voice assistants and explores which potential applications they consider useful for participation in social and cultural contexts. These questions were addressed through a survey. Eight people with aphasia took part in the study. Although the sample size does not allow for statistical analysis, the results provide valuable insights for further research. Most of the participants showed a general interest in using voice assistants, two of them were already users. The presence of physical limitations motivates the use of speech-based technology. Participants who already used voice assistants saw them as a practical support in everyday life, while non-users had lower expectations in this respect. Social influence was found to play an important role. Participants' perceptions of privacy and data security issues varied and do not allow for generalization. Finally, some participants showed a preference for communication support applications (e.g., word finding, sentence formation, grammar support) over applications used for therapy exercises such as word training.

KEYWORDS

voice assistants, aphasia, speech and language impairments, assistive technologies, technology acceptance

1. Introduction

Aphasia is an acquired language disorder caused by brain damage that can affect all language modalities (listening, speaking, reading, and writing) to varying degrees, depending on the location and extent of the brain damage. Symptoms of aphasia can manifest themselves at all levels of language, from phonology to difficulties in word formation, vocabulary and semantic problems, as well as syntactic and pragmatic abnormalities (Clark and Cummings, 2003; Damico et al., 2021; Schneider et al., 2021). A common symptom is word finding difficulties, which may manifest as semantic or phonemic paraphasias or tip of the tongue phenomena. Accompanying symptoms may include motor deficits and cognitive impairments such as deficits in attention, short-term and working memory, and executive functions (memory, action planning, problem-solving thinking; Thöne-Otto, 2017; Code, 2021).

Aphasia affects more than 100,000 people in Germany. In 80% of the cases, the brain damage is caused by a stroke due to an ischemic or hemorrhagic insult. The remaining causes include acquired brain injury, brain tumors, inflammatory diseases, hypoxia (lack of oxygen), and brain atrophy (Bundesverband Aphasie e.V., 2022). As stroke is the most common cause of aphasia and strokes affect people over the age of 55 (Sudlow and Warlow, 1997), aphasic patients are often middle-aged or elderly. Aphasia is often accompanied by negative emotional and psychosocial changes. Social participation, carrying out activities of daily living and returning to work become more difficult, resulting in the need for support in several areas of life and a change in roles within families (Nätterlund, 2010; Beals et al., 2016; Code, 2021; Schneider et al., 2021).

The variety of symptoms experienced by people with aphasia also makes it difficult to interact with products and technologies such as mobile phones, creating a barrier to digital participation (Greig et al., 2008; Brandenburg et al., 2013). A study of the digital divide among people with disabilities (Johansson et al., 2021) found that a higher percentage of people with aphasia reported difficulties with finding information, navigating, understanding information, and using passwords compared to people with autism, attention deficit hyperactivity disorder (ADHD) and bipolar disorder. In addition, women with aphasia reported feeling more digitally excluded than other disability groups, including people with visual and fine motor impairments. However, the study by Johansson et al. (2021) focused on technology controlled by touch screens or keyboards. To our knowledge, there are currently no studies on the attitudes and barriers that people with aphasia face when interacting with voice assistants, which are digital assistants that are primarily voice controlled.

A particularity of voice assistants is that they offer the possibility of a human-computer interaction that is more similar to human-to-human interactions, compared to graphical user interfaces (Yaghoubzadeh et al., 2015; Nasirian et al., 2017). Olafsson et al. (2021) found that even though traditional tap and swipe user interfaces are often preferred over conversational interfaces for tasks under time pressure and for quick transactional tasks, conversational agents are an alternative for older users and users with lower computer and smartphone literacy.

Due to the growing popularity of voice assistants and their low cost (compared to other technologies such as robots), it is necessary to focus scientific attention on such products and their potential as assistive technologies (Masina et al., 2020). Functions such as reminders (Hellwig et al., 2018; Malapaschas, 2021), Smart Home applications, infotainment, communication (calls and messages; Hellwig et al., 2018), health documentation (Hellwig et al., 2018; Zhang et al., 2023), and managing shopping, to-do lists (Pradhan et al., 2018), or structuring the day (Kopp et al., 2018) can optimize the quality of life of people with physical, cognitive, and language or speech impairments and give them a sense of independence. At the same time, the workload of caregivers and medical staff can be reduced (Hellwig et al., 2018; Zhang et al., 2023).

The most popular commercial voice assistants are Amazon Alexa, Apple Siri, and Google Assistant. Amazon and Google offer a variety of dedicated hardware devices (often called smart speakers) for their voice assistants. However, many other devices that can connect to the Internet provide additional hardware for interaction, such as smartphones, smart TVs, or tablet PCs (Hoy, 2018). Since their introduction, voice assistants have become increasingly popular, as evidenced by the growing number of users. According to a survey conducted in May 2020, two out of five internet users in Germany (39%) use voice commands (Paulsen and Klöß, 2020). One year later, 44% of Internet users were already using voice applications (Klöß, 2021).

Commercial voice assistants are considered web interfaces, meaning that users can use such systems to access information through search engines, as well as to access services and resources such as email, phone calls, and messages (Natale and Cooke, 2021). Researchers have identified music, search, and smart home devices (e.g., smart lights, thermostats) as the most commonly used command categories (Ammari et al., 2019). Other functions recognized as potential uses of mobile technologies to enhance participation of people with aphasia (Brandenburg et al., 2013) can be fulfilled by voice assistants, e.g., supporting interpersonal relationships through chatting and social networking, and enabling activities such as online shopping, managing, and remembering tasks and schedules, or video calling. The publication of the World Health Organization's International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001) has resulted in an international interest in "participation" as the most important factor for rehabilitative outcomes. The ICF defines participation as involvement in a life situation and participation restriction is defined as problems an individual may experience in involvement in life situations. In the context of language problems and aphasia a regain of participation means the regain of communicative opportunities and the enhancement of chances to take part in individual private, social and cultural discourse. Of course, there is no universal definition and operationalization of the concept of verbal or communicative participation in people with aphasia, but Schneider et al. (2021) try to outline factors for diagnostic issues and therapeutic approaches.

Voice assistants such as Alexa and Google Assistant provide access to their application programming interfaces (APIs), opening up the possibility of developing custom applications (Hoy, 2018; Coates, 2019; Walls, 2022). This allows developers to create new features to address the unique needs of people with speech and language impairments. Here, we focus on applications for people with aphasia.

International organizations and researchers recognize the usefulness of digital assistants for people with aphasia. The National Aphasia Association in the United States recommends the use of commercial voice assistants, highlighting the advantage that such systems never tire (National Aphasia Association, 2022). Beals et al. (2016) highlight that technology offers the advantage of never getting bored and potentially reducing feelings of shame about the language disorder. In Europe, The Tavistock Trust For Aphasia, a UK-based organization, also recommends the use of voice assistants and lists use cases such as practicing everyday phrases and simple conversations (Aphasia Software Finder, 2022). It also publishes a list of Amazon Alexa skills, available in English, that people with aphasia can benefit from.

Qiu and Abdullah (2021) give a very visionary positive sight on the potentials of voice assistants to assist people with language problems. Further research has explored the suitability of voice assistants in speech and language therapy for children with autism using a prototype application (an Amazon Alexa skill) that would deliver images through an iPad (Allen et al., 2018) or directly through an Amazon Echo Show (an Alexa-enabled device with display; Yu et al., 2018). Allen et al. (2018) found that the accuracy of the speech recognition was insufficient for use in a clinical setting. However, when the speech recognition succeeded and the images were successfully retrieved, the participants (children with autism) consistently followed the target directive. The study of Yu et al. (2018) reported a higher accuracy in retrieving visual content and an overall positive response by the participants (speech and language therapists). Hricová and Glady (2023) explored advantages and disadvantages of using voice assistants for speech and language therapy with children. Additionally, the authors present a list of publicly available Amazon Alexa skills and describe the therapy goals that these skills can support. Other researchers have examined the accessibility and potential uses of voice assistants with target groups such as people with cognitive (Masina et al., 2020; Malapaschas, 2021), motor, or language limitations (Masina et al., 2020). These studies suggest that voice assistants can be used as an assistive technology and increase participation in everyday life. The role of the family members in the rehabilitation process and as main supporters in choosing and learning how to use assistive technologies is emphasized in both studies. Equally relevant to this topic are studies about other implementations of speech technologies in the context of speech and language impairments. Beals et al. (2016) analyzed the components of speech technologies in terms of applicability to language disorders such as aphasia and language development disorders such as dyslexia or autism spectrum disorders. Researchers have also studied the suitability of robots in speech therapy (Malchus et al., 2013, 2019). It was found that speech therapists would be willing to use social robots in aphasia therapy if they had certain characteristics such as adaptability and very good language production and comprehension capabilities (Malchus et al., 2013).

However, people with speech and language impairments are often not understood by commercially available voice assistants because they have been trained on audio recordings of healthy speakers. As a result, variations in breathing, phonation, and articulation lead to lower speech recognition performance (Beals et al., 2016). Despite lower performance, Pradhan et al. (2018) found that people with speech and language impairments are using voice assistants. Their analysis of reviews of the Amazon Alexa Echo Show device showed that family members of people with speech and language impairments perceived an improvement from interacting with voice assistants. Opinion articles emphasize that people with speech and language disorders can benefit enormously from the use of speech technology, e.g., by providing a higher degree of participation and independence (Corcoran, 2018) or by making speech therapy more accessible (Kevin Wheeler, 2020), and criticize that this target group has not been taken into account in the design of the technology. Therefore, it is claimed that the data for training speech recognition should be improved. Perhaps as a result of such criticism, manufacturers of voice assistants are making efforts to improve speech recognition for people with language impairments (Cattiau, 2019; Deighton, 2021; MacTechNews.de, 2022).

TABLE 1 Extended UTAUT2 according to Kessler and Martin (2017).

Determinants	Meaning
Performance expectancy	"The degree to which using a technology will provide benefits to consumers in performing certain activities" (Venkatesh et al., 2012, p. 159)
Effort expectancy	"The degree of ease associated with consumer's use of technology" (Venkatesh et al., 2012, p. 159)
Social influence	"Is the extent to which consumers perceive that important others (e.g., family and friends) believe they should use a particular technology" (Venkatesh et al., 2012, p. 159)
Facilitating conditions	"Consumers' perceptions of the resources and support available to perform a behavior" (Venkatesh et al., 2012, p. 159)
Price value	"When the benefits of using a technology are perceived to be greater than the monetary cost" (Venkatesh et al., 2012, p. 161)
Habit	"The extend to which people tend to perform behaviors automatically because of learning" (Venkatesh et al., 2012, p. 161)
Data security	"Showing transparency and control over the gathered information" (Kessler and Martin, 2017, p. 17)
Connectivity	"When a user wants his purchased technology to be connected to others for interaction reasons" (Kessler and Martin, 2017, p. 18)
Relationship with the device	"The effects of the relationship between intelligent machines and human beings" (Kessler and Martin, 2017, p. 18)

Previous research has analyzed the acceptance factors influencing the adoption of digital assistants by older people (Koon et al., 2020), but to our knowledge there is no research on the acceptance of such systems by people with aphasia. By evaluating acceptance, it is possible to identify requirements and needs, the fulfillment of which can enable people with aphasia to benefit from such systems. Here, the Theory of Acceptance and Use of Technology 2 (UTAUT2; Venkatesh et al., 2012) in the version adapted by Kessler and Martin (2017) was chosen for the analysis of acceptance factors because of its focus on artificial intelligence technology. This model considers the following factors: Performance expectation, effort expectation, social influence, facilitating conditions, price value, habit, data security, connectivity, and relationship with the device (Kessler and Martin, 2017). The definitions of the determinants are summarized in Table 1.

The purpose of this study is to examine the desirability of using commercial speech assistants as a communication aid and adjunct to speech therapy for people with aphasia. In order to verify the suitability of voice assistants, this study examines the factors that influence the adoption of voice assistants by people with aphasia. In addition, our study addresses the question of which use cases people with aphasia find useful for better participation in social life. The present work is intended to serve as a basis for the future development of applications for voice assistants that support people with aphasia and aims to contribute to closing the research gap in this area.

2. Materials and methods

We conducted a survey[1] to find out about the willingness of people with aphasia in Germany to use commercially available voice assistants in their everyday life and in speech and language therapy, as well as the factors that influence the adoption of voice assistants. An online questionnaire was created using the EFS Survey Software Unipark. The study was reviewed and approved by the internal ethics committee of Bielefeld University (reference no. 2021-222).

For data collection, the link to the online questionnaire was sent to self-help groups through the Stiftung Deutsche Schlaganfall-Hilfe and placed on the web page of the Aphasia 4.2 Online Congress in Germany. In addition, cooperation partners of the researchers were asked to forward the online questionnaire to their patients with aphasia. The survey was made available between March and June 2022. One participant completed the questionnaire during a telephone conversation with one of the researchers. Two additional participants completed a paper version of the questionnaire in October 2022. Participants were made aware of the voluntary nature of their participation and informed that their data would be handled in accordance with data protection regulations. Data collection was anonymous and no compensation was offered.

2.1. Participants

The target group of the study was people with aphasia, regardless of whether or not they were using voice assistants at the time of the study. A total of eight people with aphasia (three males: A1–A3 and five females: A4–A8) participated in the study. Age was reported in age groups: 36–50 years (A1, A4, A5, A6), 51–65 years (A2, A3), and 66–80 years (A7, A8). A2 did not complete the survey, but their available responses are analyzed in this study (as this was an online questionnaire, the reason for the interruption is unknown to the authors).

2.2. Questionnaire

The questionnaire contained between 49 and 53 questions. In addition to demographic data, the survey included a 5-point Likert scale (strongly agree to strongly disagree) rating of potential applications to support people with aphasia. Participants were asked about their experience with voice assistants and with technology in general. Participants who had used voice assistants answered questions about how they used the assistant, while participants who had not used voice assistants were asked about their reasons for not using them. These questions were related to the acceptance factors of the UTAUT2 model. An overview of the assignment of the questions to the UTAUT2 model can be found in Table 2. Most of the questions used a 5-point Likert scale (strongly agree to strongly disagree). Questions with a different format are specified in Table 2. The original questionnaires are available in the Supplementary material.

TABLE 2 Summarized overview of the questions and their assigned determinants according to the UTAUT2 model by Kessler and Martin (2017).

Determinant	Questions
Performance expectancy	—Motivation for using voice assistants (open question) —The voice assistant generally understands me well —I am afraid of not being understood by the voice assistant —The voice assistant is/would be a good support in everyday life —The voice assistant is/would be a motivation to improve my language
Effort expectancy	—Using the voice assistant is easy for me —I don't know how voice assistant work —I need help in dealing with technology —I am interested in technologies —I often have to ask how my computer/tablet/smartphone works
Social influence	—I have family and/or friends who support me in dealing with technology (yes/no) —Use by friends or relatives (yes/no) —Recommendation by friends or relatives (yes/no)
Facilitating conditions	—Access to internet (yes/no) —Access to internet-enabled devices (multiple choice) —Using computers and cell phones is complicated due to physical limitations —I can imagine using voice assistants at home in the future
Price value	—Buying a voice assistant is too expensive for me
Habit	—Frequency of use (multiple choice) —Used functions (multiple choice)
Data security	—I am concerned about the security of my data
Connectivity	—On what device is the voice assistant being used, e.g. smart speakers, smartphone, etc. (multiple choice)
Relationship with the device	—I get frustrated when the voice assistant doesn't understand me well —I think it is amusing/weird to talk to a machine

3. Results

Aphasia has been present for more than a year in almost all cases, only in A7 it was present for less than six months. Two participants (A4, A5) reported using voice assistants at the time of the survey. All participants reported having an internet connection and at least one internet-enabled device at home: Computer or laptop ($n = 8$), smartphone ($n = 7$, except for A1), tablet or iPad ($n = 3$), or smart TV ($n = 2$). None of the participants used

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[1] Most of the participants answered the survey online due to COVID-19 restrictions that made it difficult to meet participants in person.

TABLE 3 Individual participants' (A1, A3–A8) evaluation of voice assistant applications for supporting people with aphasia.

Statement	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I would like to integrate voice assistants into the speech therapy I am currently doing	A4, A5, A6	A8		A1, A7	A3
Exercises with voice assistants should be used as homework in my speech therapy	A4, A5, A6	A8		A1	A3, A7
I would like to be able to ask the voice assistant for help when I cannot remember a word	A3, A4, A5, A6, A8		A7	A1	
I would like to train words with the voice assistant	A3, A4, A5, A8		A6	A1, A7	
I would like to get help with grammar from the voice assistant	A3, A4, A5, A6, A8		A7		A1
I would like to ask the voice assistant how to form a sentence	A3, A4, A5, A6, A8			A7	A1
In my opinion, a voice assistant can replace my speech therapy	A1, A4, A5		A6, A8		A3, A7

A2 did not answer these questions.

voice assistants prior to their aphasia, and only A4 and A7 reported having used a therapy app.

In this section, we present the results of the survey in two parts. In Section 3.1, we summarize the evaluation of a list of potential applications to support people with aphasia in everyday communication and during speech and language therapy. Section 3.2 is dedicated to analyzing the factors that either encourage or discourage individuals with aphasia from utilizing voice assistants. We sum up the feedback provided by both voice assistant users and non-users separately.

We analyzed the data as follows: Questionnaire responses from all participants were collected in a spreadsheet. The responses were then compiled into tables, such as Table 3, from which the acceptance factor analysis was performed. In the following description of the results, participants were grouped based on their responses (e.g., to the questions in Table 2), thus identifying profiles and individual attitudes, preferences, or usage patterns. The data is available in the Supplementary material.

3.1. Potential applications for people with aphasia

Participants were asked to rate, on a 5-point Likert scale, potential use scenarios for voice assistants to support people with aphasia. These features are not currently available, but it is possible to develop such applications. The results are summarized in Table 3. There are notable differences between participants who have used voice assistants and those who have not. A4 and A5 rated all of the proposed applications positively, whereas the opinions of the participants who did not use voice assistants ranged from very positive to very negative. In addition, some participants showed more interest in using applications to help with grammar, sentence formulation, or word finding difficulties than in speech therapy applications such as word training or doing exercises assigned by the therapist. An unexpected finding was that three participants agreed to the statement that their therapy could be replaced by voice assistants. However, the authors see the use of voice assistants mainly as a resource for better access to information and for participation in daily routines.

3.2. Perception of voice assistants

In this section, we analyze the factors that influence or inhibit the use of voice assistants by people with aphasia. For clarity, responses from users and non-users of voice assistants are discussed separately.

3.2.1. Users

Two participants reported using voice assistants several times a day on a smart speaker and a smartphone (A4 and A5). A4 also reported using the voice assistant on a tablet or iPad and on a computer. Both participants use Google Assistant and Amazon Alexa. A4 also uses Bixby (a voice assistant by Samsung).

When asked what motivated them to use a voice assistant, they refer to existing deficits (e.g., A4: *"richtig schreiben, fehlerlos, ist mit Aphasie nicht mehr möglich"* ["writing correctly, without errors, is no longer possible with aphasia"]) and to feelings of shame that do not arise during interaction with the voice assistant, possibly in contrast to interaction with other people (A5: *"um Hilfe zu finden"* ["to find help"], *"die Antworten die man bekommt ohne als dumm zu wirken"* ["the answers you get without being perceived as dumb"]). Positive aspects of the voice assistant are that users do not have to write (A4) and that the information they receive from the assistant is polite and accurate (A5). As a negative aspect, A5 reported that the voice assistant speaks too fast and sometimes cannot understand the commands.

A4 and A5 have in common that they perceive the voice assistant as a good support in everyday life, but they are neutral about the voice assistant as a motivation to improve their language. Further results show that A4 and A5 have fundamentally different perceptions of their experience with voice assistants. A5 reported finding the voice assistant easy to use and being well understood by it. A4 was neutral about the ease of using voice assistants and being sometimes misunderstood by them. There is also a wide variation in their assessment of their technology competence and the frequency with which they ask for help when using mobile devices such as computers, tablets, or smartphones. A4 reported high confidence in using technology and rejected the need to constantly ask for help, while A5 was neutral about her technological competence and reported a constant need for help in using mobile devices.

A4 and A5 are unique in that they both have someone in their environment (family or friends) who has already used a voice assistant and recommended it to them, as well as someone who supports them in using technology. In addition, both participants indicated that physical limitations make it difficult for them to use mobile devices. However, further information about these limitations was not available to the researchers.

Both participants use the following functions: timer, calls, writing messages, listening to the radio, asking about the weather and asking for addresses. A4 also uses features such as online shopping and shopping lists, and smart home features such as turning lights on and off and controlling the TV. A5 also listens to online books and asks for jokes.

Concerns about data security are partially present for A5, but not for A4.

A4 reported that she was sometimes misunderstood by the voice assistant and felt frustrated when this happened. She also rejected finding it amusing to talk to a machine. On the other hand, A5 is not frustrated with the device due to lack of understanding and is partially comfortable talking to a machine.

3.2.2. Non-users

When asked which voice assistants they had heard of, all non-users except for A3 reported knowing Amazon Alexa and Google Assistant. Other known voice assistants are Microsoft Cortana ($n = 2$), Apple Siri ($n = 1$) and Magenta ($n = 1$).

Participants were presented a list of possible reasons for not using voice assistants and were asked to evaluate the statements on a 5-point Likert scale. A8 reported having difficulties answering these questions and left them unanswered. Instead, she expressed verbally that she did not use voice assistants because it was all too new for her. Two of the non-users (A1, A6) reported that they feared to be misunderstood, for A2, A3 and A7 this was not the case. Non-users showed some skepticism regarding the potential of voice assistants to support them in their everyday life. Only A8 evaluated this statement positively, A6 and A7 were neutral about it and A1 and A3 rejected it. A6 and A8 indicated that voice assistants could be a motivation to improve their language, while A7 was neutral about it and A1 and A3 rejected this statement. A further reason for not using voice assistants was the lack of knowledge about their functionality. Only A7 reported this not being a relevant factor. A3, A6, and A8 showed interest to use voice assistants at home in the future. The rest of the participants rejected this statement (A1, A7) or left the question unanswered (A2).

Similar to the users, the assessment of their technology competence and the frequency with which they asked for help when using mobile devices such as computer, tablet or smartphone was highly variable among participants. A1 and A8 reported being interested in new technologies and being able to handle them well without the need of asking for help. A3 was neutral about the interest and indicated a low competence and a need for help. A6 indicated a high interest in technology, was neutral about her competence and reported needing help with mobile devices. A7 reported a low interest, was neutral about her competence but indicated not needing help in dealing with mobile devices. Only A8 reported having physical limitations that make the use of mobile technologies complicated. All participants except for A1 reported having someone in their environment that supports them in dealing with technology. Of all the non-users, only A7 had family or friends who used voice assistants. However, they had not recommended using them.

Regarding costs, four participants reported voice assistants being too expensive for them. It can be inferred that the participants did not know about or did not consider the possibility of using voice assistants through devices they already own, e.g., smartphones and computers. Other reasons, such as the concerns about data security and the feeling toward the idea of talking to a machine are rated differently by the participants. A1 and A2 reported having concerns about data security, whereas A3 and A7 were neutral about it and A6 rejected having such concerns. A1 and A2 affirmed finding it weird to talk to a machine, whereas A3, A6, and A7 rejected this statement. Only A8 found the idea of talking to a machine amusing.

Since it was expected that non-users were not informed about the functionalities of voice assistants, they were given a list of functions and were asked to mark the ones that they would like to use. A total of five participants answered this part of the questionnaire. Non-users reported willingness to use following functions: timer ($n = 3$), reminder ($n = 4$), call ($n = 1$), listening to the radio ($n = 3$), listening to audio books ($n = 2$), controlling TV ($n = 1$), controlling lights ($n = 2$), asking for the weather ($n = 2$), asking for addresses ($n = 3$), texting ($n = 2$), and asking for jokes ($n = 2$).

4. Discussion

Research on the use of voice assistants for and by people with speech and language disorders is a promising research area. However, the needs and barriers that may hamper the use of voice assistants by people with different speech and language impairments should be researched separately. In this study, we aim to contribute to the knowledge on the potential uses of voice assistants for people with aphasia. We explored users' perception on the interaction with voice assistants and on functions that could be developed to support this target group, along with expectations and factors that act as inhibitors in the acquisition and use of voice assistants, taking the adapted UTAUT2 model (Kessler and Martin, 2017) as theoretical framework. The rather low number of participants does not allow for a statistical evaluation, nevertheless, the data provides insights that can be used as a reference for future research.

4.1. Voice assistants as communication aids and speech therapy tools

Participants were given a list of applications that could be developed for commercially available voice assistants (such as Amazon Alexa and Google Assistant) to support them in their daily life and as complementary tools for speech and language therapy. We posed the additional question if participants believed voice assistants could replace speech therapy in order to identify the attitude toward the idea of voice assistants as replacement vs. as complement of traditional therapy. Regarding the suggested applications, we found that some participants preferred applications for communication support (word-finding, sentence formation, help with grammar) over applications for use in therapy sessions, as homework or self-training. It should be noted though that only two participants had prior experience with other therapy apps, which leads to the possibility that a rejection of using the voice assistant as a tool for therapy is related to a lack of knowledge about the technological possibilities or to a preference of traditional therapy methods. Additionally, we found that the participants who were already users of voice assistants evaluated all the proposed applications positively, while the assessment of non-users ranked from very positive to very negative. This suggests a higher expectancy of useful participation opportunities by users than non-users based on positive experiences with the technology.

People with aphasia and their relatives saw chances for voice assistants to support conversation and thereby strengthen their participative opportunities in several different ways. As pointed out, some participants see additional therapeutic potential in the training situation with their voice assistant, for instance to find the correct words for things they want to address. In addition, voice assistants may help to train the verbal communicative competences of people with aphasia in every-day situations at home. In addition, if further systems can guaranty safe personalized online conversation voice assistants, this may help to get access and support the communication in online formats, which has been shown to be very promising for people with aphasia who have problems with face-to-face conversation, especially in group settings (Cruice et al., 2021). In accordance with Qiu and Abdullah (2021), a positive view on the potentials of voice assistants was found in the answers of even some people with aphasia.

Three out of seven participants (A1, A4, and A5) considered the replacement of speech and language therapy through interaction with a voice assistant as a possible alternative. Nevertheless, the results suggest that the reasoning behind this evaluation may vary. A4 and A5 (both women, 36–50 years old) were users of voice assistants and evaluated all proposed use cases positively, whereas A1 (male, 36–50) did not use voice assistants and rejected being interested in the proposed applications. It should be noted that A1 showed no interest in using voice assistants in the future and did not own a smartphone, which could be interpreted as a general cautiousness toward the use of AI-based technology. Therefore, it is likely that A1 saw the replacement of traditional therapy through voice assistants as possible, though in a negative way. On the other hand, the positive experience of A4 and A5 with voice assistants may have led to a higher trust in the capabilities of voice assistants, and therefore to the belief that such devices could be able to replace traditional speech and language therapy. However, further research is needed in order to obtain a better understanding of this topic.

4.2. Acceptance factors

4.2.1. Performance expectancy

We found that people with aphasia who already used voice assistants perceived them as a good support in everyday life, while people with aphasia without experience with voice assistants had low expectations in this regard. Users indicated that difficulties with writing and the possibility of asking for help without feeling ashamed were a motivation for using voice assistants. From these results it can be inferred that users see the potential to cover a need in voice assistants that is not covered by other technological devices or that cannot be covered by the environment (e.g., to avoid family members being overloaded). Nevertheless, users see the voice assistant only partly as a motivation to improve their language, whereas non-users showed very different opinions. For that reason, it cannot be concluded that voice assistants represent a motivational factor.

The fear of not being understood was also rated very differently among non-users, from fear being an important to being an irrelevant factor. Unexpectedly, when relatives of people with aphasia were asked about their own reasons not to use voice assistants, some of them also reported being afraid of not being understood (Núñez Macías, 2022). Therefore, it can be concluded that a negative perception of the accuracy of speech recognition can negatively influence the acceptance and purchase of voice assistants, independent from the presence of language impairments. This fear translates directly to a low performance expectation, since users cannot benefit from the voice assistant if the latter does not understand the user's requests.

In accordance with Beals et al. (2016), the reduction of feelings of shame about the language disorder were also identified in the study. One of the participants reported that a motivation for using voice assistants was the possibility to ask questions without being perceived as unintelligent. This may also suggest a high potential of voice assistants as an assistive technology, since people with aphasia can make use of such system in spite and not because of the language impairment, which makes the technology less stigmatizing than other assistive technologies (Masina et al., 2020).

4.2.2. Effort expectancy

The participants who were already users of voice assistants reported different perceptions toward the difficulty of use. One of them perceived it as easy while the other was neutral about it. Yet both perceived the voice assistant as a good support in everyday life. It is therefore possible that users may show a high acceptance of voice assistants in spite of facing difficulties with speech recognition, as long as the technology still offers an advantage over other technologies. In this case, the second user reported having difficulties writing, resulting in a greater reliance on speech-based technology.

A lack of knowledge about the functionality of voice assistants was often given as a reason for not using them. One of the participants indicated not using them because it was all "too new" for her. This lack of knowledge is expected to be related to the perceived difficulty of use. Following Koon et al. (2020), this indicates that people should be informed about the existence of such technologies and accompanied in the process of adoption and learning.

Questions about the general interest in technology and the need for assistance in using technology were asked to examine to what extent the willingness or refusal to use voice assistants is related to the willingness or refusal to use technology in general. The assessment of their own technology competence and the frequency with which they ask for help was highly variable among participants. It was found that a general interest in technologies or a high self-assessment of technology affinity usually went hand in hand with a higher openness to voice assistants. Nevertheless, one participant reported being highly interested in new technologies but was not willing to use voice assistants in the future. The same participant also reported having concerns about data security and not owning a smartphone. From these results, it can be interpreted that concerns about data security play an important role in that decision. This factor will be further discussed below.

4.2.3. Social influence

Social influence has been found to play an important role in the adoption of voice assistants. The participants who already used voice assistants also had family or acquaintances who used them and who recommended using them. In addition to that, users knew someone in their environment that was able to provide help in dealing with technology, while this was not always the case with non-users. One of the non-users reported knowing people who used voice assistants, however, they had not recommended the person with aphasia to do so. Further research is necessary to explore whether participants purchased the voice assistant by their own or if it was a gift from someone in their environment and what impact this has in continuing the use (Koon et al., 2020).

4.2.4. Facilitating conditions

All participants had access to internet and to internet-enabled devices, yet only two out of eight participants were using voice assistants at the time of the survey. Since most of the answers were gathered via an online-survey, we were unable to reach out to participants who did not have access to such devices, which would have given us some information about the perceptions of people with aphasia who either have no access to the internet, do not feel able to use internet-enabled devices or decided against using them.

The existence of physical limitations that make it difficult to use keyboards or touchscreen displays seems to increase openness to voice-based control and thus to voice assistants, which emphasizes the potential of voice assistants as an assistive technology. Both participants who were users of voice assistants reported having difficulties in dealing with mobile technologies due to physical limitations. Similarly, one of the non-users reported having such difficulties and being interested in using voice assistants in the future. This factor is considered a facilitating condition in this study because we consider being able to use the voice for device control a resource that is not available in tap-and-swipe user interfaces.

4.2.5. Price value

In spite of the possibility of using voice assistants on several internet-enabled devices, it was found that most non-user participants considered the price of voice assistants as a reason for not using them. Nevertheless, we did not gather information regarding the knowledge about the price of smart speakers. One of the participants who answered the questionnaire on paper reported the price not being a factor only after hearing the price range from the researcher. These results may suggest that not the actual price but the expectation about the price influenced the decision of the participants not to acquire a smart speaker.

4.2.6. Habit

The participants who were users of voice assistants reported using them several times per day for a variety of functions, which denotes a strong habit. It is also noteworthy mentioning that even participants who indicated not being interested in using voice assistants at home in the future selected several functions when asked which functions they would like to use. In that sense, the question about the habit is closely linked to the knowledge about the functionalities of voice assistants.

4.2.7. Data security

We found that there is little consensus on the issue of data security. Privacy concerns play a very different role among the individual participants. While for some participants these sort of concerns are a reason for not using voice assistants, for other participants these are only partial or non-existent. These results accentuate the need of creating guidelines for the research of voice assistants as assistive technologies and the need to evaluate the prerequisites that should be met when developing such systems. This applies both to the manufacturers of voice assistants as well as app developers.

4.2.8. Connectivity

Users of voice assistants reported using at least two providers through smart speakers and a smartphone. This could indicate that the compatibility of the voice assistant with the devices they already own is an important factor for them. However, we did not gather sufficient information about this factor.

4.2.9. Relationship with the device

We found that experiencing difficulties with speech recognition lead to feeling frustrated toward the voice assistant. However, as mentioned in the discussion of effort expectancy above, occasional feelings of frustration did not seem to affect the overall acceptance of a voice assistant when it still covered a need that was not covered by other devices. Only one participant was enthusiastic about the idea of talking to a machine, while others found this to be a strange idea or were neutral about it. Notably, even one of the participants who were already using voice assistants several times per day reported feeling weird about it. Additionally, as described in the discussion about the performance expectancy, one participant reported that being able to ask questions without feeling ashamed was a motivation to start using the voice assistants. This result may suggest that a feeling of familiarity can be a facilitator for the acquisition and continued use of voice assistants.

4.3. Limitations and future directions

A limitation of the study is the rather low participation rate, which does not allow us to draw statistical conclusions. One reason for this is that we were not able to get in contact with participants because of the COVID-19 restrictions. Therefore, we conducted the survey online for the most part. Another difficulty was that some self-help groups did not forward the online questionnaire to their members, due to two assumptions: (1) there would be no interest in the topic of voice assistants due to members' age, and (2) participation would not be helpful for the study, because members were not using voice assistants, yet. Another possible reason for the low participation rate is that the questionnaire was overwhelming for people with aphasia, particularly given that participants were sitting in front of an internet enabled device without being able to ask the researchers for help. One of the participants who answered the questionnaire on paper with the support of one of the researchers expressed being particularly overwhelmed with a set of questions that used a Likert scale. In this case, the participant skipped these questions and continued answering the questionnaire. We can assume that A2 interrupted the survey because of difficulties answering the questions (in the online version of the questionnaire it was not possible to skip questions). Only one participant contacted the researchers and asked for help in answering the questionnaire, which was provided through a telephone call.

The conducted survey is also limited in that it was not possible to explore the motivation behind the Likert scale evaluations, such as the concerns regarding data security and privacy or the statement that voice assistants could replace speech and language therapy. A deeper analysis of factors that create or harm trust toward digital assistants is needed in order to better understand and be able to address the existing concerns. Additionally, people without access to internet-enabled devices as well as people who are limited in their use of keyboards due to physical or visual impairments could not participate in the study due to the chosen method (online survey). Further research should therefore consider adapting the surveying method to the preferences and abilities of the target group (e.g., giving the participants the opportunity to choose between responding to the survey online, on paper, or conducting in-person or telephone interviews). We plan to continue this research addressing the forementioned limitations as well as extending it to other languages and cultures.

This study is based on a bigger survey conducted as part of a Master's thesis in which not only people with aphasia but also relatives of people with aphasia participated. The Master's thesis also investigated the requirements posed by people with aphasia to a voice application such as an Amazon Alexa skill that provides support in searching for words. A prototype skill was developed and tested in a small usability study with two participants. To facilitate word finding, the skill asked a set of questions in order to then suggest a word (limited to items found in kitchens, e.g., "kitchen sink," "water glass," as well as food items such as "lemon" or "potato"). It was shown that people with aphasia would prefer an interaction with a maximum of five to six questions from the voice assistant. The supported words should cover as many topics and be as specific as possible, and, optionally, provide visual support (Núñez Macías, 2022). More research is needed to develop applications based on the concrete needs and preferences of the target groups. This should involve a broader number of participants for iterative testing as well as for the collection of ideas and concerns. Furthermore, researchers and developers should include relatives in the development process of voice applications, because relatives play a crucial role in increasing the participation of people with aphasia (Schneider et al., 2021).

Data availability statement

The original contributions presented in the study are included in the Supplementary material, further inquiries can be directed to the corresponding authors.

Ethics statement

The studies involving human participants were reviewed and approved by the internal ethics committee, Bielefeld University (reference no. 2021–222). The participants provided their written informed consent to participate in this study.

Author contributions

NN, HB, and MH-F contributed to the conception and design of the study. NN collected and analyzed the data and wrote the first draft of the manuscript. HB and MH-F supervised and critically revised the manuscript. All authors contributed to manuscript revision, read, and approved the final version of the manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

Supplementary material, containing the original questionnaires as well as participants answers as data, is available at the following OSF-repository: https://doi.org/10.17605/OSF.IO/9CFMS.

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EDITED BY
Kristina Jonas,
University of Cologne, Germany

REVIEWED BY
Britta Dawal nee Gebhard,
South Westphalia University of Applied Sciences, Germany
Helene Kreysa,
Friedrich Schiller University Jena, Germany

*CORRESPONDENCE
Larissa Pliska
✉ larissa.pliska@tu-dortmund.de

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Toward digital participation in individuals with Autism Spectrum Disorder

Larissa Pliska*, Isabel Neitzel and Ute Ritterfeld

Research Unit of Language and Communication, Department of Rehabilitation Sciences, TU Dortmund University, Dortmund, Germany

Introduction: Digital participation might have great potential for the everyday lives of individuals with Autism Spectrum Disorder (ASD). Previous research suggests that children with ASD enjoy and favor usage of digital technologies. As informative research on this topic is still sparse, this paper makes a contribution toward a better understanding of media usage in children with ASD.

Methods: Parents of 15 boys aged 6 to 11 diagnosed with ASD in Germany were asked about their children's media usage. For comparison, parents of 78 typically developing (TD) children were surveyed online.

Results: Statistical analyses reveal no differences between boys with and without ASD in media use, frequency, and reasons for use. However, there is a significant group difference in parents' perceptions of difficulty of restricting their child's media use: Parents of children with ASD reported greater difficulties of restriction of their child's media use than parents of TD children.

Discussion: Digital media is an integral part of the daily lives of children with ASD and has the potential to increase the social inclusion of people with ASD through digital participation.

KEYWORDS

Autism Spectrum Disorder, media use, digital media, digital participation, neurodevelopmental disorder

1. Introduction

Since the 1988 signature movie "Rain Man," Autism has been a popular topic in entertainment media. For example, there are some recent television series (i.e., "The Good Doctor," "The Big Bang Theory") where the main character shows the neurodiverse condition of Autism Spectrum Disorder (ASD) or a potential diagnosis is at least discussed. The protagonists with ASD are hereby often portrayed with extraordinary abilities presenting ASD in a rather favorable light (Ressa, 2022). However, ASD is classified as a serious neurodevelopmental disorder which is characterized by persistent deficits in social interaction as well as communication and by restricted, repetitive, and stereotyped patterns of behavior, interests, or activities (American Psychiatric Association, 2013). For example, persistent deficits in social interaction and communication include impairments in pragmatic language (Filipe et al., 2020). Pragmatic language can be understood as the ability to use and interpret language effectively in communicative exchanges (Milligan et al., 2007). The clinical presentation of ASD is heterogeneous, and symptoms are multifaceted and varies widely between individuals (American Psychiatric Association, 2013; Wawer and Chojnicka, 2022). For this reason, Autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified in DSM-IV have been condensed into one diagnosis in DSM-V: Autism Spectrum Disorder (see Hodges et al., 2020).

The prevalence of ASD diagnoses has increased worldwide (Chiarotti and Venerosi, 2020; Bougeard et al., 2021; Zeidan et al., 2022). This increase reflects the combined effects of, for example, a raised community awareness – which is particularly an improvement – and progress in case detection, enabled by significant improvements in early identification (Zeidan et al., 2022). A systematic literature review by Bougeard et al. (2021) shows that a prevalence of ASD ranged between 38:10,000 and 155:10,000 in European children aged 4 to 8 years in the period 2014 to 2019. Until 2012, the global estimate of ASD prevalence was 62:10,000 (Elsabbagh et al., 2012) and is nowadays estimated to have risen up to 100:10,000 (Zeidan et al., 2022). This means that approximately 1 in 100 children worldwide receives a diagnosis of ASD (Zeidan et al., 2022).

Boys have a higher prevalence of ASD than girls (Elsabbagh et al., 2012; Jiménez-Muñoz et al., 2022; Zeidan et al., 2022). In contrast to a previously reported 4:1 male-to-female ratio, a meta-analysis by Loomes et al. (2017) estimates the true male-to-female ratio to be closer to 3:1. Girls may be misdiagnosed, diagnosed later, or overlooked because of the female Autism phenotype (Hodges et al., 2020; Hull et al., 2020). "Female Autism" has been described as qualitatively different from typical "male Autism" (Hull et al., 2020). Ongoing research therefore strives to explain these sex differences while taking the possibility into account that females are better in masking symptoms which makes them less likely to receive the ASD diagnosis (for a review see Lockwood Estrin et al., 2021).

Generally, gold standard methods of diagnosing ASD typically take many hours to complete and contribute to long waiting times for concluding a diagnosis (Tariq et al., 2018). This long wait creates not only uncertainty for the entire family (Wiggins et al., 2006) but also delays the start of family support and child therapy (Tariq et al., 2018). This delay can have incremental effects as an early start of intervention has been proven to result in better developmental outcomes (Wiggins et al., 2006; Lin et al., 2022). Valid screenings administered at an early age could contribute substantially to cutting the waiting list. In many countries diagnosis of ASD is a necessary precondition for receiving treatment. A metanalysis conducted over 35 countries yielded a mean age of first diagnosis of 60.48 months (5.5 years, range: 30.90 to 234.57 months; van't Hof et al., 2021). Children with intellectual disabilities (IQ < 85) are hereby diagnosed much earlier than children without intellectual disability (IQ ≥ 85; Höfer et al., 2019). In Germany, the mean age of first diagnosis is with 78.5 months (6.5 years) already reaching school age, although most parents report already having had concerns when their child was about 2 years old (Höfer et al., 2019). The longer waiting time to be eligible for diagnostics in Germany compared to other countries highlights the need for improved forms of care for suspected cases of ASD in Germany (Höfer et al., 2019).

The authors are part of the recent grant-funded project IDEAS (Identification of Autism Spectrum Disorder using speech and facial expression recognition) which aims to develop an automated screening tool for the early detection of ASD. Since such an automated tool requires mediated input, we investigate the usefulness of various media formats to elicit relevant symptoms (Pliska et al., 2023) and aim to achieve a differentiation as selective as possible between autistic and typical development using this tool. As a necessary basis, media usage and competence in children with ASD must be compared to typically developing (TD) children to further understand usage and acceptance of digital technology in this particular group.

1.1. Media usage in individuals with ASD

"Digital technology is considered the main facilitator in social inclusion and community living in people with disabilities" (Glumbić et al., 2022, p. 98). It has been consistently reported that children with ASD are particularly attracted by digital technologies (Mazurek and Engelhardt, 2013; Laurie et al., 2019; Scholle et al., 2020), especially screen-based media and hereby namely video games. The time that children with ASD spend with digital media typically exceeds the time invested by TD peers (Krishnan et al., 2021). Several studies have shown that using media-based learning is well accepted in children with ASD (Lin et al., 2013) and in case of doubt would be preferred to other formats. For example, a study by Brunero et al. (2019) can support the preference of children with ASD – especially high-functioning boys – for digital media to support learning activities. Some authors argue that interacting with computers can be particularly enjoyed by children with ASD (Valencia et al., 2019; Arshad et al., 2020) because the digital space is perceived as a safe and trusted environment (Valencia et al., 2019). Moreover, the internet offers a virtual space largely free of face-to-face interaction, which often poses a stressful demand on individuals with ASD (Pinchevski and Peters, 2016).

1.1.1. New media for clinical diagnosis

The use of new technologies for clinical diagnostic purposes has also been discussed and investigated. For example, Alcañiz et al. (2022) successfully used an eye-tracking paradigm in a virtual environment to differentiate between children with ASD and TD children based on visual attention behaviors. Visual attention was used to measure perceiving and extracting socially relevant information. With regard to the diagnostically very relevant area of mimic expression, Forbes et al. (2016) indicate the feasibility of 2D-virtual reality (VR) in eliciting mimicry, thus confirming that participants with ASD imitate less than TD individuals when interacting with avatars. In sum, the results suggest that the behavior that people with ASD exhibit in face-to-face situations – e.g., in diagnostic settings – might be equally present when they interact with and respond to avatars (Forbes et al., 2016). This parallelism of behavior in real and virtual environments has been coined *media equation* (Reeves and Nass, 1996; Lee, 2008) and opens further potentials for the implementation of digital media in (automated) diagnostic or screening approaches.

1.1.2. New media for clinical intervention

Some authors proposed the effectiveness of new and especially immersive technology even for clinical intervention (Valentine et al., 2020; Robles et al., 2022). The term immersion describes a mediated experience in which the sense of mediation vanishes, and the experience feels as if being real (Biocca, 2002). For example, a VR system was evaluated to improve emotional skills in children with ASD (Lorenzo et al., 2016). In addition, interactions with autonomous virtual humans were successfully evaluated to help children with ASD in learning social skills (Milne et al., 2018). A systematic review by Cheng and Bololia (2023) examined whether augmented reality (AR) supports children with ASD in developing or promoting social skills. Findings suggest the effectiveness of AR e.g., for recognition of facial expressions or social reciprocity in children with ASD (Cheng and Bololia, 2023). The use of video games as therapeutic tools in children with ASD was evaluated in a systematic review by Jiménez-Muñoz et al. (2022). The reviewed studies show that video game-based therapeutic interventions are generally effective with small effect sizes, and helpful in the development of children with ASD. For example, they show a decrease in repetitive movements after intervention with exergames in children with ASD (Jiménez-Muñoz et al., 2022). Exergames are video games that require physical movement to play (Benzing and Schmidt, 2018).

1.1.3. Media for educational purposes

Complementary or additive to intervention approaches, the use of mobile and interactive learning technologies – so-called *lean forward-media* in contrast to *lean back-media* (e.g., TV) – in the education of older children with ASD has grown impressively (Stathopoulou et al., 2020). Several studies have suggested that usage of such modern technology can facilitate learning of individuals with ASD (Valencia et al., 2019). Some interesting examples of new technology include sensors, VR, virtual agents, and AR (Valencia et al., 2019). Studies show the potential of AR to support children with ASD in school, especially for participation and learning (Hashim et al., 2021; Assis Freire de Melo et al., 2022). Finally, studies have investigated the use of technology and computer-based interventions to teach language and social skills to individuals with ASD (Grynszpan et al., 2014). The results of these investigations provide evidence for the overall effectiveness of technology-based training (Grynszpan et al., 2014). There is also good evidence that computer-based learning is both acceptable and potentially beneficial for children with ASD (Lin et al., 2013).

1.1.4. Self-selected media use and the debate of negative effects

As summarized above, technology and media have been successfully used for clinical (diagnosis and intervention) as well as educational purposes for children with ASD. Most of the authors hereby refer to the assumption that children with ASD are especially attracted to digital media but consistently refrain from evaluating this assumption. Possibly, research on this topic is still sparse because media usage and ASD research is a relatively new matter (see Stiller and Mößle, 2018), but there is a risk that the assumption has simply been nurtured by the observation of social avoidance in a population with ASD and the assumed potential for compensation through virtual environments. Despite the ubiquitous impact of media in the childhood of today's adolescents, an analysis of the literature over the past 5 years revealed limited research output addressing media use in everyday lives of individuals with ASD: one systematic review (Stiller and Mößle, 2018) and two additional studies that provide insights into the media usage of children with ASD (Lane and Radesky, 2019; Laurie et al., 2019).

Most informative is the systematic review by Stiller and Mößle (2018) on media usage by children and youths with ASD. Forty seven studies from the years 2005 to 2016 were included to determine the significance of media in the lives of these children and adolescents. Consistent across all studies, screen-based media was a preferred leisure activity of children with ASD. The most popular medium was television, followed by playing video or computer games. However, other leisure activities (e.g., outdoor play) were neglected due to the preference for screen media as a leisure activity. Compared to TD children, the studies reported mixed evidence on screen media use. However, children with ASD spent significantly less time using social media than children without ASD. Stiller and Mößle (2018) were able to identify both positive and negative effects as a result of screen media use. For example, positive effects were seen in improved social, motor, and cognitive skills, whereas negative effects manifested in less sleep, less physical activity, oppositional behavior, and problematic media use. However, as the vast majority of the reviewed studies were conducted in North America, Stiller and Mößle (2018) highlight a research gap for several European countries, including Germany, where media usage differs and is also criticized more often. In Germany, only the large-scale and regularly conducted survey Childhood, Internet, Media (*Kindheit, Internet, Medien;* KIM), which has been conducted regularly since 1999, is available. The KIM study examines the value of media in the everyday lives of a representative sample of German-speaking children (ages 6 to 13; Feierabend et al., 2021). Since 2006, the KIM study has been conducted every 2 years. However, this study reports on children in Germany in general and does not differentiate between different clinical populations, so there is no disaggregated data on children with ASD.

One of the few European-based approaches stems from Laurie et al. (2019) who report online survey data from 388 parents of children with ASD in the UK ($n = 131$), Spain ($n = 134$), and Belgium ($n = 123$). The study addresses the overarching question of how children and older individuals with ASD use technology at home. Participants were split into five groups based on the respective age (≤5, 6–12, 13–17, 18–25, ≥26 years). The online survey–which ran for approximately 2 months in each country–collected the parent's demographics, child profiles, information about technology use at home, and attitudes toward technology use. The most commonly reported devices available were tablets and PC/laptops, whereas digital games, YouTube, listening to music, and looking at or taking photos were the most commonly reported functions of technology use already 5 years ago. The study provides evidence that adults and children with ASD were competent in the use of a wide variety of devices and interface types. In addition, the study reported that parents might be concerned about their children's use of technology, particularly the amount of time spent with devices and subsequent social consequences (Laurie et al., 2019). Regarding the specific (and already very heterogeneous) characteristics of individuals with ASD, it is important to examine media use data specifically for a population without comorbidities.

The implementations and evidence of effectiveness in diagnostics, intervention, and learning contexts described above can be seen as positive effects of media affinity in children with ASD. They exploit the potential of new technologies to adapt new offerings to the needs of individuals with ASD or to adapt existing approaches. At the same time, potential negative effects must be equally included in the analysis of media use. These have been touched upon in previous research and include problematic use of media and possible links to the intensity of autistic symptoms. Lane and Radesky (2019) hypothesize in a brief report that children with ASD may be at higher risk for problematic media use with portable and interactive media devices. Here, problematic media use means high levels of media use that crowd out sleep, exercise, homework, or play. The authors claim that no study found a definitive connection between early media consumption and the occurrence of ASD, referring to a debate that occurs again and again in social media as well as in the scientific community, namely whether high media consumption could exacerbate or even trigger symptoms of ASD. Impetus for this debate was recently provided by a study by Dong et al. (2021) who examined the screen time of 57 TD children and 101 children with ASD in detail. Their results support previous findings that screen time was significantly longer in the group of children with ASD than in the group of TD children. In their analyses, the ASD-related symptoms became more pronounced with increasing screen time (Dong et al., 2021). Some authors use evidence such as this to claim that media exposure might even cause ASD (Slobodin et al., 2019; Dong et al., 2021). As a consequence, concern about early exposure to screen media and its potential impact on developmental delays including ASD is expressed (Heffler et al., 2022). Nevertheless, the described findings do not provide any information on the direction of a possible causal relationship, which remains unclear. Longitudinal investigations are needed such as the study by Heffler et al. (2020), who examined the association between screen media exposure and risk for diagnosed ASD or ASD-related symptoms in children at 2 years of age. Their finding among a large sample of 2,152 children was that less TV and video exposure and more interactive caregiver-child play at age 1 year were associated with fewer ASD-related symptoms at age two (Heffler et al., 2020). Nevertheless, other study results suggest that the premise of the named authors may be a fallacy since children with incipient social communication problems, such as those with ASD, simply seem to be more likely to prefer object-based play, which includes television and digital devices (Lane and Radesky, 2019). However, studies show that the symptoms of ASD are associated with high and early media use (Heffler et al., 2020; Krishnan et al., 2021). The question of a causal link or effective use of digital media to support ASD seems premature given the sparse knowledge base regarding everyday use of media in individuals with ASD. This study aims to provide insight on this topic.

1.2. Research questions and hypotheses

Our literature review indicated that research on the topic of media use in children with ASD was still sparse and data on children with ASD in Germany were missing (Stiller and Mößle, 2018). In the general population, there was an exponential increase in the use of media devices by children already during elementary school age (Spina et al., 2021), also in Germany (Feierabend et al., 2021). This was the age period in which ASD typically should already be diagnosed (van't Hof et al., 2021). A meta-analysis including 35 studies ($n = 66{,}966$ individuals with ASD) found a current mean age of 60.48 months (5.5 years) for the initial diagnosis of ASD (range: 30.90 to 234.57 months; van't Hof et al., 2021). Therefore, most children at 6 years of age and older were likely to have a valid diagnosis of ASD. Since sex differences in ASD were vast (Elsabbagh et al., 2012; Jiménez-Muñoz et al., 2022; Zeidan et al., 2022) and not yet fully understood (Hull et al., 2020), boys and girls with ASD should be considered separately. To take a further step into informing about media usage in individuals with ASD compared to TD children, we were proposing the following research question:

How does the media use of boys with ASD age 6 to 11 differ from the media use of TD boys in Germany?

Specifically, we expected (1) boys with ASD to use digital media at significantly higher rates (Dong et al., 2021; Krishnan et al., 2021). Furthermore, we assumed (2) different usage motives between boys with ASD and TD boys (e.g., Lane and Radesky, 2019). We expected that boys with ASD would be less likely to use media for social purposes than TD boys (e.g., Stiller and Mößle, 2018). We also hypothesized (3) that confidence in using digital media, enjoyment of digital media, a sense of non-mediation or *being there* while being involved with new media (so-called *presence* or *immersion*; Biocca, 2002), parents' ratings about their child's digital media behavior, and parents' perceptions of difficulty of restricting their child's media use differ between children with ASD and TD children. We expected higher scores in parents' assessments of children with ASD.

2. Method

2.1. Participants

Families with children diagnosed with ASD were recruited at an autism therapy facility in a German metropolitan area in spring 2023 in the context of a superordinate research project on the medial elicitation of ASD-associated symptoms (IDEAS). Children participated in a pilot testing to evaluate suitability of media usage formats for screening purposes. In addition, parents answered a questionnaire on media usage the results of which were reported in the current study. For the TD group, participants were recruited using an online survey through private and professional contacts via social media, e-mail distribution lists, and organizations. The target group were boys between 6 and 11 years who were enrolled in elementary school. Although ASD encompassed a wide spectrum on intellectual capacities, the study focused on age-appropriate intellectual abilities that allows comparison with TD. Recruitment resulted in a group of 15 boys with diagnosed ASD with an average age of 8.93 years ($SD = 1.79$). For the TD group, 78 boys at an average age of 8.21 ($SD = 1.57$) were included. According to the parent's report, none of the boys in both groups had an intellectual disability and none in the TD group was ever suspected of a diagnosis of ASD. Regarding socio-economic status (SES), we find higher educational levels in the TD group for both parents (see Table 1).

2.2. Measures

Data on the children's media usage were collected using an online survey for parents. This instrument included questions on the availability of media in the home, the frequency of use of these media, and individual reasons for using digital media. Parents were also asked how confident they perceive their child in using digital media, how much their child seems to enjoy it and the estimated

TABLE 1 Distribution of parents' highest educational degree.

Education degree	Father's highest level of education		Mother's highest level of education	
	ASD group ($n = 14$)	TD group ($n = 78$)	ASD group ($n = 15$)	TD group ($n = 78$)
Less than high school diploma	35.71% ($n = 5$)	19.23% ($n = 15$)	33.33% ($n = 5$)	10.26% ($n = 8$)
High school diploma	57.14% ($n = 8$)	26.92% ($n = 21$)	46.67% ($n = 7$)	24.36% ($n = 19$)
College diploma	7.14% ($n = 1$)	53.85% ($n = 42$)	20% ($n = 3$)	65.39% ($n = 51$)

degree of *immersion* (sense of non-mediation or being *there*) during usage. Finally, parents were asked whether they believe that their child spends too much time on digital media and whether they had difficulties limiting their child's media usage. For most items, a ten-point Likert scale ranging from *not at all* to *very much* was applied. Availability of media in the household was assessed by frequency of media exposure to PC/laptop, tablet, mobile phone, game console, TV, radio/podcast, digital assistants, SMART-Toys (networked toys), and others. Exposure was evaluated on an ordinal scale ranging from *never* (coded as "0"), *sometimes* (once/several times a week; coded as "1") to *often* (every/almost every day; coded as "2"). These item response options have been modified from the KIM study (Feierabend et al., 2021). In addition, reasons for using digital media were examined including: playing entertainment games, playing learning games, viewing photos, taking photos, listening to music/audiobooks/podcasts, watching movies/videos, and chatting/interacting with others and other (open space for text additions).

2.3. Data analysis

Descriptive and statistical analyses were performed using R (R Core Team, 2022, version 4.2.2). For group comparison, Mann-Whitney-U-tests were used concerning availability of media in the home (individual tests per device/application) and the children's reasons for media usage (comparison per individual activity, e.g., playing learning games, chatting...) as well as self-assessment questions to parents (all 10-point scaled). In addition, frequency responses and percentages were considered for each question. Percentage was calculated by dividing the total number of responses for a given question by the number of respondents who participated in that question. To look at possible relationships between the variables, Spearman's correlations were calculated for the 10-point scaled questions. Finally, a two (TD) to one (ASD) manual matching was performed to account for the fact that parents of TD children had higher educational attainment. The matching variables were age, father's, and mother's educational attainment. Comparisons between matched participants were also performed using Mann-Whitney-U-tests. Overall, approximate significances were calculated for datasets with sample sizes >50 and exact significances for sample sizes <50.

3. Results

Table 2 displays the availability of digital media in the home and the reported frequencies of digital media usage. Over 86% of both the ASD and TD group had access to a PC/laptop, tablet, mobile phone, TV, radio/podcast/CD player/audiobook at home. Eighty percentage in the ASD group and over 65% in the TD had a gaming console available at home. The availability of digital assistants and SMART Toys at home varied between 40% and 51% in both groups. In the ASD group ($n = 15$), 86.67% ($n = 13$), and in the TD group ($n = 78$), 87.18% ($n = 68$) had five or more than five different digital media available in the home. There was no significant difference between the two groups in the number of digital media available in the home ($p > 0.05$). Also, Mann-Whitney-U-tests revealed no differences in exposure to each digital medium between both groups ($p > 0.05$).

The children's reasons for using digital media are shown in Table 3. Most Mann-Whitney-U-tests on the individual reasons for using digital media did not reach statistical significance. Significant differences in media use were found for playing entertainment games ($p = 0.007$). The mean score for using digital media to play entertainment games was higher for children with ASD ($M = 1.67$, $SD = 0.49$, $n = 15$) than for TD children ($M = 1.14$, $SD = 0.69$, $n = 76$). According to Cohen (1988, 1992), this effect was small ($r = 0.29$).

Mann-Whitney-U-test between groups was calculated with each individual parent self-report question about their children and media (see Table 4). Here, only the variable that the parents have difficulties limiting their child's media usage became statistically significant ($U = 285$, $z = -3.20$, $p = 0.001$) with a moderate effect ($r = 0.33$). The mean score was higher for children with ASD ($M = 4.93$, $SD = 2.84$, $n = 15$) than for TD children ($M = 2.57$, $SD = 2.11$, $n = 77$).

Table 5 displays correlations between the self-assessment questions to parents about their children and media. Significant correlations were found between assessment of the child's confidence in using digital media and enjoyment of digital media usage ($p < 0.001$), as well as belief that their child spends too much time using digital media ($p = 0.028$). Furthermore, significant correlations occurred for enjoyment of digital media usage and immersion ($p < 0.001$) as well as belief that their child spends too much time using digital media ($p < 0.001$) and between the latter two ($p = 0.006$). Moreover, there was a significant correlation between belief that their child spends too much time using digital media and difficulties limiting their child's media usage ($p < 0.001$).

To control for the higher SES in the TD group, a 2:1 manual matching was performed on age, father's and mother's educational attainment (see Supplementary Table 1 for details). After the matching, the mean difference for father's educational attainment was reduced from 0.64 to 0.12 and for mothers from 0.68 to 0.56. Consequently, educational attainment of the fathers in the matched dataset no longer differs, mothers in the ASD group are still less

TABLE 2 Availability of digital media in the home and frequency of use (children with ASD: $n = 15$, TD children: $n = 78$).

Digital media	Group	Available at home	Never used	Sometimes used	Often used	U	z	p
PC/Laptop	ASD	93.33% ($n = 14$)	42.86% ($n = 6$)	28.57% ($n = 4$)	28.57% ($n = 4$)	403	−1.55	0.122
	TD	98.72% ($n = 77$)	60% ($n = 45$)	30.67% ($n = 23$)	9.33% ($n = 7$)			
Tablet	ASD	93.33% ($n = 14$)	0% ($n = 0$)	50% ($n = 7$)	50% ($n = 7$)	416.5	−1.13	0.26
	TD	94.87% ($n = 74$)	12.5% ($n = 9$)	48.61% ($n = 35$)	38.89% ($n = 28$)			
Mobile phone	ASD	93.33% ($n = 14$)	35.71% ($n = 5$)	28.57% ($n = 4$)	35.71% ($n = 5$)	514	−0.21	0.834
	TD	100% ($n = 78$)	27.63% ($n = 21$)	50% ($n = 38$)	22.37% ($n = 17$)			
Game console	ASD	80% ($n = 12$)	41.67% ($n = 5$)	33.33% ($n = 4$)	25% ($n = 3$)	343	−0.93	0.351
	TD	65.39% ($n = 51$)	28.57% ($n = 14$)	34.69% ($n = 17$)	36.74% ($n = 18$)			
TV	ASD	93.33% ($n = 14$)	7.14% ($n = 1$)	35.71% ($n = 5$)	57.14% ($n = 8$)	453.5	−0.21	0.832
	TD	88.46% ($n = 69$)	7.46% ($n = 5$)	38.81% ($n = 26$)	53.73% ($n = 36$)			
Radio/Podcast/CD player/Audio-books	ASD	86.67% ($n = 13$)	16.67% ($n = 2$)	58.33% ($n = 7$)	25% ($n = 3$)	386	−0.02	0.982
	TD	92.31% ($n = 72$)	28.13% ($n = 18$)	35.94% ($n = 23$)	35.94% ($n = 23$)			
Digital assistants (e.g., Alexa)	ASD	46.67% ($n = 7$)	28.57% ($n = 2$)	14.29% ($n = 1$)	57.14% ($n = 4$)	87	−1.38	0.233*
	TD	48.72% ($n = 38$)	47.22% ($n = 17$)	27.78% ($n = 10$)	25% ($n = 9$)			
SMART toys (web-connected devices)	ASD	40% ($n = 6$)	16.67% ($n = 1$)	66.67% ($n = 4$)	16.67% ($n = 1$)	66	−1.81	0.069*
	TD	51.28% ($n = 40$)	67.57% ($n = 25$)	13.51% ($n = 5$)	18.92% ($n = 7$)			

Due to individual missing values, the sample size for the frequency of digital media use data differs in part from the sample size for the availability media devices in the home. The exact sample sizes can be found in the respective columns. *Exact significance ($n < 50$).

educated than in the control group (see Supplementary Table 2 for details). Analyses with the matched sample mainly confirm the group differences reported above. However, the use of smart toys was statistically significant in the Mann-Whitney-U-test with the matched dataset ($p = 0.007$) with a strong effect ($r = 0.55$). Boys with ASD ($M = 1$, $SD = 0.63$, $n = 6$) show higher exposure to SMART Toys than TD boys ($M = 0.29$, $SD = 0.73$, $n = 14$). Significant differences in media use for playing entertainment games with a higher mean score for children with ASD (ASD: $M = 1.67$, $SD = 0.49$, $n = 15$; TD: $M = 1.24$, $SD = 0.64$, $n = 29$) was also found in the matched dataset ($p = 0.043$). This effect was moderate ($r = 0.32$). On the parent self-report question about their children and media, a statistically significant difference in parents having difficulty limiting their child's media use was also found in the matched dataset ($U = 130$, $z = -2.20$, $p = 0.027$) with a moderate effect ($r = 0.33$). The mean score in the matched dataset was also higher for children with ASD ($M = 4.93$, $SD = 2.84$, $n = 15$) than for TD children ($M = 3.03$, $SD = 2.46$, $n = 29$). The detailed results of the analyses with the matched dataset can be found in the Supplementary Tables 3–5.

4. Discussion

4.1. Group differences

The present study aimed to evaluate media usage of school-aged boys with ASD in comparison to TD boys in Germany. Therefore, we assessed the availability of digital media in the home and frequency of digital media use as well as the individual reasons for using digital media and further media use issues. An additional question surveyed a possible concern of the parents regarding their children's media usage. Our findings show that over 86% of all the participating families had five or more than five different digital media available in the home. However, the number of digital media did not differ significantly between children with ASD and TD children. This shows the growth of digital media in society (e.g.,

TABLE 3 Reasons for using digital media as named by parents across both groups (children with ASD: $n = 15$, TD children: $n = 78$).

Child uses digital media to...	Group	Never used	Sometimes used	Often used	*U*	*z*	*p*
Play entertainment games	ASD $n = 15$	0% ($n = 0$)	33.33% ($n = 5$)	66.67% ($n = 10$)	337.5	−2.72	0.007
	TD $n = 76$	17.11% ($n = 13$)	51.32% ($n = 39$)	31.58% ($n = 24$)			
Play learning games	ASD $n = 14$	0% ($n = 0$)	64.29% ($n = 9$)	35.71% ($n = 5$)	441	−1.16	0.247
	TD $n = 75$	6.67% ($n = 5$)	69.33% ($n = 52$)	24% ($n = 18$)			
View photos	ASD $n = 13$	23.08% ($n = 3$)	46.15% ($n = 6$)	30.77% ($n = 4$)	442	−0.62	0.536
	TD $n = 75$	18.67% ($n = 14$)	66.67% ($n = 50$)	14.67% ($n = 11$)			
Take photos/videos	ASD $n = 13$	15.39% ($n = 2$)	53.85% ($n = 7$)	30.77% ($n = 4$)	351	−1.78	0.076
	TD $n = 74$	28.38% ($n = 21$)	62.16% ($n = 46$)	9.46% ($n = 7$)			
Listen to music/podcasts/ audiobooks	ASD $n = 15$	13.33% ($n = 2$)	33.33% ($n = 5$)	53.33% ($n = 8$)	643.5	−0.91	0.361
	TD $n = 76$	3.95% ($n = 3$)	32.9% ($n = 25$)	63.16% ($n = 48$)			
Watch movies/videos	ASD $n = 15$	6.67% ($n = 1$)	26.67% ($n = 4$)	66.67% ($n = 10$)	435	−1.59	0.113
	TD $n = 75$	0% ($n = 0$)	60% ($n = 45$)	40% ($n = 30$)			
Chat/interact with others	ASD $n = 15$	60% ($n = 9$)	33.33% ($n = 5$)	6.67% ($n = 1$)	488.5	−0.6	0.547
	TD $n = 71$	69.01% ($n = 49$)	23.94% ($n = 17$)	7.04% ($n = 5$)			

Spina et al., 2021) and its omnipresence in the life of school-aged children independently of ASD. Children in both groups have the device categories (1) PC/laptop, (2) tablet, (3) mobile phone, (4) game console, (5) TV, (6) radio/podcast/CD player/audiobook most often available at home. This is in line with the findings of the German KIM study (Feierabend et al., 2021). However, our hypothesis that boys with ASD use digital media at significantly higher rates as was reported previously (Dong et al., 2021; Krishnan et al., 2021) could not be confirmed both in unmatched as well as matched dataset. However, in the matched dataset, children with ASD used SMART Toys at higher rates than TD children.

The observed group difference in playing entertainment games revealed a small effect in the unmatched and a moderate effect in the matched dataset, indicating a robust finding. Thus, boys with ASD are more likely to use digital media to play entertainment games than TD boys. Possibly, children with ASD prefer spending time and enjoy themselves with digital media rather than with their peers. This interpretation is supported by findings that children with ASD prefer digital media as a leisure activity over other leisure activities such as outdoor play (Stiller and Mößle, 2018). Since the survey did not specifically ask for preferences of media time over social contact, no well-founded statements can be made about this at this point. Overall, we could not show that the reasons for using media differed between the two groups. Therefore, the second hypothesis, that the usage motives differ between boys with ASD and TD boys (e.g., Lane and Radesky, 2019) could not be confirmed either.

Nevertheless, the third hypothesis could only be confirmed in parents' perceptions of difficulty of restricting their child's media use. Both, in the unmatched and the matched dataset the effect was moderate, so this finding is also robust. The other group differences were not significant. One explanation could be the high standard deviations across both groups. For example, standard deviations are highest for reported immersion and are especially high in the ASD group. Since immersion is a mediated experience in which the sense of mediation vanishes and the experience feels as if being real (Biocca, 2002), it is difficult for parents to assess this. However, parents' report of confidence in using digital media, enjoyment of digital media, parents' ratings about their child's digital media behavior, immersion, and parents' perceptions of difficulty of restricting their child's media use is higher among the ASD group.

Overall, we have no indication that ASD children use digital media more frequently and for different reasons than TD children,

TABLE 4 Parents perception of their children media usage across both groups (children with ASD: $n = 15$, TD children: $n = 78$).

Parents perception …	Group	*M (SD)*	Total: *M* (*SD*)	*U*	*z*	*p*
Of child's confidence in using digital media	ASD	7 (2.45)	6.45 (2.16)	492	−0.98	0.329
	TD	6.45 (2.07)				
Of child's enjoyment of digital media usage	ASD	9.53 (0.64)	8.81 (1.75)	468.5	−1.32	0.189
	TD	8.81 (1.75)				
Of child's immersion during digital media use	ASD	7.33 (3.29)	7.02 (2.72)	510	−0.72	0.472
	TD*	7.1 (2.57)				
That their child spends too much time with digital media	ASD	6.2 (2.46)	5.32 (2.61)	459.5	−1.32	0.188
	TD	5.21 (2.65)				
Of difficulty in limiting their child digital media usage	ASD	4.93 (2.84)	2.96 (2.39)	285	−3.20	0.001
	TD*	2.57 (2.11)				

The variables were assessed on a 10-point scale. *$n = 77$.

TABLE 5 Spearman's correlations.

Variable		1	2	3	4
1. Assessing the child's confidence in using digital media	*Spearman's Rho*				
	p-value				
	N				
2. Enjoyment of digital media usage	*Spearman's Rho*	0.41			
	p-value	**<0.001**			
	N	96			
3. Immersion	*Spearman's Rho*	0.04	0.39		
	p-value	0.712	**<0.001**		
	N	95	95		
4. Belief that their child spends too much time using digital media	*Spearman's Rho*	0.22	0.34	0.28	
	p-value	**0.028**	**<0.001**	**0.006**	
	N	96	96	95	
5. Difficulties limiting their child's media usage	*Spearman's Rho*	0.06	0.1	0.11	0.51
	p-value	0.575	0.348	0.315	**<0.001**
	N	95	95	94	95

The variables were assessed on a 10-point scale. Significant *p*-values are in bold.

except for playing entertainment games. Furthermore, our results also show no group differences for parents' reports regarding their child's media usage, except for parents' perceived difficulty of restricting it.

4.2. Study limitations and future research desiderates

The main limitation of the current investigation results from the difference in sample sizes–including the small size of the ASD group–and the partly large reported standardized mean differences. However, children with ASD are a vulnerable target group with a rather low prevalence: approximately 1 in 100 children worldwide has ASD (Zeidan et al., 2022). It is therefore common that recruitment of children with ASD is more difficult than that of TD children. Nevertheless, the dataset should be extended. So far, our data provide a first insight into the use of digital media in school-aged boys in Germany. The fact that there were no group differences for media exposure and reasons for digital media use, may also be a result of the chosen age range (6 to 11 years). With age, the preferences of media and consumption evolve (Feierabend et al., 2021). Although the age range in our study was with 6 to 11 years rather large, small sample size did not allow for separating age subgroups. The sample consist of primary school children only, but we do not know about relevant differences between younger and older children. Other studies on children media usage, however, find the main age gap appearing after primary education in Germany around the age of 11 years (Ritterfeld and Lüke, 2021).

Parents in the TD group are better educated than parents in the ASD group. Recruitment did not particularly emphasize SES. As lower SES is often associated with higher media use time or possibly problematic use behavior (Nikken and Opree, 2018) group differences might at first glance be attributed to SES. However, as parents of children with ASD are also reporting higher concerns regarding and difficulties in limiting their child's media consumption, SES does not seem a valid explanation. This interpretation is confirmed by the analyses in which age and parents' educational attainment was controlled.

Another limitation lies in the method chosen. In the current investigation, we surveyed children's behavior through parents' reporting. Although a study by Wood et al. (2019) shows that parents' and children's judgments of media use were similar, parents may have had a different threshold for the questions and operationalize the values differently for themselves. This may explain some of the high standard deviations. Further studies should also collect data on how parents operationalize too much time with digital media and what they consider to be the threshold for limiting exposure. In addition, when asking whether the child spends too much time with digital media, it should be taken into account that the response might be different for parents who strongly limit their children's media use than for parents without such intention. Conversely, it could be that it is precisely those parents who apply a limitation of media time who are particularly concerned about their children's media use but did not express this due to the item wording in the present study. This could be supported by the correlation between spending too much time with digital media and difficulties in limiting digital media usage. Thus, the items may need to be expanded to include whether and to what extent the child demands time with digital media and what restrictions exist in the individual families. Active demand for the use of digital media could also be considered as an additional variable. In this context, a possible relationship between the frequency of digital media use and the difficulty of restricting should be examined in further studies. In addition, further research should explore the parent's attitudes toward digital media and ASD, e.g., when parents believe that media are the only entertainment for their child that they can provide for him or her. Parents may generally be concerned that children with or without ASD will develop problematic behaviors because of media use. For example, a study by Mazurek and Engelhardt (2013) examined the correlation between video game use and problematic behavior in boys with ASD aged 8 to 18 years. One finding was that problematic game use and role-playing game genre were significant predictors of oppositional behavior, even after controlling for age and time spent playing video games (Mazurek and Engelhardt, 2013). However, this is also debated for (apparently) TD adolescents who are the subject of media attention due to a school rampage.

Taken together and in line with the extensive literature overview, our results suggest that digital media already play an important role in everyday lives of children with ASD. Especially with the increasing use of digital media as well as the development of new media formats, media usage and effects should be continuously explored for children with ASD. Special emphasis should be given to identify formats than can support their needs and account for their disorder-driven barriers. Formats that rather enhance their symptoms should be constrained. Hereby, age is an important factor to be considered. For example, a recent study by Krishnan et al. (2021) shows that children with ASD were exposed to digital media at an earlier age compared to TD children. But it remains unclear whether this tendency is useful or harmful and what the parent's reasons for this decision might be.

4.3. Implications for digital participation in individuals with ASD

In today's world, digital media are an essential factor for social participation as even social communication is often mediated. As Glumbić et al. (2022) recently stated, the great potential of digital participation in the daily lives of people especially with ASD is evident. It is important to emphasize that individuals with ASD are not generally lacking interest in social contact, but rather feel – or are informed subliminally by their counterpart – an inability to adhere to social conventions of exchange (Begeer et al., 2008). The question arises as to what extent this can be achieved more easily in the digital space, and whether digital participation could thus function as a substitute for real-world contacts.

Social-communicative abnormalities are a core aspect of ASD-associated symptomatology. Since corresponding interactional deficits can restrict the children's participation, two possible consequences could arise for the aspect of digital participation: on the one hand, it is conceivable that the corresponding pragmatic deficits could also show up in the digital space and result in comparable interactional restrictions and possibly in exclusion or negative communication experiences. At the same time, however, some research indicates that the children find communication easier or even more successful in the digital setting, when the direct pressure of face-to-face contact is removed (Pinchevski and Peters, 2016). Further investigation of online communication by pragmatically impaired children would be desirable and could potentially have societal and even educational implications. At the same time, digital space for children should not be lightly equated with a safe space, as phenomena such as cyberbullying are unfortunately widespread.

In the introduction above, we highlighted great potential of new media for diagnostics, intervention, and education for individuals with ASD. However, we are just about to explore, develop and capitalize it. For example, mediated social interaction as provided by an avatar may not only be a suitable and economic approach in clinical or educational settings, but may even cater to the specific needs of children with ASD in overcoming typical barriers in face-to-face-interactions while communicating with others. According to the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), health status (disability), body function and structure, contextual factors, and participation are interrelated. Technologies as well as the competence in dealing with digital media as context factors play an important role in the lives of individuals with ASD (Glumbić et al., 2022). For example, Schutt (2018) demonstrated that social communication can be facilitated through digital participation. The Online Lab program applied in the study by Schutt (2018) was designed for children and adolescents aged 10 to 16 years with ASD who have trouble interacting with others, at worst with the consequence of social isolation. However, the effects of the program on the development of social and technical skills were mixed. Although young people with ASD enjoyed participating in this online program and they reported that it strengthened their relationships with others, only four out of seven participants reported improved social participation in daily life, both within and through the program. The study offers some encouragement for improving (everyday) social participation using digital tools but points to the necessity of further research. Specifically, the potential of gamification for motivation, immersion, engagement, and intervention needs to be addressed (Atherton and Cross, 2021). In addition, mobile applications have been shown to be helpful to participate for children with ASD (Wojciechowski and Al-Musawi, 2017) since they can even facilitate communication in everyday activities. For example, the mobile assistance system "Let's Play" aimed to support children with ASD in their process of learning the pronunciation and meaning of new words embedded in everyday communication (Wojciechowski and Al-Musawi, 2017). A preliminary evaluation with two children by the authors raises some hope for more efficient vocabulary learning compared to a corresponding period without the support of an assistive application (Wojciechowski and Al-Musawi, 2017).

Summarized, the presented small study provides an initial insight into the media use of boys with ASD in Germany while allowing a view into the wide field of the importance of digital media in the life of children with ASD. Our research supports findings that digital media are highly attractive to children with ASD, that they use digital media frequently, and are confident in their usage. There is no question that new media are an integral part of the daily lives of children with ASD, as well as concerning educational services, interventions, and screenings. As such, digital media and the digital environment have the potential to enhance the social inclusion of people with ASD.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Ethics Committee, Department of Rehabilitation Sciences, Technical University Dortmund. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

LP, IN, and UR developed the concept for the present study. The literature review and most of the writing were done by LP. IN and LP collected the data. All results were computed by LP and the paper was revised by IN and UR. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fcomm.2023.1224585/full#supplementary-material

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Digital participation and digital education for people with profound and multiple disabilities and complex communication needs

Caren Keeley* and Tobias Bernasconi

Chair for Pedagogics and Rehabilitation for Persons With Intellectual and Profound Disabilities, Department of Rehabilitation and Special Education, Faculty of Human Sciences, University of Cologne, Cologne, Germany

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EDITED BY
Petra Jaecks,
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Ingo Karl Bosse,
Interkantonale Hochschule für Heilpädagogik
(HfH), Switzerland

*CORRESPONDENCE
Caren Keeley
✉ ckeeley@uni-koeln.de

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"Digitalisation" is the buzzword of many societal as well as social changes. Participation in society is increasingly realized digitally, which is why it is important to be involved in these processes and to participate in the digital world. The UN CRPD also assigns an important role to (digital) technology as a prerequisite for inclusion and participation. Universal design, accessibility, assistive technology, and reasonable accommodation should help to avoid exclusion for people with disabilities. People with profound intellectual and multiple disabilities (PIMD), who often have complex communication needs (CCN) in addition to severe cognitive impairments, have fundamentally limited opportunities for participation. These are also visible in the context of digitalisation. At the same time, digital media also offer specific opportunities, particularly for people with PIMD and CCN. Among other things through the combined use of assistive technologies, digital media can significantly facilitate their daily lives. The present paper examines the significance, requirements and challenges as well as the potentials of digital participation and digital education in the lives of adults with PIMD and CCN and presents considerations for the design of digital education for adults. Finally, a conceptual framework for digital education for people with PIMD is presented.

KEYWORDS

digital participation, people with complex communicational needs (CCN), digital literacy, digital education, augmentative and alternative communication (AAC), people with profound intellectual and multiple disabilities (PIMD)

1. Introduction

"The term digital participation refers to the active involvement in digital society through the use of modern information and communication technology (ICT), such as the Internet" (Seifert and Rössel, 2019). In the everyday lives of people without disabilities, there is a tendency toward a fully digitalised living environment in which abstaining from digital technologies becomes increasingly challenging (Moser, 2019), as everyday tasks such as booking doctor's appointments, carrying out banking transactions, buying train tickets but also social communication and participation are becoming progressively carried out online or through digital media. The associated current development is thus a societal process, "in which digital media and digital tools are increasingly taking the place of analog processes and not only replacing them, but also opening up new perspectives in all social, economic and scientific areas, but also bringing with them new questions [...]" as the German Standing Conference [Kultusministerkonferenz (KMK), 2017, own translation] of the Ministers of Education and Cultural Affairs pointed out in a strategy paper.

In this context, digital media have a cross-sectional function that ensures the right to comprehensive participation and digital inclusion for all citizens and thus equally for persons with disabilities. The United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) also contains many references to the right to use media, e.g., Art. 8 (awareness raising), Art. 9 (accessibility), Art. 21 (access to information), Art. 24 (education), Art. 29 and 30 (participation in political, public and cultural life). These legal claims can be met by expanding digital participation opportunities through barrier-free access, which according to Zorn et al. (2012) can be seen in terms of "[...] technical usability, perceptibility with different senses, as well as the comprehensibility of the language and simplicity of the user guidance" (own translation). In addition to the requirements regarding access and accessibility, digital participation for people with disabilities also involves further considerations according to Bosse (2014):

- Participation in media, i.e., how accessible are modern media?
- Participation in the media, i.e., how are people with disabilities portrayed in media and how frequently are they represented?
- Participation through media, e.g., in the form of competent use of modern technologies and media.

So when talking about digital participation, it is necessary to consider a variety of aspects that can influence it. These include, for example, access possibilities, functionalities, support needs, etc. In order to be able to take individual participation needs into account in addition to necessary structural measures, expanded possibilities are needed, which can be realized above all through educational and empowering offerings, because "in a mediatised society, education with, about and through media is fundamental for social belonging and participation" (Zorn et al., 2012, own translation). Digital education thus contributes to participation and equal opportunities and is therefore an overriding and important component of digital participation. For people with profound intellectual and multiple disabilities (PIMD) and complex communication needs (CCN), this presents special challenges, as these people acquire their surrounding world primarily through basal-perceptive and active approaches, which are still (too) little considered in digital and even educational contexts, which is why this article attempts to meet both requirements and explicitly develop possibilities for this group of people. After giving a brief description of the living conditions of people with PIMD and CCN, we will outline the state of research and describe the advantages, barriers and potentials of digital technologies for these people before outlining conceptual considerations.

2. Digital participation of people with intellectual disabilities and profound intellectual and multiple disabilities

2.1. Advantages and disadvantages of digital media for people with ID and PIMD

People with PIMD are an extremely heterogeneous group that is not clearly defined in the international discourse. Instead, there are different attempts to describe the persons.

Dins and Keeley (2022) summarize: "Most descriptions of this group of persons refer to medical classifications." The latest and 11th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-11) include the following key characteristics: "A profound disorder of intellectual development is a condition (…) characterized by significantly below average intellectual functioning and adaptive behavior that are approximately four or more standard deviations below the mean."

Thus, the group of persons with PIMD consists of people with a profound intellectual disability (ID) in combination with severe motor disabilities (Nakken and Vlaskamp, 2007). Additionally, they commonly experience severe communication disabilities, sensory disabilities, and they often have complex health needs (Doukas et al., 2017). This is also in line with the definition of the group given by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), which describes these individuals as "a heterogeneous group. They are characterized by very severe cognitive, neuromotor and/or sensory disabilities, which lead to very intensive support needs" Bernasconi (2007). These support needs manifest across all domains of daily life, so that a common characteristic of this group of people is that they "typically require daily support in a supervised environment for adequate care" (Dins and Keeley, 2022).

All of these various congenital conditions (e.g., autism, cerebral palsy) in addition to acquired disabilities (e.g., amyotrophic lateral sclerosis, stroke) and contextual factors (e.g., lack of augmentative and alternative communication (AAC) tools or lack of expertise in their use) lead to complex communication needs: "People with PIMD experience extensive problems in communication. Language is limited or non-existent and communication may include very subtle cues including physiological signals such as a rise in body temperature or change in level of alertness" (Wessels and van der Putten, 2017). This poses particular challenges for support, because "due to the fact that these signals are highly individual, the number of those interaction partners who are actually capable of understanding and appropriately reacting to these signals is very restricted" (Engelhardt et al., 2020). Thus, in all considerations on the design of participation opportunities, a person-centered approach must be taken into account, which carefully considers the communicative and cognitive abilities of each individual with PIMD. It is particularly significant to regard communication and interaction as an ongoing, responsive process. To facilitate the realization of full and effective participation of people with PIMD, it is imperative to consider not only their individual communication needs but also to ensure that their supportive environment adopt a responsive and interactive stance toward these needs.

Therefore, it can be stated that successful and functional communication capabilities represent a key to participation in all social and societal areas, which is particularly evident in the context of digitalisation, since digital media are primarily communication media. Bosse et al. (2020) state, that people with CNN face additional barriers that prevent them from using the Internet and social media more extensively. Consequently, Kleinert (2020) states that if there is no possibility of communication with, via and in digital media, exclusion and disadvantage are often the result.

Findings on the use of digital media and on the possibilities of digital participation of people with (intellectual) disabilities are currently still a desideratum, even though there is an increase in studies that also take this group of people into account (Caton et al., 2022). Basically, it can be stated that "existing surveys examining Internet access and use often exclude persons with intellectual disabilities due to questions not being cognitively adapted. Therefore, knowledge about access to and use of the Internet comparing adolescents with intellectual disabilities with young people without intellectual disabilities is limited (Chadwick et al., 2013, 2017; Alfredsson Ågren et al., 2020).

The studies that also consider the group of adults with ID highlight potential benefits as well as risks. For instance, Chadwick et al. (2013) found in their study that older people and people with cognitive, physical or sensory impairments in particular experienced difficulties in using digital media or the internet. Alfredsson Ågren et al. (2020) conducted a comparative study between young people with and without disabilities and concluded that internet use differs significantly between the two groups: "The results reveal that a significantly lower proportion of the 114 participating adolescents with intellectual disabilities had access to internet-enabled devices and performed internet activities, except for playing games, than the reference group ($n = 1{,}161$)."

Advantages are highlighted in terms of personality development through self-expression and self-awareness (Steinfield et al., 2008; Caton and Chapman, 2016). Furthermore, opportunities for expanding social contacts and interactions are seen. Löfgren-Mårtenson (2008) describes the social internet as a new "free zone" for people with intellectual disabilities for socialization and personal development without constant control by caregivers.

These positive aspects are contrasted in other studies with aspects around the so-called digital divide (see below), which means that the potential benefits can often not be accessed at all due to structural difficulties (Chadwick et al., 2013). Caton and Chapman (2016) also confirm that although people with ID do have positive experiences with social media but generally have fewer opportunities to access them. A study examining the use of Facebook by individuals with intellectual disabilities identifies potential advantages, including interaction with others, self-presentation, expanding social networks, and equal participation. However, it also acknowledges the limited access opportunities both in terms of content and technology (Shpigelman and Gill, 2014).

In addition to the identification of positive aspects, there seems to be a tendency to regard people with ID as particularly vulnerable and in need of support in view of the potential risks. In this context, it should be questioned whether the risks associated with internet use apply exclusively to people with ID or whether they are not general risks in the use of social media or the internet? Accordingly, Borgström et al. (2019) also ask whether a protective approach to the internet might also become a barrier to access.

Seale (2014) discusses how potential risks can be reconciled with the simultaneous advantages of modern digital technologies and argues for an approach that also sees risks as positive potential for development. Accepting and dealing with risks can then ultimately lead to acquiring enhanced competences in digital media and gaining more control over one's own (digital) life. Therefore, the avoidance of risks should be considered secondary to the developmental potentials that arise in the use of social media by people with ID: "the potential benefits outweigh the potential harm" (Seale, 2014).

The increasing pervasion of everyday life by and through media reveals a division between people who participate in and through media and those who are unable to do so. In the context of internet use, this disparity is commonly referred to as a 'digital divide'. According to Norris (2001) this term refers to a multi-dimensional phenomenon that must be focussed on a global level (i.e., with regard to different countries and their respective access possibilities), on a democratic level (i.e., with regard to a population's opportunities for co-determination and information) and finally on a social level (i.e., on individual possibilities and preconditions for use). For people without access to digital media, this creates new risks of (digital) exclusion. This applies in particular to people with disabilities. These risks arise from a combination of structural preconditions, personal skills and technical conditions.

This is compounded by the fact that "cognitive disabilities are the least understood and least discussed type of disability among web developers. As a result, developers rarely design web content to be accessible to people with cognitive disabilities. This is unlikely to change overnight, because the amount of research related to the accessibility of web content is relatively scarce" (Bohman, 2004).

In addition to internet applications, the field of digital media also includes assistive technologies (AT). These are considered technical aids that are intended to compensate for physical and cognitive impairments for medical-rehabilitative purposes Schüller et al. (2021). Weed et al. (2011) distinguish various categories of assistive technologies, including augmentative and alternative communication (AAC), adapted computer access, devices to assist listening and seeing, environmental control and adapted play and recreation. Thus, there is a close connection between AT and AAC. Especially when combined, these possibilities also represent a significant contribution to compensating for communication and disability-related impairments for people with PIMD and CCN. Through their use, they can, for example, take over the function of speech if the spoken language abilities of an interlocutor are not sufficiently present. Due to their digital tools, digital media already have features that may at first sight not consider assistive technologies in the classical sense, but can be used to support their function, such as speech output or speech recognition (Schüller et al., 2021). Especially access to social media has many advantages for people with CCN, e.g., building and maintaining social relationships, reducing loneliness or opportunities for self-expression (Bosse et al., 2022). AAC media and tools tend to be used as assistive devices from a medical perspective but can also be understood as significant media for communication and information from a media education perspective (Krstoski, 2016). Thus, it can already be stated that the use of tablets has facilitated communication opportunities that did not previously exist in this form. In this manner, these digital technologies are already making a valuable contribution to the inclusion and participation of people with PIMD and CCN. In addition, technological advancements enable participation in social media. Video calling, for example, or camera footage of personal experiences can be seen as a means of articulation. In the context of AAC support, experiences with video-assisted therapy have existed for over 10 years (Hall et al., 2019). So-called tele-AAC as a form of video-assisted therapy provides insights into individual possibilities of digital communication and participation in digital media. In particular, the "on-site facilitator" (Hall et al., 2019) required for tele-AAC can be seen as a possibility for personal participation support. Technical support is provided, such as ensuring the proper positioning of the camera, the (digital) device and the communication aid, while the supporting person can facilitate participation in specific situations or contexts (e.g., by individually responding to situational needs and requirements).

2.2. Barriers to the use of digital media

In addition, the increasing complexity of web applications also creates new barriers for users. For example, the almost infinite amount of information on the World Wide Web represents an easy and low-threshold way of accessing information, but at the same time, it requires individuals to process and utilize this wealth of information cognitively. Phenomena such as 'cognitive overload' or 'getting lost in hyperspace' (Bernasconi, 2007) describe possible difficulties that may arise. Moreover, technical requirements, such as the control of technical devices or reliable internet connections, are possible barriers contrary to the potential of the internet and the possibilities of modern technologies.

Berger et al. (2010) have classified the barriers that affect internet usage in multiple dimensions as follows: application-related barriers (resulting from the design of the application or the technology and/or coding which is used), disability-related barriers (arising from the negative interaction between user limitations and application requirements e.g., missing reading function for people with limited reading ability) and individual barriers (i.e., other aspects such as lack of technical equipment or prior knowledge and limited experience with web 2.0 applications).

More specifically related to the needs of people with ID, Lussier-Desrochers et al. (2017) identify five challenges: [1] access to digital devices, [2] sensorimotor, [3] cognitive and [4] technical requirements and [5] the comprehension of codes and conventions. These five dimensions interact with the person and the conditions of the environment and illustrate the synergy between individual resources and support from the environment.

Since people with ID and especially with PIMD are dependent on (professional) support, attention should also be directed toward the digital competencies of supporting professionals, as well as the institutional structures and services. For example, Hoppestad (2013) was able to show that barriers to participation resulted from the fact that the people providing support did not have sufficient media skills. And Ramsten et al. (2017) demonstrated in their study a "lack of organizational support and comprehensive strategies for the use of Information and Communication Technologies (ICT) in municipal social care for people with intellectual disability."

In this context, Sachdeva et al. (2015) extend the above-mentioned term to the "digital disability divide," which refers to the additional exclusion of individuals with disabilities from the potentials of modern media, due to their often marginalized position in society, lack of economic or educational resources and competencies.

However, it is important to emphasize that while the mentioned studies provide valuable insights, they seldom consider the specific needs of people with PIMD and CCN. Consequently, there is a fundamental lack of knowledge about the possibilities of digital participation for this group of people, and there are only a few studies that put this group of people into perspective at all. Notably, Caton et al. (2022) conducted a study that examined the digital participation of people with profound disabilities during the COVID-19 pandemic in the UK. They conclude that "during the COVID-19 pandemic, there has been a worldwide increase in the use of digital technology. (…) However, the experiences of digital participation or nonparticipation for people with profound and multiple learning disabilities (PMLD) is less understood" (Caton et al., 2022). In this study, Caton et al. (2022) explicitly addressed the internet use of people with PIMD and conclude by identifying potential barriers: "The challenging technical requirements of getting online (Lussier-Desrochers et al., 2017) and the accessibility of websites (Williams and Hanson-Baldauf, 2010; Shpigelman and Gill, 2014) are particular barriers for people with complex needs."

The specific ways and possibilities of communication for people with PIMD increase the problem in two directions: first, adequate ways of communication often have to be explored, and second, they have to be adapted and adjusted to digital contexts. Hoppestad (2007) notes that negative attitudes toward the use of digital media can also significantly limit available opportunities. Copley and Ziviani (2004) also conclude that major barriers include lack of appropriate staff training, negative staff attitudes or difficulties procuring and managing equipment. Furthermore, people with PIMD typically also require personalized access to educational topics that correspond to their learning capabilities. Because they "often have specific sensory and other challenges they need multisensory approaches to communication. The importance of touch for communication (Elliott-Graves, 2021) can suggest that digital connections may not be ideal for people with profound and multiple learning disabilities" (Caton et al., 2022). It is crucial to remain attentive to these exclusionary tendencies and respond with constructive developments and accessible solutions. As Weed et al. (2011) say, "for many individuals with disabilities, however, technology may not be the only solution. Rather, the combination of aided (e.g., mechanical, electronic, and computerized devices) and unaided (i.e., using the body or a body part alone) approaches with high- and low-technology strategies, is essential to provide maximum accommodation."

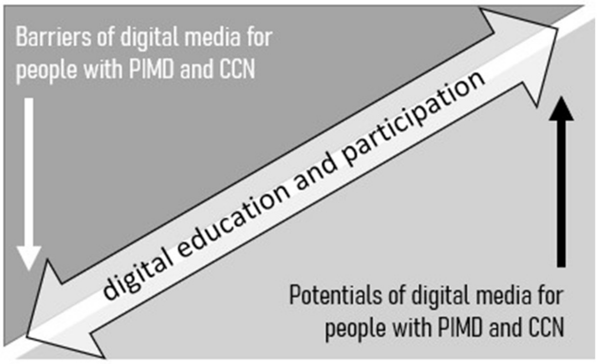

FIGURE 1
Continuum of digital participation and education (own illustration).

3. Summary: potentials of digital media in supporting people with PIMD and CCN

People with PIMD and CCN may benefit from the basic technical characteristics inherent to digital media. Two of the most significant characteristics that should be mentioned here are multimodality and multimediality (Miesenberger et al., 2012). The last enables content to be offered or made accessible equally via different channels, e.g., visual, auditive, haptic, etc. In this way, variants or alternatives can be provided that take into account the respective individual approaches or make the content perceivable in different ways. Multimodality refers additionally to the possible devices, media and tools, i.e., the different possibilities to support technical or digital interaction. This allows, for example, a comprehensive flexibilization and adaptation to the abilities and skills of the users.

The reciprocity between compensating possibilities and simultaneously occurring barriers can be described as a space of possibilities of digital participation. This refers to a spectrum in which challenges and potentials coexist. For example, digital media offer possibilities for both synchronous and asynchronous communication through AT and AAC. At the same time, digital (educational) settings must be designed in such a way that they do not generate new barriers through technical, content-related, or structural aspects.

Digital education through, with and by digital media for people with PIMD and CCN cannot be described as an either/or-situation or as a fixed goal, but rather as an ongoing process in which possibilities and limitations are always defined in relation to technical, content-related and ultimately structural conditional factors. These factors can either act as potential or as barriers, directly influencing the extent of individual digital participation.

The level of digital media acting as barriers directly correlates with limited opportunities for participation, whereas drawing on their potentials corresponds to increased possibilities for individual participation among individuals with PIMD and CCN (see Figure 1).

This means that the more individual aspects act as barriers (descending arrow), the less the advantages of digital technology can be used (ascending arrow). Accordingly, the continuum of digital participation results from the advantages and barriers of the individual life situation. In order to face the barriers and to be able to use the potentials of digital media, i.e., to enable digital participation for people with ID and PIMD, support is needed in terms of enabling and facilitating (digital) participation, which is why educational opportunities, also beyond school contexts, are of utmost importance in this area.

4. (Lifelong) education for people with PIMD

The right to education is a central human right, which was further specified and strengthened in its importance for enabling participation with the ratification of the UN CRPD. Article 24 in particular emphasizes the right to lifelong education, which applies to all people. In the context of schooling (with the following explanations referring to the implementation in Germany), this right is upheld. Children and adolescents with ID and PIMD have the right and the possibility of formal education within specialized educational institutions (special schools) as well as in the context of inclusive education. The same should apply to the post-school sector. However, a significant gap can be identified here, especially for people with PIMD. This gap exists not only regarding general aspects of education but also becomes particularly evident in the context of digital education (Bosse and Haage, 2020; Bernasconi and Keeley, 2021; Bernasconi, 2022). Specifically for the field of digital education, it can be said that it takes place primarily in school settings (Keeley et al., 2022; Heitplatz, 2023) and that extracurricular and post-school settings are only marginally taken into account.

Education understood as a possibility for (self-)empowerment initiated by educational processes (Sjöström and Eilks, 2020) enables individuals to subjectively engage with the world, thus realizing their participation in it. Education occurs through interaction with others and the encountering of different experiences and perspectives, meaning that education takes place through social and cultural participation. Accordingly, education is an indispensable prerequisite of participation and participation is the indispensable prerequisite of education (Keeley, 2018).

People with PIMD often require lifelong support and individualized educational opportunities to be able to actively engage with the world and to participate in education. People with PIMD acquire knowledge and skills primarily through active engagement with objects or through educational settings that address multiple sensorial modalities (Forster, 2010; van der Putten et al., 2011; Bottcher, 2012; Dins and Keeley, 2022). In the context of digital education, this raises implementation challenges, as digital environments generally provide limited opportunities for tactile or other more basal sensorial experiences. Besides, active manipulation is rarely possible. Digital education for people with PIMD therefore needs to address these specific challenges and start from there to foster digital participation.

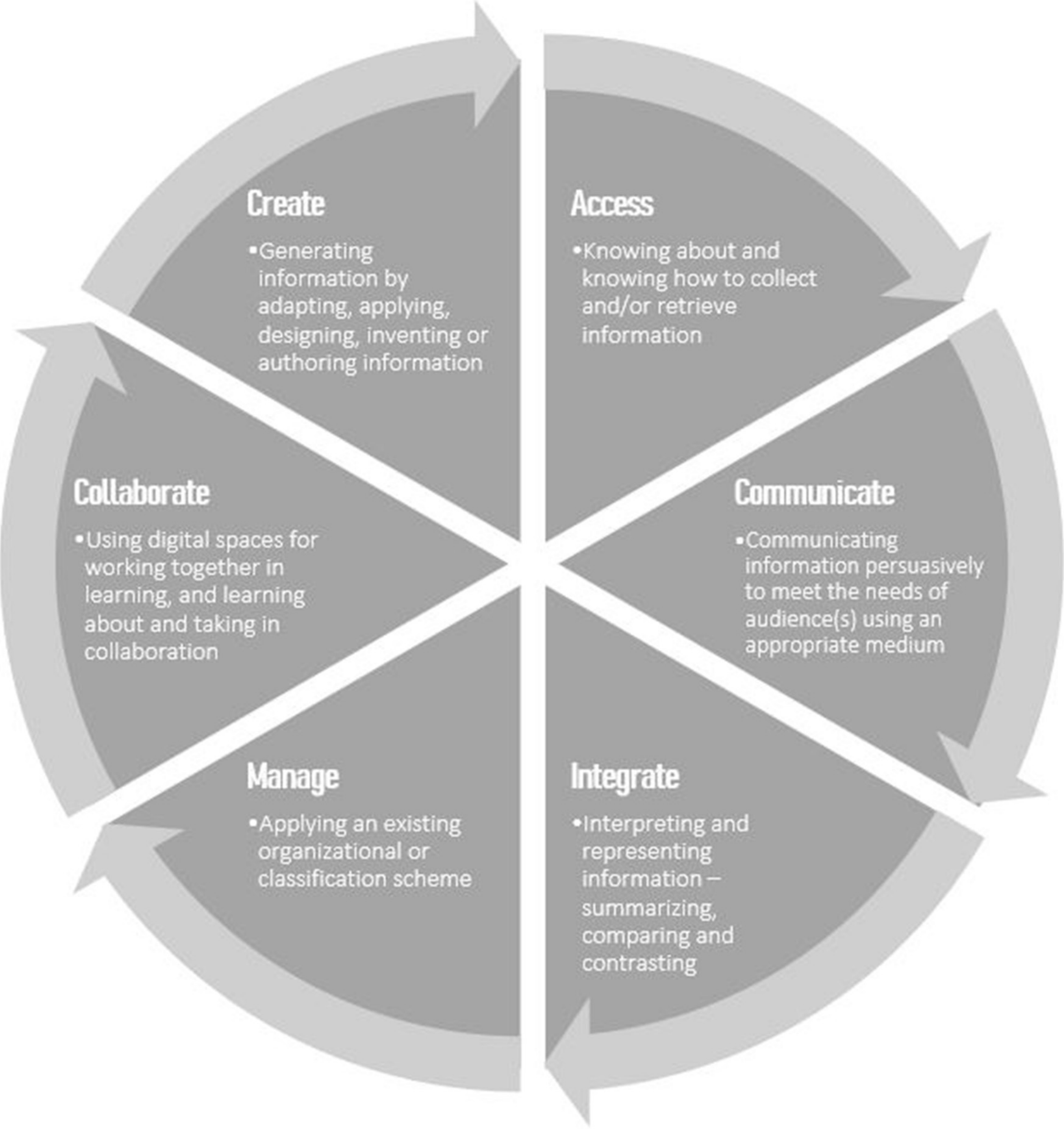

FIGURE 2
Elements of the Digital Literacy Framework (Special Education Support Service, 2014, own representation).

5. Conceptual considerations on digital literacy for people with PIMD and CCN

Based on these considerations on the (lifelong) education of people with PIMD and CCN, there are also necessary requirements or constituent aspects for the field of digital education that should be taken into account when designing digital education offers. In the following, the question of digital literacy of and for people with PIMD and CCN will first be addressed, and then, in a second step, the so-called 4 As will be presented. These are conceptual principles developed by the Committee on Economic, Social and Cultural Rights (CESCR, 1999) as a basis for creating globally valid key elements for the implementation of the rights to education. From the consolidation of these two perspectives, a new conceptual framework is then constituted in a third step, from which criteria for the design of offers of digital adult education for people PIMD (and CCN) can be derived.

5.1. Digital literacy

Digital education as "teaching digital competencies in the sense of enabling people to reflectively use and engage with digital media with the objectives of digital self-determination and autonomy" (Keeley et al., 2021, own translation) requires the use of digital media and the development of corresponding digital competencies. These are also referred to as digital literacy. The UNESCO Institute for Statistics (2018) defines it as follows: "Digital literacy is the ability to access, manage, understand, integrate, communicate, evaluate and create information safely and appropriately through digital technologies for employment, decent jobs and entrepreneurship. It includes competences that are variously referred to as computer literacy, ICT literacy, information literacy and media literacy." This definition focuses primarily on skills that are intended to enable participation in working life and thus only captures a fraction of the significance of digital competencies when considering that they serve as the foundation for digital inclusion across all societal domains. For this paper, we therefore follow the definition of the Irish Special Education Support Service (Special Education Support Service, 2014), which understands digital literacy as "the creation, communication and interpretation of meaning through multimodal digital formats, leading to fuller participation." This broad understanding of digital literacy also explicitly includes people with PIMD and CCN and provides starting points for the design of digital educational settings for this group of persons. To this end, SESS developed the "Digital Literacy Framework" (see Figure 2), which is primarily intended to support teachers in facilitating digital literacy for students with ID and PIMD. The framework focuses on students with moderate, severe and profound levels of learning disabilities who are not literate in the conventional sense (Special Education Support Service, 2014). It delineates a total of six dimensions (access, manage, integrate, collaborate, create and communicate) of digital literacy, which are not hierarchical but rather exist in parallel or are interconnected. It becomes clear that in addition to the "classic" functional skills, a number of other components go hand in hand with digital literacy, so that various starting points for digital education (also) for people with PIMD and CCN can be derived.

5.2. 4As

The 4As scheme, which was developed by by the CESCR (1999) to implement the right to education, is suitable for the design of inclusive education programmes. It provides a framework that identifies four relevant aspects with regard to the design of educational settings and thus ensures the right to, in and through education. As the following figure shows (see Figure 3), these rights are to be achieved by ensuring availability, accessibility, acceptability and adaptability (cf. Tomaševski, 2001):

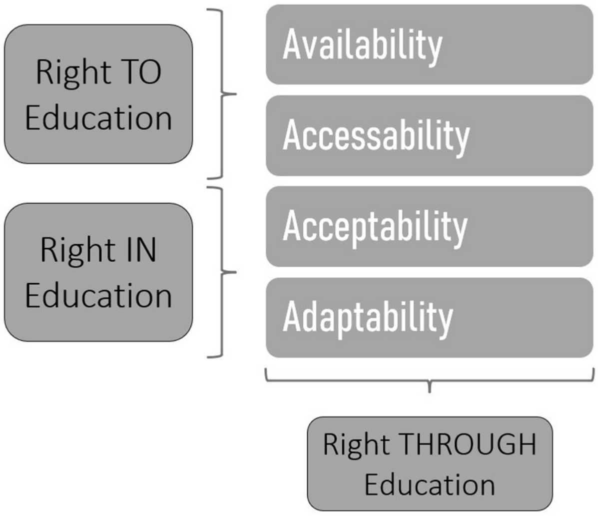

FIGURE 3
4 A Conceptual Framework (Tomaševski, 2001).

The concept can also be profitably applied to adult education, which will be explained in the following.

1. Availability:

First of all, it is important to provide educational opportunities and thus ensure the lifelong right to education. In the context of adult education, there is still a need for significant developments as there is currently a lack of both structural and institutionalized measures, as well as conceptual considerations to foster lifelong education.

2. Accessibility:

CESCR (1999) views accessibility primarily from an economic perspective (Tomaševski, 2001). In relation to people with PIMD, this perspective can be expanded, since in addition to possible financing issues of education services, it is above all questions of mobility and accessibility, reachability and suitable adjustments (e.g., regarding the manner educational content is presented) that can affect this group of people. Accordingly, accessible adult education takes into account different needs and demands, ensures appropriate funding as well as physical reachability and adequate suitable adjustments of the services.

3. Acceptability:

Regarding the acceptability of adult education for people with PIMD, (professional) attitudes and perceptions play a significant role (Copley and Ziviani, 2004; Hoppestad, 2013; Keeley, 2018; Heitplatz et al., 2019). Most providers and services in adult education have limited experience with individuals with disabilities (especially PIMD) and hold reservations toward this target group. The fundamental issue here is the recognition of the right to lifelong education and the claim to a "qualitative" education for people with PIMD.

4. Adaptability:

In order to accommodate the needs and demands of people with PIMD, a person-centered approach must be adopted as the overarching paradigm in adult education. The individual educational needs of the respective person should serve as the starting point for deciding on the content and methodological design of educational services (Dins and Keeley, 2022). At the same time, it is essential to consider relevant topics of adulthood which must inherently guide the identification of educational content. This content must then be prepared in a multimodal and multimethodical manner and take into account the different ways in which people with PIMD acquire knowledge (Nakken and Vlaskamp, 2007; Forster, 2010; Bottcher, 2012; Dins and Keeley, 2022). In this context, digital technologies and multimedia approaches can also assist in effectively meeting the individual communicative and cognitive needs (Grace et al., 2019).

5.3. A conceptual framework for digital education and participation

Basically, there is a lack of (conceptual) approaches to digital adult education for people with PIMD and CCN. The starting points outlined above can be brought together in a conceptional framework (see Figure 4), which encompasses "quality criteria" of digital adult education for people with PIMD (and CCN).

5.3.1. (Digital) availability

Availability refers to the technical infrastructure and structural as well as individual adjustments that address the needs and demands of people with PIMD as well as everybody who uses education services. The potential for empowerment, increased participation and inclusion, which is inherent in digital media, is currently not adequately realized for people with PIMD. These structural barriers in particular prevent participation in and through media and must be considered when designing education services. If we focus on people with PIMD and CCN at this point, a beneficial development can be named: many of these people have an electronic communication aid, which has been increasingly provided in the form of an Ipad for several years (Krstoski, 2016). This means that some of them already have a digital medium and also (basic) digital skills, which can be used as a starting point for extended digital education. However, individual use is still subject to some structural limits (financing, accessibility, etc.) that need to be addressed in the future.

In the context of digital education, it is essential to incorporate specific knowledge about the possibilities, but also the risks and dangers of digital media. Digital education services must customize this knowledge to individual users, considering their unique contexts and circumstances. In addition, at a broader level, it is necessary to incorporate digital perspectives into the mission statements of both service providers and funding agencies, thus ensuring their visibility. Furthermore, adult education programmes and services require fundamental concepts which address not only questions of digital participation but also opportunities to foster digital literacy.

5.3.2. (Digital) accessibility

Accessibility, in this context, primarily refers to the design of education environments, with a particular focus on the individual usability of the utilized media. The potential of the Internet as an audio-visual medium should be emphasized here. At the same time, there is great need for the development of guiding principles with regard to the accessible design of social media. Advancing these conceptual developments and consistently highlighting the existing inadequacies remains an important task. Another framework that can be referenced here is the Universal Design for Learning [Center for Universal Design, 1997; Center

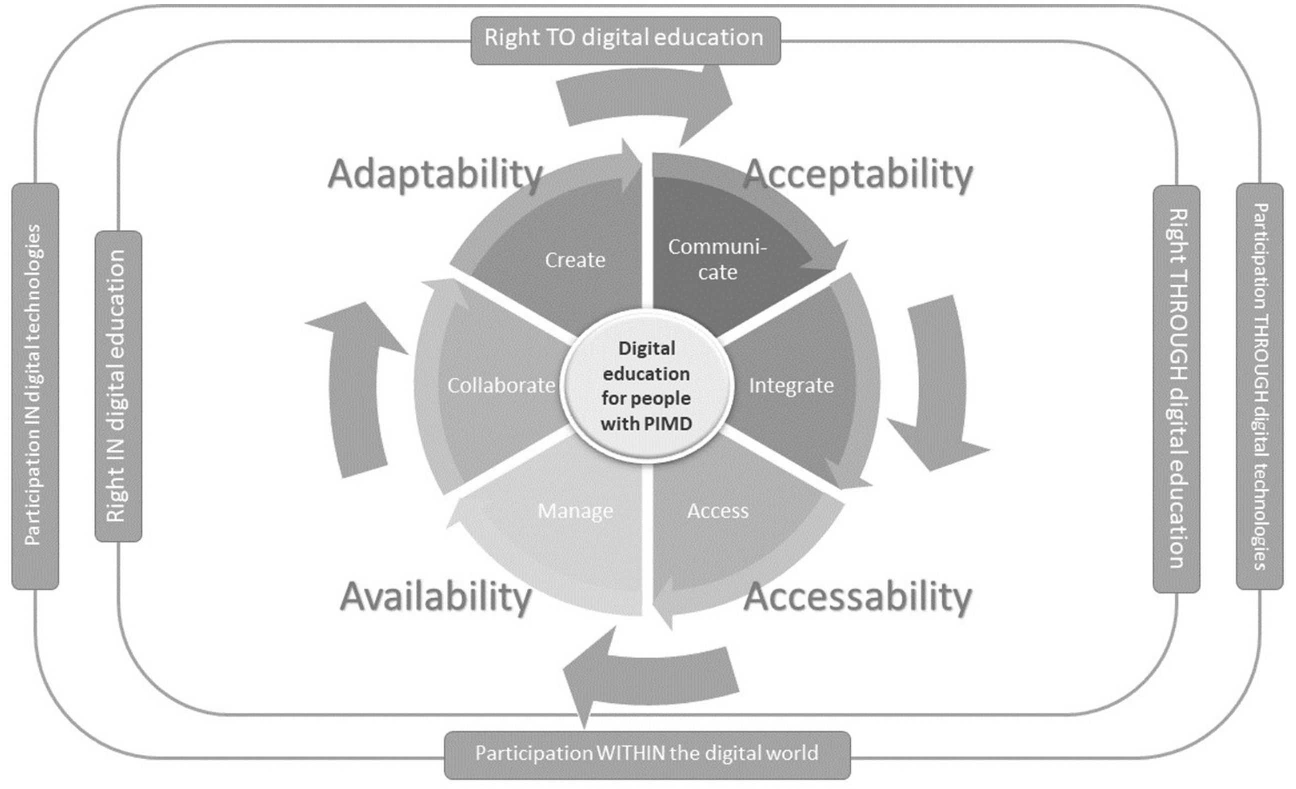

FIGURE 4
Framework of digital education [Own representation with consideration of Tomaševski (2001), Bosse (2014), and Special Education Support Service (2014)].

for Applied Special Technology (CAST), 2018], an initiative which aims at implementing educational environments in a manner that ensures accessibility for a broad range of users. Depending on the cognitive, motor or perceptual functional limitations of the target group, specific adaptations may be necessary, e.g., enhancement of visual contrast, text-to-speech functions, easy language, explanatory videos, etc. Article 2 of the UN-CRPD refers to the concept of ’reasonable accommodation’. Unlike universal design, which is aimed at groups, this concept focuses on the individual case and the specific situation.

According to Bohman and Anderson (2005), possible difficulties that could be encountered with regard to digital accessibility are aspects of “perception and processing” as well as tasks involving “memory, problem-solving, attention.” Based on these problems, general recommendations for the design of digital content are that “content should be simple, consistent, clear, multi-modal, error-tolerant, delay-tolerant, attention-focusing” (Bohman and Anderson, 2005). This means that in order to enable digital participation, people’s individual needs must be considered, and creative and appropriate solutions must be found. It is also important to explore how multimedia design can support the presentation of content through different sensory ways, so that people with limited and basal capabilities can also benefit from digital education through digital media. Specific guidance for people with ID and PIMD can be found, for example, in the “Top 10 Features” provided by the Institute on Disabilities at Temple University in Philadelphia, which offers suggestions for designing digital content for people with ID (Friedman and Bryen, 2008).

With a focus on expanding digital accessibility in the context of communicative impairments, it is important to use existing access and to legitimize these possibilities for all concerned. This means that the use of digital media as a communication aid should be recognized as a necessary support and therefore financed by the public health care system. In terms of language promotion, the use of these digital tools as digital education could contribute to the expansion of individual possibilities of expression and at the same time represent an expansion of social participation opportunities.

5.3.3. (Digital) adaptability

Adaptability focuses on the possibilities of integrating and using assistive technologies as a prerequisite for participation in social media. This entails, for example, ensuring that social media platforms support screen readers, or that digital services facilitate the integration of AAC devices, or to implement the option to navigate through websites via special keyboards or head mice. Another positive development is named by Kversøy et al. (2020) as follows: “The widespread introduction of touchscreen mainstream devices has changed the accessibility of Internet use for some people with more complex needs.” In addition, the development of technology “enables participation in social media, e.g., video telephony via widespread apps or camera recordings of personal experiences as a means of articulation” (Krstoski, 2019; own translation). For AAC and AT users, it is therefore crucial to have digital interfaces for individual communication devices and to provide enhanced visualization options as well as the possibility to use their own control devices such as a mouth mouse or an external special keyboard.

5.3.4. (Digital) acceptability

Acceptability refers to the form and content of digital education. Content should be transformed and adapted to meet the needs of people with PIMD and CCN. At present, many people with disabilities already use digital media, not only to communicate with others, but also to expand their horizons and explore new opportunities. The described possibilities that arise through the use of AAC media (e.g., recording devices, computers, talkers, tablets) in the context of digital participation can be understood not only as communication support, but also as a basis for educational opportunities (Krstoski, 2019). With the help of these devices, the individual educational opportunities and thus also the existing educational space can be expanded (ibid.).

In addition to one’s own participation in the social world, which can be expanded through the use of digital media and functions by people with PIMD and CCN, social media also have an important function for “external representation.” Oriented to the postulate of participation IN digital media coined by Bosse (2014), social media platforms offer the potential to make people with PIMD visible as part of society and to enable them new individual possibilities of representation. It is imperative to increase visibility and expand participation formats.

As an aggregation of the presented considerations on the 4 As from a digital education perspective, the following model has emerged, which offers a conceptual framework of digital education.

The framework encompasses the contextual factors to consider when designing digital education services and programmes and relates the considerations of digital literacy to the legal entitlements for (digital) education and participation. The framework can serve as a fundament for the design of services and programmes of digital adult education. In addition to structural requirements, which primarily concern the perspectives of availability and accessibility, the requirement to condense educational content in a way that takes into account both age-appropriateness and subjective relevance poses a significant challenge, as does the methodological processing and design of such content. As described, further challenges arise regarding acceptability when it comes to preparing services in such a way that they meet the needs and requirements of people with PIMD and their ways of acquiring knowledge. In addition to these requirements, it is therefore crucial to ensure that the content of digital education can provide opportunities for experiences and personal growth. Linking individual experiences of engaging with the world through digital media (e.g., the possibility to meet relatives online or to engage in cultural activities), can be just as meaningful and empowering as, for example, experiencing one’s own impact through assistive technologies or digital devices that support spoken language. The topic of communication is a section of six different fields of application of digital education but can also be understood as a cross-cutting issue that affects all content-related aspects as well as the (multi-)methodological approaches and implementation possibilities of digital education. Communication is the basis of human action and accordingly a constituent part of participation. The expansion of digital (communication) possibilities is therefore a central requirement for participation for all.

6. Discussion

In summary, it can be stated that the right to digital education and participation has not been adequately realized for people with PIMD and CCN. The presented framework can serve as a solution to address this issue. By considering the outlined requirements within the framework, appropriately designed educational programs and services can support the development of individual digital competencies. With the expansion of these digital participation possibilities, opportunities for an expansion of communication always arise as well, both in the sense of individual expression (through the use of digital media in the sense of electronic communication aids or through the use of assistive technologies), and in the sense of social communication and interaction, which can be massively expanded through the use of digital technologies (Caton et al., 2022). This can be achieved by providing opportunities to actively engage with digital media, enabling the acquisition and cultivation of knowledge, skills, and reflective abilities.

Overall, digital technologies can be considered 'enabling technologies', offering new opportunities for disadvantaged groups of people. However, there is also an increased risk of social exclusion due to insufficient use of or limited access to digital media. Accordingly, participation in digital media should be supported both through content-related, technical and structural offers and through the promotion of competences in the use of digital media (Luder, 2003).

The support environment plays a central role in the concrete implementation of digital educational programs and services for people with PIMD and CCN. Due to potentially significant impairments, independent use of digital media may not always be possible for this group of people, thus they often require close assistance and guidance. In terms of digital education and participation, supporters play a central role in the sense of a gatekeepers who can either act as barriers or facilitators. It is therefore imperative that supporters have the time and skills to accompany processes in the context of digital literacy. This means that supporters themselves must be competent in dealing with digital media in order to be able to provide guidance and stimulate the development of individual digital literacy skills with empathy and creativity.

The support needs to be provided in a sensitive manner, as people with PIMD and CCN can often only participate in digital education through the personal support in the sense of a person who selects, produces or activates content on behalf of the person with PIMD. In the context of participation in digital media, this can mean, for example, that content is selected or deliberately withheld for people with PIMD and CCN. It may also involve actively producing and publishing content with their involvement, e.g., through a blog or a WhatsApp group. This can be encouraged through guided and conjoint exploration or support for active participation. However, the aspect of acting on behalf of others remains a highly sensitive process that requires constant reflection on the part of the supporters. This does not only involve technical skills in handling devices and software, but also employing information and communication technologies that aim at shaping social practice (Wagner and Peschke, 2006).

Ultimately, participation in digital education is a basic right for people with PIMD and CCN, which has only been partially realized so far. Accordingly, it is necessary to further develop concepts and services on all levels mentioned—in terms of content, technology and infrastructure—while also critically reflecting on the adequate support and assistance. By facilitating experiences, the support environments of people with PIMD can facilitate long-term individual digital participation and thus contribute to fulfilling this right. The mere use of digital technology is therefore by no means sufficient to enable participation. Professional and informal assistance, human interaction and social support are required.

This requires further research with regard to actual avenues and possibilities for access, as well as identifying the barriers and challenges. Beyond that concrete concepts are needed that enable joint exploration of the digital space for both people with PIMD and CCN and their supporters. This can lead to a mutual increase in competence. The developed framework can provide a foundation for such endeavors.

Author contributions

CK and TB contributed the conception, design of the analysis, and wrote the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Petra Jaecks,
Bielefeld University, Germany

REVIEWED BY
Susana Silva,
University of Porto, Portugal
Katharina Weiland,
Humboldt University of Berlin, Germany
Susan Buell,
University of Dundee, United Kingdom

*CORRESPONDENCE
Andreas Säuberli
✉ andreas@cl.uzh.ch

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Enabling text comprehensibility assessment for people with intellectual disabilities using a mobile application

Andreas Säuberli[1]*, Silvia Hansen-Schirra[2], Franz Holzknecht[3], Silke Gutermuth[2], Silvana Deilen[2], Laura Schiffl[2] and Sarah Ebling[1]

[1]Department of Computational Linguistics, University of Zurich, Zürich, Switzerland, [2]Johannes Gutenberg University Mainz, Germersheim, Germany, [3]University of Teacher Education in Special Needs Zurich, Zürich, Switzerland

In research on Easy Language and automatic text simplification, it is imperative to evaluate the comprehensibility of texts by presenting them to target users and assessing their level of comprehension. Target readers often include people with intellectual or other disabilities, which renders conducting experiments more challenging and time-consuming. In this paper, we introduce *Okra*, an openly available touchscreen-based application to facilitate the inclusion of people with disabilities in studies of text comprehensibility. It implements several tasks related to reading comprehension and cognition and its user interface is optimized toward the needs of people with intellectual disabilities (IDs). We used *Okra* in a study with 16 participants with IDs and tested for effects of modality, comparing reading comprehension results when texts are read on paper and on an iPad. We found no evidence of such an effect on multiple-choice comprehension questions and perceived difficulty ratings, but reading time was significantly longer on paper. We also tested the feasibility of assessing cognitive skill levels of participants in *Okra*, and discuss problems and possible improvements. We will continue development of the application and use it for evaluating automatic text simplification systems in the future.

KEYWORDS

Easy Language, easy-to-read, readability, reading comprehension, text simplification, intellectual disabilities

1. Introduction

The terms “Easy Language”, “Plain Language”, “easy-to-read language”, and “simplified language” all denote varieties of standard language which aim to improve comprehensibility for a wide range of target groups, including people with intellectual disabilities[1] (IDs) or communicative impairments, people who are deaf or hard-of-hearing, or non-native speakers (Maaβ, 2020). As efforts to automate the process of simplifying texts are increasing (Schulz et al., 2020; Al-Thanyyan and Azmi, 2021), it also becomes increasingly important to develop and apply accurate and reliable methods for evaluating simplified texts.

Much of the previous work on comprehensibility assessment of simplified texts has focused on comprehension tests and perceived difficulty ratings by experts (e.g., simplified

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[1] We use the term *intellectual disability* as an umbrella term to include all forms of cognitive impairment leading to a right to information in Easy Language according to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).

language translators) or readers sampled from a general population, which are not necessarily representative of the target group (Alva-Manchego et al., 2021). The reason for this is that target groups are often difficult to access and experiments involving them require significantly more time and expertise (Saggion et al., 2015; Stajner, 2021). Particularly in the field of automatic text simplification, evaluation studies involving the target audience are rare (Stajner, 2021), and most researchers resort to experts or users on crowdsourcing platforms for human evaluation (e.g., Xu et al., 2016; Sulem et al., 2018c; Zhao et al., 2020). In addition, although many people in the target group are active users of digital media and devices (Ramsten et al., 2018), existing tools and platforms for human evaluation are rarely optimized for people with disabilities (Uzor et al., 2021), leading to a high threshold to including the target group in evaluation studies. These impedes digital participation, because people with IDs are excluded from research on improving communication technology targeted at them.

We believe that this situation can be improved by providing tools which enable more efficient, effective, and inclusive evaluation studies with participants from diverse target groups, particularly, people with IDs. Developing digital applications for comprehensibility assessment and adapting them to the needs of these target groups reduces the need for close supervision and increases flexibility in terms of where and when experiments can be conducted. In addition to reducing cost, this also enables a more naturalistic reading environment compared to paper-and-pencil tests in a laboratory setting. In the present work, we introduce and test such a tool and apply it in an initial experiment with participants with ID.

The main contributions of this paper are:

1. We describe the design and implementation of *Okra*, a mobile application for testing text comprehensibility with people with IDs (Section 3).
2. We present results from a small-scale study with *Okra* aiming to detect potential effects of the digital testing modality compared to traditional paper-and-pencil methods, and to test the feasibility of administering low-level cognitive tasks (Section 4).

2. Background and related work

2.1. Human evaluation of text difficulty

Although there is no consensus on best practices, it is generally accepted that evaluating Easy Language with target readers is crucial for obtaining representative results (Alva-Manchego et al., 2020, 2021; Stajner, 2021; Stodden, 2021). However, human evaluation of text difficulty is mostly done with populations such as crowdworkers (Leroy et al., 2013; Redmiles et al., 2019), experts (Sulem et al., 2018a,b), students (Fulmer et al., 2015; Leroy et al., 2022), or target groups that are more easily accessible, such as non-native speakers (Crossley et al., 2014; Vajjala et al., 2016; Vajjala and Lucic, 2019). Exceptions include studies with deaf and heard-of-hearing participants (Alonzo et al., 2021), readers with dyslexia (Rello et al., 2013a,b,c), and people with IDs (Huenerfauth et al., 2009; Fajardo et al., 2014; Saggion et al., 2015; Gutermuth, 2020). Particularly in the field of automatic text simplification, output texts are rarely evaluated with vulnerable populations. The main reasons for this are the difficulty and time involved in accessing these groups and adapting the experiments to the special needs of the participants, as well as ethical issues (Saggion et al., 2015; Deilen and Schiffl, 2020; Stajner, 2021).

Several different methods have been proposed and used to measure the difficulty of texts. For subjective perception of difficulty, Likert scales are most frequently used (e.g. Leroy et al., 2013, 2022; Fulmer et al., 2015). For measuring actual or objective difficulty, various types of comprehension testing are applied, including multiple-choice questions (Leroy et al., 2013, 2022; Fajardo et al., 2014; Charzyńska and Dębowski, 2015; Alonzo et al., 2021), cloze tests (Charzyńska and Dębowski, 2015; Redmiles et al., 2019), and free recall questions (Leroy et al., 2013, 2022). Some studies also measure different aspects of reading behavior, such as the time taken to read a text (Crossley et al., 2014; Saggion et al., 2015; Alonzo et al., 2021), gaze patterns recorded through eye-tracking (Rello et al., 2013c; Vajjala et al., 2016; Gutermuth, 2020), or scrolling interactions (Gooding et al., 2021).

2.2. Tools for computer-based reading experiments

Many tools used in behavioral and psycholinguistic research support various types of reading tasks, for example, *PsychoPy* (Peirce et al., 2019), *PsyToolkit* (Stoet, 2017), or *jsPsych* (de Leeuw, 2015). Survey platforms such as *Qualtrics* or *SurveyMonkey* provide basic features for multiple-choice or text-based responses, and *Amazon Mechanical Turk* and *Qualtrics* support custom front-end implementations to collect behavioral measurements such as reading time and scrolling behavior, which often involves considerable technical expertise (e.g. Alonzo et al., 2021; Gooding et al., 2021), and making implementations accessible requires user testing. We are not aware of any tools specifically developed for reading experiments with people with IDs. Large-scale digitized testing for this target group is uncommon, and studies designed for participants with IDs are still mostly done using paper-based methods (e.g. Huenerfauth et al., 2009; Fajardo et al., 2014).

2.3. Usage of technology by people with ID

Insights from interviews and surveys have shown that the use of information and communication technologies, and mobile devices in particular, has become widespread among adults with IDs (Ramsten et al., 2018), and may even have significant personal and social benefits (Chadwick et al., 2018; Martin et al., 2021). Use of technology has also been found to be beneficial for people with IDs in education (Maebara et al., 2022) and the development of skills in daily life (Jung et al., 2021), particularly due to the variety of modalities (text, images, video, audio, etc.) supported by the devices. This strongly suggests that participation in digital comprehensibility studies should be possible for this group. However, existing software solutions, including crowdsourcing platforms such as *Amazon Mechanical Turk*, are generally suboptimal in terms of accessibility for many user groups, including users with IDs (Uzor et al., 2021).

Due to this increased use of technology and the growing need of human evaluators from target groups of Easy Language, developing a digital application that is accessible for people with ID is a logical next step. However, the feasibility of such applications and potential effects of the digital modality compared to conventional paper-based methods must be thoroughly tested. Our work presents a first step in this direction.

3. Application description

In response to the increasing demand for and importance of representative human evaluations of text simplification and the lack of suitable tools for one of the main target groups of Easy Language (people with IDs), we present a prototype of a mobile application for touchscreen-based assessment of reading comprehension. Its main goal is to create a simple way for researchers to set up and configure experiments, which can then be presented to participants in an accessible way, either on their own device, or a device provided to them by the researcher (in a laboratory setting).

3.1. Requirements

Based on the specific needs and difficulties of the target users and the shortcomings of existing tools for collecting reading comprehension data described in Section 2, we formulate the following requirements for our application:

From a participant's perspective, the application should:

- Provide an easy-to-understand and easy-to-use interface, specifically for participants with mild to moderate IDs or limited language skills.
- Support independent use as best as possible, i.e. on a personal device, without supervision.
- Keep up the user's motivation.

From a researcher's perspective, the application should:

- Collect all data which is potentially useful for evaluating Easy Language.
- Allow conducting both remote and in-lab experiments.
- Provide a simple and reproducible way of setting up customized experiments.

3.2. Design and implementation

To allow conducting experiments both in a lab and remotely using participants' personal devices, we chose a client-server implementation. The client application is installed on a touchscreen device and used by the participant to complete tasks. On the server side, we implemented a web application which includes a dashboard where researchers can configure experiments and download results, and an application programming interface (API) to communicate with registered clients.

To address the requirements described in the previous section, we designed the graphical user interface to reduce the amount of information visible on screen simultaneously and provide clear indicators of the next steps at every point in time. As it is safe to assume that most participants are at least somewhat familiar with modern Android or iOS applications (Ramsten et al., 2018), we follow Material Design specifications[2] to implement components and navigation behavior reminiscent of widely used apps. When participants open *Okra*, they are asked to scan a QR code given to them by the researcher, which registers their device and allows them to receive experiments to participate in. Each experiment starts with a screen with instructions written in Easy Language, followed by a practice task and a number of main tasks. After each task, an encouraging message is shown for positive reinforcement, and the participant is allowed to take a break and continue at their own pace. Where easily possible, we included gamification elements such as colorful pictures and animations (see Figure 1 for sample screenshots). During tasks, user interactions (i.e., scrolling and touch events) are recorded, and the log is sent to the server after the task is finished.

No personal information is collected or stored in the client application, and participants are only identified by randomly generated identifiers. The researcher is responsible for collecting personal information and mapping them to participant identifiers. This means that data confidentiality can be handled by the researcher according to individual requirements.

The client application is implemented using the cross-platform user interface (UI) toolkit *Flutter*[3], meaning that it can be compiled into a native Android/iOS app or a Progressive Web App (PWA) which can be installed directly from a web browser. The server is a *Django*[4] app and contains a dashboard for registering participants and configuring experiments, and the API for communicating with clients.

3.3. Tasks

We identified tasks which can be made accessible to target users while remaining useful for Easy Language research and evaluation of text simplification. In a typical study, measuring low-level cognitive skills may also be relevant for screening or comparing to a control group. Therefore, apart from reading comprehension tasks, we also include tasks for measuring skills such as working memory and visual attention. The following types of tasks are currently implemented in the prototype:

- Reading tasks with multiple-choice questions and Likert-scale or slider ratings [screenshots (A) and (B) in Figure 1].
- Multiple-choice cloze tests, where a short segment of text with a single gap is shown at a time.
- Lexical decision tasks, where the user judges whether a string of characters is a word or a non-word.

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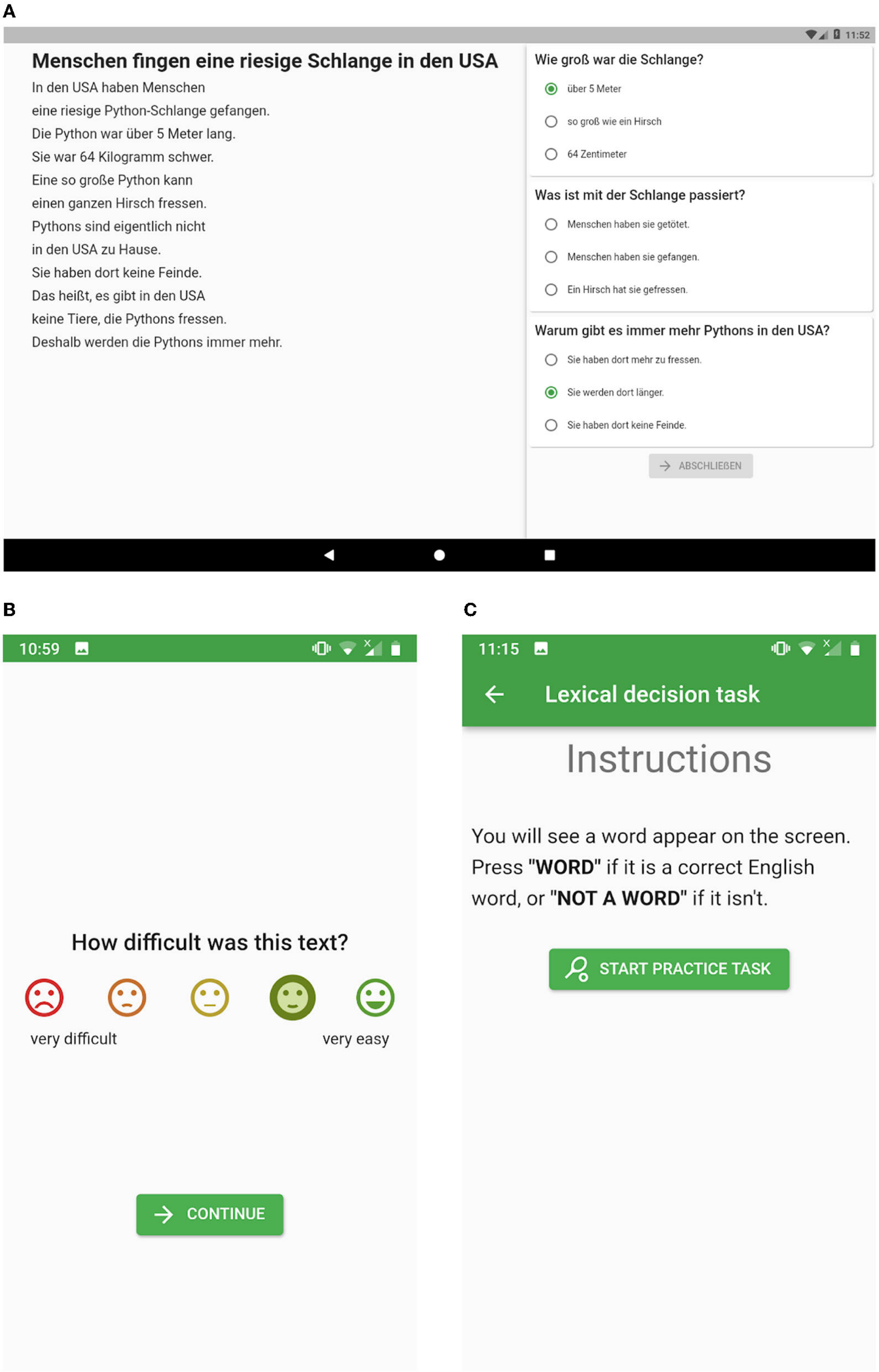
[2] https://material.io/

[3] https://flutter.dev/

[4] https://www.djangoproject.com/



Menschen fangen eine riesige Schlange in den USA

In den USA haben Menschen
eine riesige Python-Schlange gefangen.
Die Python war über 5 Meter lang.
Sie war 64 Kilogramm schwer.
Eine so große Python kann
einen ganzen Hirsch fressen.
Pythons sind eigentlich nicht
in den USA zu Hause.
Sie haben dort keine Feinde.
Das heißt, es gibt in den USA
keine Tiere, die Pythons fressen.
Deshalb werden die Pythons immer mehr.

Wie groß war die Schlange?

- ● über 5 Meter
- ○ so groß wie ein Hirsch
- ○ 64 Zentimeter

Was ist mit der Schlange passiert?

- ○ Menschen haben sie getötet.
- ○ Menschen haben sie gefangen.
- ○ Ein Hirsch hat sie gefressen.

Warum gibt es immer mehr Pythons in den USA?

- ○ Sie haben dort mehr zu fressen.
- ● Sie werden dort länger.
- ○ Sie haben dort keine Feinde.

How difficult was this text?

very difficult

very easy

Lexical decision task

Instructions

You will see a word appear on the screen. Press "**WORD**" if it is a correct English word, or "**NOT A WORD**" if it isn't.

FIGURE 1
Screenshots of *Okra*. **(A)** Reading task with comprehension questions on a tablet screen (in German), as it was presented to participants (cf. Section 4.2). **(B)** Difficulty rating on a phone screen. **(C)** Instructions for a lexical decision task on a phone screen.

- *n-back* tasks for testing working memory, first introduced by Kirchner (1958).
- Digit span tasks, where participants need to remember and recall sequences of digits of increasing length.
- Word-picture-matching tests, where participants choose the matching picture for the displayed word, as described by Deilen (2020).
- Reaction time tests, where an image appears on screen and participants tap it as quickly as possible.
- Trail Making Tests for testing visual attention (Reitan and Wolfson, 1993).
- An adaptation of the electronic short-term memory skill game *Simon*, where participants remember an increasingly long sequence of buttons to press.

Implementations of these tasks are contained in the client application installed on participants' devices. Instructions, stimulus data, and procedure details (number of trials, size of UI elements, timing etc.) can be configured by the researcher through a web application. The client is currently available in German and English.

3.4. Availability

The source code for both client and server implementations are available under free and open source licenses at https://github.com/saeub/okra and https://github.com/saeub/okra-server. The client application is currently not available through any official app store.

4. Experiment: effect of testing modality and feasibility analysis

We used *Okra* in a small-scale experiment with participants with IDs. The goal of this experiment was to gather initial evidence for the following two questions:

- Is there a measurable difference between reading comprehension and perceived difficulty rating tasks performed in *Okra* compared to paper-and-pencil testing?
- Is it feasible to test low-level cognitive skills with people with ID using *Okra*?

The latter question is relevant because in future studies, these cognitive tasks will be useful for characterizing the target group, screening participants, or correlating reading behavior to certain cognitive skills.

A selection of results of this study has been reported in Säuberli (2021).

4.1. Participants

After institutional review board (IRB) approval and a pilot study with two participants, 16 participants took part in the main study. They were recruited directly through their instructor in an educational program for people with learning difficulties and disabilities in Austria. There were no additional inclusion criteria. They took part on a voluntary basis and were compensated monetarily. Participants were not screened for disability specifically, but all participants in the educational program have some form of cognitive impairment or learning disorder (the most common being Autism Spectrum Disorder, Down Syndrome, and developmental delay) and a degree of disability of at least 50% according to Austrian legislation.[5] They were aged between 18 and 38 (median: 26) at the time of the first session. Eight of them identified as female, eight as male. All were native German speakers. According to their survey responses from the first session, 14 of them use a smartphone on a daily basis, two only weekly. This is in line with previous research of technology usage among people with ID (Ramsten et al., 2018) and validates our assumptions for the design of the application (cf. Section 3.2). Self-reported reading frequency ["How often do you read texts (for example, in newspapers, books, or the internet)?"] was distributed between *every day* ($n = 4$), *once per week or more* ($n = 8$), and *less than once per week* ($n = 4$). All of them had at some point read texts in Easy Language before.

4.2. Procedure, tasks and variables

There were two sessions per participant. Each session was administered one-on-one by an employee at the facility where the participants' educational program took place. The experiment consisted of a reading task, which was split across the two sessions, and three different low-level cognitive tasks at the beginning of the second session. Each task was preceded by written instructions and a practice trial. These instructions and the remaining text material were checked by a professional in Easy Language to ensure that they adhere to guidelines designed for the target group. In addition, the session administrator constantly monitored the participants' screens during the experiment and, if necessary, added oral instructions, in order to prevent misunderstanding of the tasks.

For the reading task, we selected eight newspaper articles written in German Easy Language taken from the APA (Austrian Press Agency) corpus (Säuberli et al., 2020), ranging between 63 and 122 words in length. For each text, we wrote three multiple-choice comprehension questions with three answer choices. After initially reading the text (without seeing the questions yet), participants had to rate the difficulty of the text on a 5-point rating scale (1 = *very difficult*, 5 = *very easy*). The text was then shown again, together with the comprehension questions, and participants had unlimited time to answer them. This was followed by two more 5-point ratings on the difficulty of the questions (1 = *very difficult*, 5 = *very easy*) and enjoyment ("How much did you enjoy this task?"; 1 = *not at all*, 5 = *very much*). Each participant read four texts on an Apple iPad 2018 (9.7 inches) using *Okra*[6], and

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[5] *Verordnung des Bundesministers für Arbeit, Soziales und Konsumentenschutz betreffend nähere Bestimmungen über die Feststellung des Grades der Behinderung (Einschätzungsverordnung)*, BGBl. II Nr. 261/2010.

[6] *Okra* was built as a PWA from the code in public repository (https://github.com/saeub/okra) at commit hash `b56c7a7` and run in the Safari web browser.

four on paper, using a pen to mark their answers. Care was taken that the visual presentation (font size, layout, etc.) was the same in both conditions. In the paper condition, the administrator used a stopwatch to measure the initial reading time.[7]

In the reaction time (RT) task, a red balloon was visible and the participant was instructed to tap it as quickly as possible. After popping the balloon, the next one appeared after a random delay between 0 and 1 second. In the lexical decision task, a string of letters was shown on screen and the participant was instructed to tap the correct button (labeled "WORD" or "NOT A WORD") as quickly as possible. We selected ten words from a list of the 5000 most frequent German words (Perkuhn et al., 2009), and generated ten pseudowords using *Wuggy* (Keuleers and Brysbaert, 2010). In the short-term memory task, participants had to observe four differently colored buttons light up in a specific sequence, starting with a sequence of length 1. They then had to repeat this sequence by tapping the buttons in the correct order. The sequence was then extended by an additional button press and presented again, and so on. The trial ended as soon as the participant pressed an incorrect button. Since the three cognitive tasks heavily rely on precise stimulus timing and touch-based user interaction, they could only be performed on the iPad. The main reason for including them is to test their feasibility with the target group.

4.3. Analysis

We used item response theory (IRT) to answer the question on the difference between modalities. IRT models are used to study how underlying latent traits (i.e., unobservable traits such as reading ability) are linked to observed performances (i.e., scores on a reading test or questionnaire responses on reading difficulty) (see also Ockey, 2021). One particular method of IRT is many-facet Rasch measurement (MFRM; Linacre, 1994), which allows researchers not only to investigate the link between latent traits and observable performances, but also how other factors (so-called "facets") influence the performances (Eckes, 2015). As the factor we were particularly interested in is the condition (paper-and-pencil or *Okra*), we constructed a MFRM model consisting of three facets (participant, item, and condition) and used MFRM bias analyses to study differences between the item and condition facet. For the analysis, we first coded the answers to the items dichotomously as either correct or incorrect. For the three ratings, we applied separate MFRM models with three facets (participant, text, and condition) using the 5-point rating scale responses.

To test the difference in reading time between modalities, we applied a linear mixed-effect model with participants and texts as random effects using the R package *lme4* (Bates et al., 2015) and the formula `reading.time~condition + (1 | participant) + (1 | text)`.

4.4. Results

4.4.1. Reading task

Out of the 128 data points obtained (16 participants × 8 texts), one measurement was lost due to a software bug (which was immediately fixed), leading to a total of 127 data points.

Figure 2 shows the distribution of measurements for participants and items (questions). Question 2 of text G was answered correctly by all participants. For the remaining data points, mean-square infit statistics range between 0.70 and 1.44 for participants and between 0.75 and 1.38 for items, indicating an acceptable model fit. The model could not statistically separate the two elements in the condition facet (separation = 0.00), indicating that participants performed equally well in the two conditions. The bias analysis showed no significant difference between the two conditions for any of the items (all $p > 0.17$). Overall, the ratio of correct answers was quite high, with an average of 17.5 out of 24 correctly answered questions per participant (s.d.: 3.3).

Figure 3 shows mean rating responses for each text. For most participants, there was a strong tendency toward very positive responses, and some of the participants gave the same responses for all texts (four participants in the case of text and question difficulty ratings). All three rating dimensions are also highly correlated with each other (Pearson's $r > 0.55$, $p < 0.001$). For all ratings, the MFRM analyses resulted in 0.00 separation of the condition facet, suggesting that there was no difference in perceived difficulty and enjoyment/motivation between modalities.

Average reading time was noticeably shorter on the iPad than on paper for almost all texts, as Figure 4 shows. According to the linear mixed-effect model, this effect is 9.97 seconds with a standard error of 2.22 seconds ($p < 0.001$). The model also shows considerable variance between individuals, with a standard deviation of 17.53 seconds for the random effect of participants, and less variance between texts (s.d.: 7.83 seconds).

4.4.2. Cognitive tasks

Since the three cognitive tasks heavily rely on precise stimulus timing and touch-based user interaction, they could only be performed on the iPad. A summary of the most relevant measurements is presented in Table 1.

The RT task resulted in a relatively low variance (mean: 0.68 sec, s.d.: 0.10 sec), and there is no significant correlation with any of the other measurements. This suggests that the effect of differences in motor response speeds between participants on other tasks is minimal.

Results from the lexical decision task are in line with psycholinguistic expectations, with pseudowords generally causing a longer RT than words. However, three participants (3, 5, and 10) gave the same response "WORD" to all trials and did not exhibit any difference in RT between words and pseudowords. Responses by participant 11 were also equal to random guessing and showed no difference in RT.

Since the short-term memory task consisted of a single main trial which stopped immediately after the first incorrectly pressed button, we used the maximum score out of practice and main trials

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[7] Reading time was measured as the duration between the start of the initial text presentation and the end of the first rating after reading the text (in both conditions). Because the text difficulty rating was on the same page as the text in the paper condition, it was not possible to measure the end of reading precisely.

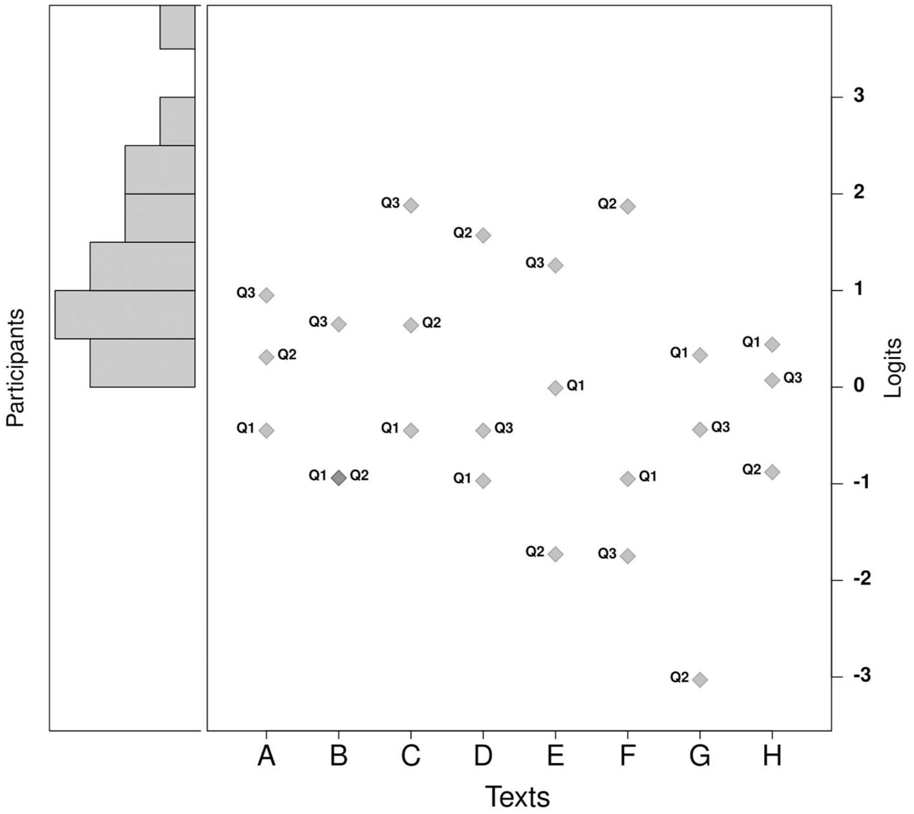

FIGURE 2
Wright map (Many-Facet Rasch Measurement) of performance in comprehension question responses. Participants and comprehension questions (Q1–3 for texts A–H) are projected onto a common logit scale. The higher a participant's logit value, the better their performance, and the higher a question's logit value, the higher its difficulty. A participant has an estimated chance of 50% of correctly answering a question with the same logit value as theirs.

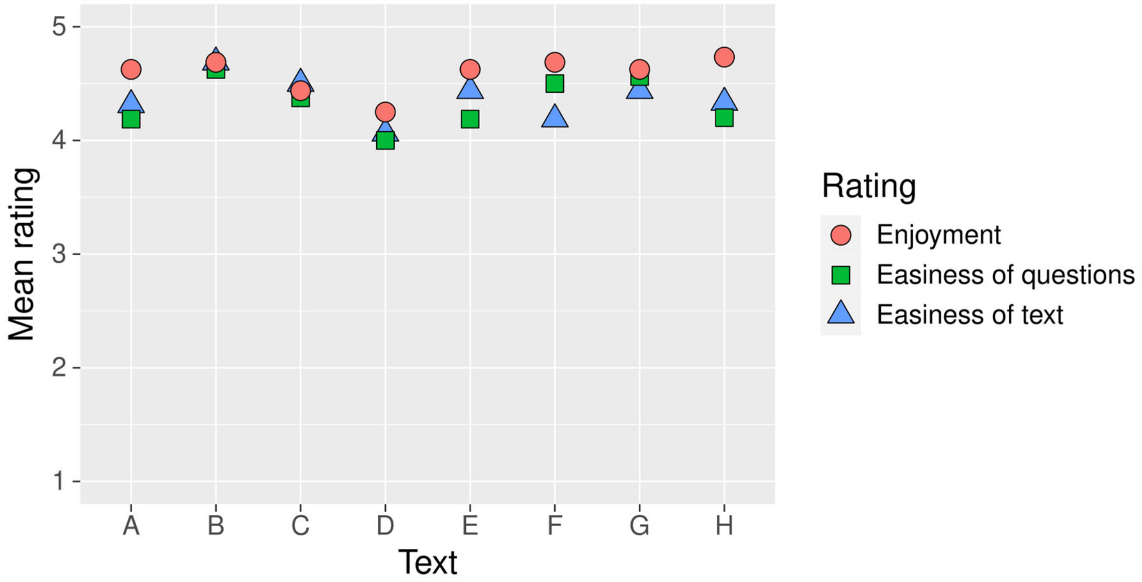

FIGURE 3
Mean rating responses for each text. 1 is the lowest (most negative), 5 is the highest (most positive) response. The questions were "How much did you enjoy this task?" (1 = *not at all*, 5 = *very much*), "How difficult were the questions?" (1 = *very difficult*, 5 = *very easy*, "How difficult was the text?" (1 = *very difficult*, 5 = *very easy*) (presented to participants in German, here translated to English by the authors).

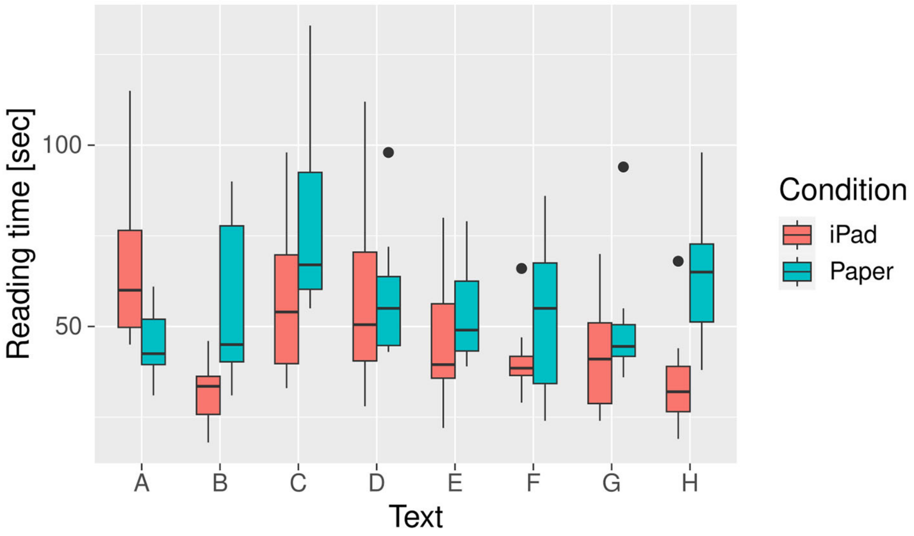

FIGURE 4
Comparison of initial reading times between the two modalities for each text. Reading times are not normalized by text length, as they include the time taken for both reading and the text difficulty rating.

TABLE 1 **Summary of aggregated measurements for all participants and tasks.**

Participant	Reading		RT	Lexical decision			Memory
	Avg. correct responses	Reading time [s]	Reaction time [s]	Ratio of correct responses	Correct word RT [s]	Correct pseudoword RT [s]	Longest sequence
1	2.63	45.0	0.68	0.85	1.70	2.79	7
2	2.29	43.1	0.55	0.90	1.59	2.13	5
3	2.38	45.5	0.67	*0.50*	*1.89*	—	4
4	2.13	46.4	0.77	0.95	2.44	4.11	3
5	2.13	43.3	0.70	*0.50*	*1.23*	—	5
6	2.63	52.9	0.65	0.95	2.27	2.43	8
7	2.00	97.8	0.52	0.75	4.11	14.57	2
8	1.63	51.4	0.67	0.85	1.86	5.17	7
9	2.88	37.0	0.69	0.95	1.58	2.04	11
10	1.88	33.8	0.68	*0.50*	*0.88*	—	4
11	2.50	59.3	0.72	*0.50*	*0.97*	*0.88*	4
12	2.13	70.1	0.61	0.75	2.67	4.64	4
13	2.75	50.4	0.69	1.00	1.39	2.32	20
14	1.63	31.4	0.60	1.00	1.60	1.76	5
15	1.88	85.9	0.95	0.75	1.64	3.43	5
16	1.63	55.3	0.80	1.00	2.27	2.43	9
Mean	2.19	53.0	0.68	0.79	1.88	3.75	6.4
±s.d.	±0.41	±18.0	±0.10	±0.19	±0.78	±3.47	±4.3

Time measurements are in seconds. Measurements in *italics* were excluded from further analysis due to chance-level performance.

to get a more reliable measurement. Still, we can observe a very large variance between participants.

4.5. Discussion

4.5.1. Effect of testing modality

Both in terms of accuracy of responses to the comprehension question and in terms of subjective perception ratings, we found no evidence of any difference between the two modalities. However, Figures 2, 3 suggest that there is a ceiling effect due to low text and/or question difficulty. This underlines the need for a sufficiently large sample size in the pilot study, since variance between participants is difficult to predict in such a diverse target group. The relatively small sample size is another obvious limitation. At the least, the results allow us to exclude large effect sizes from modality for this target group. This confirms our expectations, given the frequency of technology use reported by the participants and the population of people with IDs in general (Ramsten et al., 2018).

The large difference in reading time is more difficult to explain. One possibility is that actual reading speed was faster when reading on the iPad than on paper, which contradicts previous research which found differences in comprehension but not in reading speed (Kong et al., 2018). Another explanation could be that participants are less inhibited to make the conscious decision that they have finished reading and push the "CONTINUE" button in the application, compared to the paper modality, where the end of the initial reading stage was indicated by participants using the pencil to mark an option on the rating scale. In any case, since the difference in reading time did not appear to affect comprehension, we consider it unproblematic.

4.5.2. Feasibility of cognitive tasks

In order to be feasible in studies with people with ID, the administered tasks must be understood by participants, and maintain participants' attention by avoiding excessive strain or boredom. At least in the RT and lexical decision tasks, the high performance and relatively low variance show that most of the participants have correctly understood the tasks. Moreover, based on comments by some participants, the cognitive tasks were perceived as games (the short-term memory task in particular), which may have supported motivation and attention (cf. Bratu et al., 2022).

However, given the random-guessing accuracy of several participants in the lexical decision task and the large variance of performance in the short-term memory task, which cannot be plausibly explained by differences in memory capacity alone, there are clearly still problems with some of the tasks. Particularly in the memory task, we suspect that performance was heavily influenced by task familiarity and individual learning curves. Some participants had to repeat the practice trial several times, while one participant, who performed very highly, remarked that they often played similar games. Choosing tasks with a high error tolerance (which the memory task was not) or using a larger number of trials may also yield more reliable results. Regarding the lexical decision task, it is unclear whether the three participants who always gave positive responses without any difference in RT between words and pseudowords misunderstood the task or lost motivation, since two of them did give some negative responses during the practice task. Further testing is necessary to determine how this task can be improved.

In this study, we refrained from displaying any feedback about correct or incorrect responses in the application, in order to avoid discouraging participants. However, depending on the difficulty of the task, it may be better to show feedback, especially if there is little to no personal supervision, to avoid misunderstanding and strengthen extrinsic motivation (cf. Rodríguez et al., 2022). In the future, we would also like to further develop the gamification elements and put more measures in place to monitor motivation or misunderstanding of instructions.

5. Conclusion and outlook

We presented *Okra*, a prototype mobile application for conducting reading experiments with people with IDs. Our primary goal was to provide a tool for researchers to enable digitized comprehensibility evaluation with target readers (instead of experts or general populations) by making use of the increased technological literacy among people with IDs, and ultimately lowering the threshold to including target groups in research on Easy Language and text simplification.

Therefore, our mobile application contributes to participation *in* digital technologies (Bosse, 2016) of persons with disabilities. At the same time, automatic text simplification as an assistive technology increases participation *through* digital technologies; here, more representative evaluations of texts in Easy Language of the kind made possible through our mobile application are capable of improving the quality of automatic text simplification models.

We also conducted a study with people with ID, testing the effect of modality (paper vs. iPad) on reading comprehension and subjective ratings and the feasibility of assessing cognitive skills in *Okra*. Although there was no evidence of a modality effect, we found that reading times were significantly longer on paper than on the iPad. Observations from this initial study confirm that it is feasible to use the application for evaluating Easy Language and basic cognitive assessment with this target group. However, we have identified several issues concerning usability and reliability of results, which we are going to address in future versions of the application. An additional limitation of our study is that we did not conduct any standardized testing of language competence or a detailed survey of reading habits. As a next step, we will conduct more systematic usability testing and use *Okra* to evaluate the output of human and automatic text simplification with people with ID.

While the experiments described in this paper were conducted in a highly controlled environment and with close supervision, we will also work to improve the usability and accessibility of the application to allow participants to use it more independently (ideally, outside of laboratory conditions), and to implement and test a wider range of task types. As a long-term goal, the user interface should also be made accessible for other target groups of Easy Language. Thus, we hope that it will become a tool for researchers to simplify and encourage the inclusion of people with disabilities.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by Ethics Committee of the Faculty of Arts and Social Sciences, University of Zurich. The patients/participants provided their written informed consent to participate in this study.

Author contributions

AS implemented the application, designed the experiment, prepared stimulus data, performed analyses, and wrote the manuscript. SE contributed to conceptualization and study design. SH-S, SG, SD, and LS contributed to study design and served as expert testers for the application. FH contributed to study design and data analysis. All authors contributed to stimulus material and manuscript revision, read, and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Hendrike Frieg,
University of Applied Sciences and Arts
Hildesheim, Germany

REVIEWED BY
Benjamin Tschuschke,
Katholisches Klinikum Bochum, Germany
Petra Jaecks,
Bielefeld University, Germany

*CORRESPONDENCE
Karolin Schäfer
✉ karolin.schaefer@uni-koeln.de

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Social media use and mental health in deaf or hard-of-hearing adults—Results of an online survey

Karolin Schäfer* and Felix Miles

Department of Special Education and Rehabilitation, Faculty of Human Sciences, University of Cologne, Cologne, Germany

This paper presents the results of an online survey on digital participation through the use of social media of $n = 38$ German deaf or hard-of-hearing (DHH) adults. In addition, information about the respondents' mental health is collected with four different scales: the Rosenberg Self-Esteem Scale (RSES), the Fear of Missing Out Scale (FoMoS), the Patient-Reported Outcomes Measurement Information System Social Isolation Scale (PRO-MIS SI-S) and the Social Media Disorder Scale (SMDS). Correlation analyses using Pearson correlation and Spearman rank correlation tests were conducted to identify relationships between mental health and use of social media. The results indicate that the DHH adults have 4.13 social media accounts on average and use social media 3.78 h per day. This is consistent with other research findings, so that the DHH individuals in this study do not differ from other DHH adults or hearing adults in the number of their social media accounts and in their media usage time. However, there are differences in usage of social media that concern, for example, the social media platforms that are used and time of usage due to communication modality (spoken language, sign language, bimodal bilingualism, and mixed forms). DHH individuals who use sign language use social media less overall compared to DHH people who use spoken language. In terms of mental health, it was found that, as expected, addictive social media behavior and high usage time are interrelated. Addictive behavior, in turn, is often associated with low self-esteem, a sense of social isolation, and a fear of missing out. In general, many participants in the study score high in scales for self-perception of social isolation and loneliness. Nevertheless, there are also positive effects and opportunities of using social media, especially in terms of digital participation, for DHH people, which are also discussed in the article.

KEYWORDS

deaf, hard-of-hearing, social media, mental health, digital communication

Introduction

Digital communication has increasingly gained in importance as a new form of communication since the 90′s of the last century across the globe. This signifies the change of everyday communication and interaction between people through digital media (Grimm and Delfmann, 2017). The opportunity to constantly access the Internet from any place and our ability to express ourselves through language create a feeling of closeness between people regardless of where people are physically located. Moreover, this process of change toward digital media is characterized by an enormously accelerating innovation and by the particularity that the newly evolving digital communication media do not replace the existing digital forms of communication (as it was the case with previous technological developments) but that they pop up all of a sudden and persist in parallel to the already existing forms of communication (Taddicken and Schmidt, 2017; Wampfler, 2019). This has resulted in a veritable oversupply of digital communication opportunities in the recent years.

For deaf and hard-of-hearing (DHH) people, digital media represent an important opportunity to access information and to communicate with others while having the opportunity to see the interlocutor on a screen. For DHH people who use spoken language, listening to speech, and watching mouth and lip movements at the same time or reading captions is essential to understand what is being said. For DHH people who use sign language, digital communication offers the chance to communicate in sign language on a screen—an advance that only digital media have made accessible to people from the Deaf community. In addition, the possibility of gaining information via digital media plays a very important role for DHH people (Rachdito and Hidayat, 2022). Nevertheless, recent studies suggest that there is a digital divide between DHH and hearing people, which is not due to difficulties in accessing the internet, but rather to the ability to interact while using digital media (Lago and Acedo, 2017).

Deafness does not necessarily lead to communication disorders, but people with congenital hearing loss are at risk of developing speech and language delays that might also affect communication (Nelson and Crumpton, 2015). In addition, written language acquisition can be challenging for congenital DHH people (Mayer et al., 2021). For people whose first language is sign language, written language is a foreign language that has yet to be learned in school (Clark et al., 2014). Thus, communication and comprehension of written content on the internet might represent a barrier for DHH people that prevents them from digital participation.

Furthermore, lack of experience with the internet might lead to limited knowledge about how to use digital media and how to communicate online. Rachdito and Hidayat (2022) found that DHH people have difficulties in understanding the meaning of untrue or hoax messages in social media. The authors state that emoticons have an essential meaning for DHH people in digital communication to express their feelings and to prevent misunderstandings with others.

In addition to access to digital media and use of different types of media there are other aspects that should be considered. During the COVID-19 pandemic, when e-learning played a crucial role in school education, DHH students either benefited or were left behind (Rodrigues et al., 2022), which was related to the extent to which the advantages of digital media, such as reading captions or using technology for gaining information, could be used by the students.

So, despite the many advantages and the widespread use of digital media, it is conceivable that there are access barriers for DHH people that lead them being digitally excluded. To date, there has only been little research on this topic.

Digital communication—Social media

Today, digital communication is mainly performed via social media that encompass different types of media, such as video and networking platforms, chat services, weblogs, and others (Taddicken and Schmidt, 2017). Even though these services differ in their modes of functioning, they all serve to establish and maintain social contacts.

An online survey that has been conducted on a yearly basis since 1997 examines to what extent social media are used by people living in Germany (Beisch and Koch, 2021). For this, 2,001 German-speaking people aged 14 or older were questioned about their behavior of internet use through the dual frame procedure, a random telephone sampling using a combination of landline and mobile phone numbers, in 2021. The results show that 94% of the people questioned state that they use the Internet in general. Fifty-nine percentage of those also use social media occasionally, 31% even daily. Among the people aged between 14 and 29, even 66% state that they use the Internet on a daily basis. This means that more than half of the German-speaking people from the age of 14 use social networks daily to watch video and live streams, for example, and to comment on posts (25%), to read articles (44%), or to share, post, or like information themselves and to watch the news feed (52%). Increasing age, however, is correlated with reduced daily use of social media; 39% of the people between 30 and 49 years, 17% of the people between 50 and 69 years, and only 4% of the people over 70 years use social media daily. This decrease is not *per se* only connected to people's age but also to the different experiences with socialization, the access to digital media, and the different personal interests of younger and elder people.

In 2021, WhatsApp (81%), YouTube (40%), Facebook (28%), Instagram (26%), Snapchat (10%), TikTok (9%), and Twitter (4%) were the most favored social media platforms in Germany that are used daily or at least weekly (Beisch and Koch, 2021).

Compared to older adults, adolescents and young adults differ in their preference for different types of social media. Ninety-five percentage of the young target group state that WhatsApp is their clearly preferred tool among all messenger service providers and that they use WhatsApp at least once a week. In this group, the social networks Instagram (73%) and Snapchat (44%) are considerably more relevant than Facebook (35%), closely followed by TikTok with 32%. Twitter is only rarely used by young people (9%).

The representativeness of the current data on the use of social media is controversial as the collection and analysis of data mostly take longer than the different trends and tendencies in the use of certain social media. This particularly applies to adolescents, whose behavior in social media usage changes particularly quickly (Wampfler, 2019).

Today, there are no systematic and large-scale studies on social media use of people with disabilities in general, but there are, for example, reviews on the main challenges to the realization of information and communication technology (ICT)-enabled inclusive development (Raja, 2016). Due to differences in access to digital media depending on the various needs of people with disabilities, studies on social media use of all people with disabilities would be methodologically challenging and difficult to implement. For DHH people, specific findings and needs can be derived, which are described in Section "Findings regarding social media use in DHH individuals—A research gap".

Impact of the use of digital media on mental health

There is no doubt that digitalization and the establishment of social media in everyday life as a consequence thereof have provoked a change in the German society (Buttkewitz, 2020). Some refer to it as revolution of social communication (Leiner, 2012) whereas others regard this change in the creation of interpersonal relationships as digital stress (Müller, 2020). Even though the use of social media is mainly determined by the social needs and motifs of the single users, it is still doubtful if social networks can meet those needs or if they even constitute a risk to the users' mental health (Riehm et al., 2019; Kreutzer, 2020).

This could also be particularly relevant for DHH people as it is known that the implications of a hearing loss can go far beyond the linguistic domain (Vissers and Hermans, 2018). DHH children are at risk in their social-emotional development, in executive functioning, and theory-of-mind development (Fellinger et al., 2008). The prevalence of social-emotional problems in DHH children is about twice to three times higher than in hearing children (Hintermair, 2014). Furthermore, many DHH adolescents experience some degree of isolation from their peers or family (Charlson et al., 1992), and older people with acquired hearing loss often suffer from social isolation and loneliness, which is in turn associated with increased mortality (Shukla et al., 2020).

If social media offer many benefits but also represent a potential risk to mental health, it would be of particular interest to find out how this relates to DHH people. In the following, mental health dimensions are defined and study results on the impact of social media use on the different dimensions of mental health are presented.

The WHO defines mental health as the state of wellbeing in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community (World Health Organization, 2022). According to this definition, mental wellbeing can contribute to an improvement in quality of life, performance, and social participation; it is both negatively and positively influenced by individual, genetic, and biological factors as well as family and social conditions, environmental factors, and living conditions (Hapke et al., 2012).

Negative influencing factors, such as little social support or serious events in life, might foster the development of mental disorders like anxiety disorders, depression, or psychoses which are mostly characterized by burdensome and depressive thoughts, emotions, behavior patterns and relations to others (World Health Organization, 2022). This risk, however, can be encountered by means of specific constructs, such as resilience, self-esteem, self-efficacy, optimism, life satisfaction, hope, feeling of coherence, and social integration (Hapke et al., 2012). This means, all these factors have a complex relation to each other and need to be balanced out successfully to obtain mental health. There are several assessment tools for the scientific evaluation of the different protection and risk factors (Hapke et al., 2012). In this context, potential multidimensional risk factors for mental health are also discussed in relation to the use of social media. In the following, a series of study results are summarized—first in general, then specifically for DHH people.

Self-esteem

By now, social media offer their users innumerable opportunities of controlled self-presentation through posts, disclosure of personal interests, and publicly accessible personal information and photos according to personal preference. As this self-presentation is mostly based on an ideal concept of oneself, which should be liked by as many other people as possible, this results in both social and self-related consequences. Whereas, few studies have shown that the observation of one's own self-presentation on social media might increase one's self-esteem and thus manifest one's own self-concept through self-affirmation (Gonzales and Hancock, 2011; Toma and Hancock, 2013), scientific research in this field mainly focuses on the impact of the observation of other people's social media profiles (Vogel et al., 2014).

Hawi and Samaha (2017) observed in their study that the usage time is related to the self-esteem of social media users: People who frequently use social media (Facebook in this case), have a lower level of self-esteem and try to compensate this lack of self-esteem by a higher activity on social media. In addition, Feinstein et al. (2013), Vogel et al. (2014), and Jan et al. (2017) investigated the impact of social media on the social comparison of oneself with others and on one's self-esteem. In particular, when looking at profiles, posts, and photos of other users who are regarded as highly attractive, sportive or popular, feelings of inferiority arise which might result in depressive symptoms if this feeling comes up too often (Beranek, 2021). Furthermore, they ascertained that users who spend more time on social media than others are more likely to assume that other people are happier and have a better life than they do themselves (Chou and Edge, 2012).

Social integration vs. social isolation

Primack et al. (2017) surveyed 1,787 North American young adults aged between 19 and 32 years and found that more time spent on social media (≥121 min daily) is associated with an increased feeling of social isolation, which in turn impacts negatively on the users' general mental health. As these results are completely contradictory to the actual purpose of social media which is to bring people closer to each other, the authors assume that feelings of social isolation depend on the type of experiences that people make with social media. Another study by Primack et al. (2019) demonstrated that the feeling of social isolation gets strengthened by negative experiences with social media but that this feeling cannot be encountered by positive experiences as initially assumed. Tobin et al. (2015) reported a similar impact of negative experiences and moreover found that social media users, who do not get feedback on their posts, have a decreased sense of belonging and feel socially excluded. On the other hand, there are studies that show that the use of social media can facilitate social integration and reduce the feeling of loneliness. Ellison et al. (2014) and Krämer et al. (2017), for example, concluded in their studies that users who use social media for relationship building and who actively contribute to the establishment, maintenance, and cultivation of social contacts, expand their social capital in doing so. Due to the heterogeneity of social media contacts, this in turn reinforces the emotional and social cohesion, facilitates access to new information and knowledge, and increases the users' wellbeing (Ellison et al., 2014). Further studies found that active and intensive relationship building on social online platforms—besides the establishment of a social capital—also creates a strong community spirit and feeling of connectedness and might considerably reduce the feeling of loneliness (Steinfield et al., 2008; Gruzd et al., 2011; Lou et al., 2012; Deters and Mehl, 2013).

Social media addiction

As many studies revealed intensive social media use as a potential cause of mental health issues, several scientific studies have been trying to find out if excessive social media use equates addiction (Chou and Edge, 2012; Vogel et al., 2014; Andreassen et al., 2017; Brailovskaia et al., 2018; Hou et al., 2019). Indeed, these studies show that excessive social media use might cause symptoms that are normally related to substance addiction (e.g., drugs or alcohol) and that might lead to health issues. As there is no definition of the term social media addiction and as there are no instruments for the diagnosis of social media addiction, Müller (2020) pointed to the criteria for the diagnosis of computer gaming addiction stipulated in Revision 11 of the international statistical classification of diseases and related health issues (ICD-11) which can also be applied to social media use. Based on that, a person is affected by social media addiction if:

- He/she has notably reduced control of the social media use (loss of control).
- The social media use is gaining excessive importance in the user's life, through which other fields of interest and everyday activities get replaced or considerably reduced.
- He/she does not change the behavior of social media use despite noticeable negative impacts in spheres (e.g., social contacts, level of performance, health).
- The psychosocial level of functioning gets constantly impaired by the symptoms mentioned above (Müller, 2020, p. 231).

According to another study by Müller et al. (2018), particularly girls aged between 10 and 17 years demonstrate problematic usage behavior, which meets the criteria mentioned above and which is indicative of an addiction to social media. Experts also assume that excessive social media use can be ascribed to previous critical experience in life, as two thirds of the people questioned answered that they were affected by an extraordinarily strain in the previous year.

Hou et al. (2019), however, observed that social media addiction does not necessarily derive from an already existing reduced mental health status but that the psychological dependence on social media *per se* has a negative impact on mental health, for instance in terms of reduced self-esteem. Experts, however, do not exclude that reduced mental health might in general lead to social media addiction, especially if people with reduced self-esteem try to compensate this through their activities on social media (Hawi and Samaha, 2017).

Brailovskaia et al. (2018) conducted the first study in Germany on this topic: they investigated the relation between Facebook addiction and the users' personality and mental health status and concluded that Facebook addiction does not only derive from excessive Facebook use but that it particularly affects people who constantly thrive for self-affirmation and thus try to increase their self-esteem through positive feedback by others. Furthermore, they observed that Facebook addiction is also accompanied by health issues, such as depression and states of anxiety.

These findings were underpinned by a study by Andreassen et al. (2017) who found that besides people who excessively thrive for self-affirmation also young people, females, singles, university students, people with a low educational level, people with low income, and people with low self-esteem are particularly prone to the development of an addiction to social media. People with disabilities, especially disabilities or disorders that affect communication, were not considered in these studies.

Fomo—Fear of missing out

Reinecke et al. (2017) assume that besides the aspects that were just mentioned there are also motivational factors, such as social pressure and the fear of missing out, that might lead to a problematic usage of social media and thus to digital stress which might manifest in symptoms of burn-out, anxiety disorders, sleeping disorders, depression, inner restlessness, and lack of drive. In this context, the psychological concept of FoMo (Fear of Missing out) is important; it describes the fear of missing out on special events in a social community, of losing popularity, and of getting socially excluded if one does not fully dedicate to the respective community (Müller, 2020). Resulting from this, the people affected develop the need of being constantly informed about what other people do and experience.

Przybylski et al. (2013) first investigated potential risk factors that might promote the development of FoMo. They concluded that the fear of missing out is stronger if the three psychological basic needs of self-determination, self-efficacy, and social integration are not at all or only insufficiently satisfied. Reer et al. (2019) investigated the relation between FoMo and social comparison with others and ascertained that people with psychosocial issue (e.g., depression, loneliness, or states of anxiety) do not only have a high level of FoMo but also strongly tend to compare themselves with others, thus demonstrating a problematic usage of social media. Roberts and David (2020) also demonstrate that the omnipresent opportunities of connecting with other people online might result in a general increase of FoMo.

Different studies finally conclude that people who are strongly affected by FoMo, demonstrate a problematic social media usage (Przybylski et al., 2013; Abel et al., 2016; Reinecke et al., 2017; Reer et al., 2019; Roberts and David, 2020; Tandon et al., 2021). In this context, FoMo constitutes the crucial relation between mental health and social media use (Przybylski et al., 2013; Roberts and David, 2020; Tandon et al., 2021).

Even though these scientific findings hypothesize only negative impacts of the FoMo phenomenon, Roberts and David (2020) highlight that FoMo might also have positive impacts on the users' social connectedness and mental wellbeing if FoMo makes them actively build relationships with others.

Findings regarding social media use in DHH individuals—A research gap

The establishment of social media in everyday life offers great advantages to target groups like DHH individuals because they facilitate communication and relationship building and, as a consequence, social inclusion thanks to the direct communication in writing, audio-based or sign-language posts (Blom et al., 2014; KoŽuh et al., 2015; Martzos et al., 2021). Several scientific findings assume that the primarily written communication on social media helps disguise the hearing loss in many cases which makes DHH individuals feel less stigmatized (KoŽuh and Debevc, 2020). However, the dominance of written language on social media might make passive and active interaction on social media more difficult for DHH individuals depending on their competence in written language, which might in turn further promote social isolation, loneliness and stigmatization (KoŽuh et al., 2015; Martzos et al., 2021).

Mack et al. (2020) found in a survey in DHH individuals that people whose first language is sign language often feel forced to create posts in written form even if their competence in writing is rather low. Although there is the opportunity of uploading and sending videos in sign-language, this is often hindered by bad internet connection, high battery consumption, or low data volume. It is also regarded as challenging to create sign-language videos on social media as the person signing first needs to position the smartphone in a way that the camera fully covers them and as they might even be forced to sign while holding the smartphone in the other hand, which considerably exacerbates sign-language communication on social media. According to the results of the study by Mack et al. (2020), the main reason why DHH individuals primarily communicate in written form on social platforms is the wish for social interaction and participation in digital communication.

As sign-language videos on social media (as opposed to audio-based video posts) cannot be automatically subtitled, the contents of those videos are not accessible to most people, which precludes the opportunity of multimodal and barrier-free communication for everyone.

Nevertheless, digital communication by DHH individuals via social media is primarily seen as relieving as it involves less effort and stress than face-to-face communication or (even worse) telephone conversation (Blom et al., 2014; KoŽuh and Debevc, 2020). In a way, the selection of the communication modality, however, seems to depend on the social platform that DHH individuals are active on and which modality can be used with the least effort. According to a study by KoŽuh and Debevc (2020), this provokes that DHH individuals with good written language knowledge rather use written language on Facebook, for example, as written language is predominant there and regarded as intuitive.

A Greek study on the online behavior of DHH individuals concluded that people focusing on sign language prefer the use of Instagram because they feel at ease when searching for information, communicating with people, looking for entertainment, and building relationships as they can easily communicate via sharing short videos and photos on this platform (Martzos et al., 2021). The video platform YouTube, however, is not barrier-free accessible to all DHH individuals as it mainly uses spoken language although many videos are provided with captions.

Regarding the general usage behavior of DHH individuals in the different social networks, KoŽuh et al. (2015) and Martzos et al. (2021) conclude that DHH people tend to increasingly use digital communication in social networks. Blom et al. (2014) state this is related to the fact that DHH people use social media to reach out to relatives and friends whereas hearing people still prefer to contact people via the phone. This type of relationship building via social media has a huge impact on the feeling of belonging of DHH individuals according to KoŽuh et al. (2015) and Paglieri et al. (2022). Away from that, deaf individuals use social media to spread awareness of the Deaf community (Bart et al., 2022). Yet, there is not much evidence on how exactly digital participation is ensured and to what extent social media use impacts on mental health of DHH individuals.

Lake (2020) conducted a study in 191 North American DHH and hearing university students on the potential relations between the use of social media and feelings of isolation, cultural adaptation processes, self-esteem, FoMo, and social media addiction and potential differences between the study participants. He observed that DHH individuals used four different social media accounts on average which they used daily for around 3.78 h and thus hardly differed from the control group of hearing people. However, this study clearly demonstrated lower self-esteem, a stronger feeling of loneliness, a higher rate of the FoMo phenomenon, and a higher rate of social media addiction in the DHH study participants. The author assumed that the cultural feeling of belonging in deaf individuals who use sign language impacts on the social media use and might be decisive whether DHH individuals exclusively communicate online and interact with DHH people or also with hearing people. Generally, Lake (2020) concluded that people who feel affiliated with the Deaf community spend less time on social platforms.

Materials and methods

Research on digital participation and the psychological impacts of social media use in hearing people is already quite advanced whereas hardly any scientific evidence exists on the potential impacts in DHH individuals. Since it is known that DHH individuals are at a higher risk of being affected by reduced mental health than hearing people (Blom et al., 2014; Bogner and Hintermair, 2021), this article aims to make a contribution to this highly topical and important research field, whereas at the same time, the advantages of digital participation should in no instance be diminished.

The present study is a quantitative cross-sectional study based on a one-off data collection in Germany. The assessment tool used is a specifically designed German online questionnaire. Considering that today web surveys constitute one of the most important and most frequently used method of online surveys, a standardized questionnaire was designed based on the SoSci Survey web application (Leiner, 2019) and provided to the study participants via a link. To ensure data quality, a conscientious and error-minimizing questionnaire design is of utmost importance. Therefore, the online questionnaire was designed based on the study design by Lake (2020), building up from simple to complex topics in order to counteract a high drop-out rate.

The study aims to answer the following questions:

1. What social media usage behavior can be observed among the users surveyed, considering
    - age,
    - usage of different platforms,
    - daily usage time,
    - type of usage (active/productive vs. passive/receptive),
    - communication modality (spoken language, sign language, bimodal-bilingualism, signed speech/key word signing)?
2. How does social media usage relate to the following dimensions of mental health in the people surveyed:
    - Self-esteem,
    - Fear of missing out (FoMo),
    - Feeling of social isolation, and
    - Social media addiction?

After the collection of demographic data, such as age and hearing status, the participants were questioned regarding their interests, personal preferences, and their behavior when using social media and communicating on social media. For this, the participants were at first questioned for which of the seven social media platforms (Facebook, Instagram, TikTok, Snapchat, Twitter, YouTube, WhatsApp) they have an account. Then, the participants were asked to indicate which of the previously mentioned social media they really use. As a next step, the participants were asked about their personal preferences when using social media. Here, they were asked to indicate on a 6-point Likert scale which of the previously mentioned social media they prefer to use to publish content themselves; only the endpoints of the scale were labeled (1 = mostly preferred, 6 = not preferred at all). For the WhatsApp messenger service, information was added in brackets to make it clear to the participants that the aim of the study was to find out about their use of the public status function and not about their private chats on WhatsApp.

The next two questions aimed at assessing how often the participants use the social media and whether they use it rather passively/receptively (reading messages, browsing through newsfeeds) or actively/productively (writing private messages, publishing posts, commenting posts). For this, two 6-point Likert scales were created which the participants were supposed to use for indicating if they use the social media "less than once a day, once or twice daily, 3–4 time daily, hourly, half-hourly, or often than half-hourly", once for the active use and once for the passive use. The next question focused even more on the usage time. For this, the participants were asked about their estimated daily use of the different social media in minutes. Here, the participants could either refer to their documented screen time on their smartphones or give a self-estimation and then enter the time into the open text field.

As a next step, four standardized scales for the assessment of self-esteem, feeling of social isolation, fear of missing out, and degree of social media addiction were applied.

For the assessment of self-esteem, the Rosenberg Self-Esteem Scale (RSES) developed by Rosenberg in 1965 and revised and improved by Collani and Herzberg in 2006 was applied (Rosenberg, 2015). The RSES comprises ten items that alternate between positive (items 1, 3, 4, 7, and 10) and negative (items 2, 5, 6, 8, and 9) statements, which allow for a holistic evaluation of one's own person and personality. In the original version of the RSES, the positive statements are analyzed on a 4-point Likert scale with 1 = strongly disagree up to 4 = strongly agree and in reversed order for the negative statements. The total score can reach between 10 and 60, the higher the score the higher the level of self-esteem. In our study, the RSES was applied as a six-point Likert scale (strongly agree, agree, somewhat agree, somewhat disagree, disagree, strongly disagree). The number of response options in the Likert scale (4, 5, 6, or 11 points) on the scale has no influence on the scale's reliability (Leung, 2011). The revised version of the RSES has a high internal consistency (Cronbachs α) of 0.84 and a high power of the items (between 0.50 and 0.71), which indicates high measurement accuracy and content validity of the translated scale.

To be able to assess the phenomenon of FoMo in this online survey, the Fear of Missing Out Scale (in the following abbreviated as FoMoS) in English language was applied. This scale developed by Przybylski et al. (2013) serves to assess and operationalize the phenomenon of FoMo and measure on a 10-item scale to what extent the participants are affected by FoMo and that other people could have more rewarding experiences than they do themselves. The 10 items are to be answered on a 5-point Likert scale (1 = "does not apply at all" up to 5 = "fully applies"). The total score can range from 10 to 50; the higher the score, the higher the degree of FoMo. The FoMoS is generally considered to have a high level of reliability and internal consistency of Cronbachs α = 0.87 up to 0.90 (Elhai et al., 2020).

The feeling of social integration and social isolation was assessed using a translated version of the originally English assessment tool Patient-Reported Outcomes Measurement Information System Social Isolation Scale (PRO-MIS SI-S) (Health Measures, 2016). This is a standardized scale in different versions that only differ from each other in the number of test items. In the present study, the Short Form v2. Social Isolation 8a version was used, because in this version, in contrast to the original version, all participants answer the same questions, which in turn allows for direct comparison of the data collected. With the PRO-MIS SI-S, the study participants were confronted with eight statements on the subjective perception of the feelings of social exclusion and loneliness which the participants were asked to evaluate on a 5-point Likert scale (1 = "never" up to 5 = "always"). A t-value higher than 50 corresponds to an excessive perception of feelings of social exclusion and loneliness and thus to a higher perception of social isolation. The PROMIS SI-S is a scale with an excellent internal consistency (Cronbachs α = 0.92) and high validity and measurement accuracy (Primack et al., 2017).

To assess a potential social media addiction among the study participants, the Social Media Disorder Scale (SMDS) was used (van den Eijnden et al., 2016). This scale comprises nine dichotomous-discontinuous items which the participants could simply answer with "yes" or "no". The items relate to retrospective self-estimation and survey if the participants observed a feeling or behavior of conquering thoughts, withdrawal symptoms, tolerance development, unsuccessful attempts of abstinence, or loss of interest in previous activities in themselves in the past year. If at least five items are answered with a "yes", a social media addiction is diagnosed according to the SMDS. With a high internal consistency (Cronbachs α = 0.81) and a high validity and reliability, this scale is regarded as a suitable tool for the diagnosis of social media addiction.

The RSES for the online survey within our study was available in the revised version by von Collani and Herzberg (2006) in German whereas the FoMoS, PROMIS SI-S, and SMDS were only available in the original English version. Therefore, they were translated into German based on the principle of back-translation (Brislin, 1970). This means, the three original English scales were translated into German and reviewed by experts. The back-translation into English was then done by an English native speaker who was not familiar with the original English version of the scale. The two English versions of the three scales were than compared to each other, checked for translation quality and equivalence, and a final German version of the scale was created based on this.

To answer the research questions, Pearson correlation analyses and Spearman rank correlation tests were conducted.

Participants and recruitment

For the recruitment of the sample, DHH people involved in 12 German-speaking Facebook groups on topics about deafness and hearing were invited to participate in this online survey. The invitation was also forwarded to DHH students of the University of Cologne via Facebook. The inclusion criterion was a person's age over 18 years and the indirect inclusion criterion of written language comprehension since the questionnaire was only offered in written modality. At the beginning of the survey, the respondents were informed about the purpose and content of the survey. Subsequently, the participants gave their consent to participate in the survey by accepting the privacy statement.

Within 3 weeks, the link to the online survey was opened 257 times; 51 of these 257 people partially completed the questionnaire, 38 people fully completed the questionnaire. This means, 14.8% of the 257 link clicks resulted in a complete participation in the survey. To avoid data distortion, only fully completed online questionnaires were included in the study. In the other remaining 13 cases, where the questionnaire was only partially answered, a reason for dropout is not always apparent. In three quarters of the cases, the dropout occurred after the first few pages, in others at a later time. It is possible that the written modality of the questionnaire presented a barrier in some cases. However, it is not possible to conclude this with certainty. All participants who only completed part of the questionnaire, were not included in the study and in the data analysis.

TABLE 1 Participant overview.

Participant information	Deaf and hard of hearing (DHH) social media users ($n = 38$)
Age: mean (standard deviation)	40.61 (14.37)
Gender: n_{women} (%$_{\text{women}}$)	28 (73.6)
Communication modality: n (%)	Spoken language: 18 (48) Bimodal bilingual: 13 (34) Signed speech/key word signing: 2 (5) Sign language: 5 (13)

The sample of the people surveyed comprises 38 DHH adults (28 female, 10 male) aged between 19 and 69 years ($M = 40.61$, SD $= 14.37$). Almost half of the 38 ($n = 18$; 48%) state that they only communicate in spoken language in their everyday lives (Table 1). Five of the 38 (13%) state that they only communicate via sign language; 13 of the 38 (34%) are bimodal-bilingual users as they use spoken language as well as sign language. The data were based on self-assessment. In addition to the predefined options of spoken language, sign language and bimodal bilingualism, there was the possibility to select the option "other forms of communication". Here, both sign supported speech and key word signing were named. Only two persons of the 38 (5%) state that they primarily communicate using sign supported speech and key word signing as a supportive medium for spoken language.

Data analysis

For the data analysis, correlation analyses were performed using the SPSS Version 28.0.1.1 statistical software. For the at least interval-scaled variables, the Pearson correlation was performed which served to analyze the power of the linear relation between two variables. For the at least ordinal-scaled variable, the Spearman's Rho ρ correlation coefficient was calculated, which also tests the power and the direction of the relations.

Results

As expected, the participants in the study were extremely diverse, which becomes particularly evident in the type of hearing care they use. The majority of the study participants (42%) is provided with hearing aids on both ears. This group mainly comprises people who communicate in spoken language and bimodal-bilingual people. Thirteen percentage of the participants have a cochlear implant on either one ear or both ears. Ten percentage use a hearing aid in one ear. Four participants (11%) state they do not use any type of hearing aid or hearing implant. Three of these four participants communicate via sign language whereas one of the four uses both sign langue and spoken language in everyday communication. Four participants stated they use a different type of hearing aid or implant (11%). One of them has bimodal provision with an active bone conduction implant and a hearing aid. One person uses a CROS (Contralateral Routing of Signals hearing aid for unilateral hearing loss). One person has bimodal provision with a hearing aid and a cochlear implant. One person stated that she would get the first cochlear implant soon. The data on the diversity of hearing care and thus on the hearing status of the participants reflect the heterogeneity of the group of people with DHH. The onset of hearing loss (congenital, acquired) was not recorded in the questionnaire.

Social media use

The study participants were first asked whether they preferred face-to-face or digital communication. Fifty-eight percentage stated that they preferred face-to-face communication with friends and acquaintances whereas 60% preferred communication with foreign people via chat.

On average, the 38 people surveyed have 4.13 accounts on different social media platforms. All study participants in our sample have at least one account. The daily usage time is 3.78 h according to self-estimation. With an average daily use of 170 min (∼2.8 h), our study participants communicating in sign language are below average.

Eighty-seven percentage of the people questioned stated that they use WhatsApp. This is the most frequently used social media platform in our survey. Most WhatsApp users (52%) only use spoken language in their everyday life. The second most popular social media network among the study participants is Facebook. In total, 26 people (68%) stated that they really use their Facebook account. Most Facebook users (54%) also use spoken language in their everyday life. The third most frequently used social network with 25 active accounts is Instagram. Forty-four percentage of the Instagram users in our study are bimodal-bilingual users. The fourth most frequently used network with quite a gap to Instagram is the video platform YouTube. Twelve people stated that they really use their accounts on this platform. Half of the YouTube users in our study are people who only use spoken language in their everyday life. The other half comprises two users who use sign language and four users who use both spoken language and sign language in everyday communication. TikTok ($n = 7$), Snapchat ($n = 6$), Twitter ($n = 4$), and other platforms are considerably less frequently used social media tools.

Table 2 shows how often the study participants receptively use social media according to their self-assessment, e.g., for reading messages or going over the newsfeed. On the other hand, it shows how often they productively use social media to write private or public message and to publish, share or comment content. Only 38% of the people questioned state that they use social media less frequently than on a daily basis. Most people surveyed (45%; $n = 17$) use the different social media channels passively three to four times a day. Similar to this, these channels are also actively used three to four times a day by most people surveyed (32%; $n = 12$). Ten percentage of the study participants ($n = 4$) actively use social media even more often than half-hourly; 5% ($n = 2$) of the study participants state that they do so passively.

TABLE 2 Comparison of passive and active social media use.

Passive and active social media use	Passive: *n* (%)	Active: *n* (%)
	DHH (*n* = 38)	DHH (*n* = 38)
Less than daily	1 (2.6)	9 (23.7)
Once or twice a day	9 (23.7)	7 (18.4)
Three or four times a day	17 (44.7)	12 (31.6)
Hourly	5 (13.2)	5 (13.2)
About half hourly	4 (10.5)	1 (2.6)
More often than half-hourly	2 (5.3)	4 (10.5)

Thirty-five of the 38 study participants provided information on their daily social media use. The people surveyed stated that they spend 203.31 min per day on social media on average (SD = 176.31). with a range of $r = 993$, the values of usage time range between 27 and 1,020 min per day.

With a mean usage time of 269.91 min (SD = 227.18; $R = 993$), the bimodal-bilingual participants use social media the longest every day. The social media community Facebook is mostly used by people solely communicating in spoken language with a usage time of 54.35 min per day (SD = 48.47; $R = 120$). Also, the study participants using spoken language in everyday life have the highest daily usage time on Twitter with an average of 3.81 min (SD = 14.99; $R = 60$), 22.94 min on Youtube (SD = 54.26; $R = 200$) and 70.06 min (SD = 59.20; $R = 190$) on WhatsApp. 23 of the 35 study participants (66%) reach the critical value of ≥121 (Primack et al., 2017) minutes social media use per day.

Social media and mental health

In the following, the results of the participants in the four scales of mental health are briefly explained, taking into account that in some cases there were only very few participants per group, e.g., only two participants using signed speech or key word signing and five participants using sign language. Table 3 provides an overview of the mean and the standard deviation of the test results of the four different scales obtained, also factoring in the participants' communication modality.

The lowest scores for self esteem were achieved by the sign language users (RSES score: 35.40). The other participants scored higher for self-esteem with an average gap of up to 10 score points compared to the sign language users. While the two people who used signed speech and key word signing scored highest on self-esteem, their scores on fear of missing out were also highest (FoMoS score: 25.50).

In terms of social isolation, the average of the participations in the sample fell below the critical value of the scale. Here, the spoken language users were the most affected according to their self-assessment (PORMIS SI-S score: 55.11; critical value: >50).

Subsequently, when looking at the results of the social media disorder scale, the participants of this study did not show any results above the critical value on average. The highest scores, and thus those closest to the critical value, were observed among the

TABLE 3 Results of the scales considering the communication modality.

DHH ($n = 38$)	Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 2015) (German version)		Fear of Missing Out Scale (FoMoS) (Przybylski et al., 2013) (Translated into German)		Patient-Reported Outcomes Measurement Information System Social Isolation Scale (PROMIS SI-S) (Health Measures, 2016) (Translated into German)		Social Media Disorder Scale (SMDS) (van den Eijnden et al., 2016) (Translated into German)	
	M	SD	*M*	SD	*M*	SD	*M*	SD
Min–max	10–60	–	10–50	–	33.9–76.9	–	0–10	–
Critical value (if applicable)	–	–	–	–	**>50**	–	**≥5**	–
Sign language users ($n = 5$)	35.40	6.77	20.80	10.62	52.56	5.79	3.40	2.70
Spoken language users ($n = 18$)	43.83	8.42	22.11	6.28	55.11	7.06	1.28	1.96
Bimodal bilingual users ($n = 13$)	44.85	7.95	20.08	6.54	51.95	4.40	2.31	2.32
Signed speech/key word signing users ($n = 2$)	46.50	6.36	25.50	4.95	52.65	5.30	1.50	0.71
Mean in total	43.21	8.31	21.00	6.80	53.56	5.98	1.92	2.21

Marked in gray: lowest score for self-esteem/highest score for fear of missing out; scores above critical value; marked in bold: critical values; M, mean; SD, standard deviation.

TABLE 4 Pearson correlation analyses of different aspects of social media use and dimensions of mental health.

	(1)	(2)	(3)	(4)	(5)	(6)	(7)
(1) Age	–						
(2) Daily usage time	−0.064	–					
(3) Number of social media accounts	−0.056	0.124	–				
(4) Self-esteem	0.085	−0.216	0.384*	–			
(5) Fear of missing out	−0.083	0.316	−0.320	−0.437**	–		
(6) Social isolation	0.141	0.053	−0.273	−0.509**	0.458**	–	
(7) Social media addiction	0.177	0.350*	−0.230	−0.392*	0.377*	0.339*	–

$^{*}p < 0.05$; $^{**}p < 0.01$; $r = 0.01$ (small effect); $r = 0.03$ (medium effect); $r = 0.05$ (high effect).

sign language users (SMDS score: 3.40; critical value ≥ 5). Six of the 38 study participants (16%) had a critical value of more than 5 points on the SMDS scale.

Table 4 shows the results of the Pearson correlation analyses of social media use and the different dimensions of mental health.

The participants' age neither correlates with the behavior of usage of social media nor with their mental health (time of usage: $p = 0.703$, daily used social-media accounts: $p = 0.737$, RSES: $p = 0.612$, FoMoS: $p = 0.621$, PROMIS SI-S: $p = 0.399$, SMDS: $p = 0.288$). Moreover, the time of usage is not related to self-esteem ($p = 0.193$). However, as expected, there is a significant positive correlation of medium degree between the daily time of usage of social media and social media addiction ($p < 0.05$).

Likewise, the Pearson correlation coefficient shows a significant positive correlation of medium degree between the daily used social media accounts and the study participants' self-esteem ($p < 0.05$). In addition, there is a significant highly negative correlation between the participants' self-esteem and the feeling of social isolation ($p < 0.01$). Moreover, the Pearson correlation coefficient shows significant medium-high negative correlations between the participants' self-esteem and the degree of FoMo ($p < 0.01$) and social media addiction ($p < 0.05$). The degree of social media addiction correlates significantly positive with the degree of FoMo ($p < 0.05$) and the personally perceived feeling of social isolation ($p < 0.05$). Furthermore, a significant positive correlation between the personal perception of social isolation and FoMo was observed ($p < 0.01$).

Table 5 shows the results of the Spearman rank correlation test.

There is a significant highly positive correlation between the frequency of daily active social media use and personally perceived social isolation ($p < 0.01$) and a significant medium-high positive correlation between active social media use and the degree of social media addiction ($p < 0.01$). However, no significant correlation was observed between the frequency of daily passive social media use and the participants' mental health.

Discussion

Digital participation is essential for DHH people and digital media offer many advantages, but they might not be fully accessible to everyone. Access for DHH people is not so much a technical

TABLE 5 Spearman rank correlation test of different aspects of social media use and dimensions of mental health.

	(1)	(2)	(3)	(4)	(5)	(6)
(1) Social media use (active/productive)	–					
(2) Social media use (passive/receptive)	0.205	–				
(3) Self-esteem	−0.109	−0.215	–			
(4) Fear of missing out	0.246	0.150	−0.426**	–		
(5) Social isolation	0.511**	0.063	−0.452**	0.476**	–	
(6) Social media addiction	0.415**	0.151	−0.469**	0.493**	0.370*	–

$^{*}p < 0.05$; $^{**}p < 0.01$; $r = 0.01$ (small effect); $r = 0.03$ (medium effect); $r = 0.05$ (high effect).

issue but more influenced by competencies such as spoken/sign language and communication skills (Constantinou et al., 2018). In terms of communication, especially social media play an important role today. Social media offer both chances and risks as far as new opportunities of digital and social participation but also negative impacts on people's mental health are suspected (Karim et al., 2020).

The way how DHH individuals use social media for digital participation and how social media affect the different dimensions of their mental health has hardly been investigated to date. The present study contributed to this topic by looking at social media use as well as correlations between usage and mental health of DHH people.

The results show that the people in this study who use sign language for everyday communication use WhatsApp the least with a daily usage time of 31 min. Also, they only spend 1 min per day on Twitter on average. This suggests that passive and active social media use, particularly on primarily written language-based social media platforms, such as WhatsApp or Twitter, seem to be less attractive for people communicating in sign language and thus are less frequently used by this population. With an average daily usage time of 54.35 min on Facebook and 22.94 min on YouTube, people using spoken language for everyday communication spend the most time on these platforms.

However, particularly with the use of Facebook one can see that the usage time in the participants communicating in sign language only differs by 10 min from the usage time in the participants communicating in spoken language (sign language users: 44.00 min; SD = 47.09; $R = 120$). This might be explained by the fact that Facebook offers manifold functions and opportunities of communication and interaction that can be used regardless of the communication modality. The photo and short video platform Instagram is the mostly used social media platform among the study participants communicating in sign language with a daily usage time of 75 min.

In summary, we can state that the social media use of the DHH participants surveyed in our study does not generally differ from other people's behavior of social media use. The results of the 38 people with DHH surveyed comply with the study results of Lake (2020) in that the number of accounts (4.13 on average) and usage time of social media (3.78 h per day) of our study participants do not differ from other DHH individuals or hearing adults.

Nevertheless, DHH people communicating in sign language are below average in social media usage time of 2.8 h per day. This also confirms the results of the study by Lake (2020) who found that people who use sign language tend to spend less time on social media than hearing people or DHH individuals who communicate in spoken language. Access barriers could be responsible for this, mainly a lack of sign language communication on the internet and difficult access to written information. Consequently, there seem to be differences in DHH people in the use of social media depending on the preferred modality of communication. People mainly communicating in sign language in everyday life rather tend to use intuitive photo and video platforms, such as Instagram, whereas people mainly communicating in spoken language rather tend to be more active on social media platforms that primarily provide content in written or spoken language.

Apart from differences in social media use, which may be affected by access barriers or low attraction, the question arises to what extent social media influences the mental health of DHH people, especially adolescents, who represent a vulnerable group here (Brown and Cornes, 2015).

In this study, there was no correlation between **(a) self-esteem** of the DHH participants surveyed and the number of social media accounts, the usage time or usage mode (active/productive vs. passive/receptive). On the contrary: the more social media accounts the DHH study participants had, the higher their level of self-esteem was.

Regarding the impact of social media use on **(b) the fear of missing out (FoMo)**, the study results indicated that according to the participants' self-estimation they were only affected by slight degrees of FoMo. No significant correlation between the time of social media use and the number of used accounts or the degree of FoMo was observed.

Regarding the phenomenon of **(c) social isolation**, it was observed that the DHH study participants exceeded the critical t-value of the PROMIS SI-S by 2.56 points on average and thus experienced more feelings of loneliness and social exclusion than the hearing participants from the norm sample. This outcome was not related to the communication modality although the spoken language users scored highest in the feeling of social isolation. The results show that the perception of social isolation and loneliness is associated with more frequent active social media use. Passive social media use, however, is not related to the perception of social isolation and loneliness.

Regarding the **(d) social media addictive behavior**, a significant correlation was observed between the active time of social media usage and social media addiction: the more the DHH study participants actively used social media, the more frequently they were affected by social media addiction. The length of passive social media use, however, has no impact on the personal perception of addiction.

Based on the findings of this study and considering the main research question, how all of these findings affect digital participation of DHH people, there are several aspects to consider: First, digital participation can not be measured as the time spent using digital (and in this case social) media, as it becomes clear that there also might be possible risks—not only for DHH people (Brown and Cornes, 2015). Rather, digital participation could be measured by the extent to which a person sees him- or herself as self-efficacious when it comes to using digital media. This could be achieved with qualitative research approaches. Second, our study sample of DHH adults had high values in the perception of social isolation. Thus, there is a need for research into the extent to which digital participation can lead to a sense of being part of the society and whether social media can make a positive contribution here.

However, in this study only correlations were determined. This means we could not determine if social media have a negative impact on mental health of DHH people or if those who are generally exposed to different risks regarding their mental health are more likely to develop a problematic and addictive behavior of social media use. To find that out, further studies with a mixed method study design (quantitative & qualitative) and long-term studies are needed.

Limitations

The validity of the results of the present study is subject to several limitations. The sample of 38 DHH study participants is too small to be able to draw conclusions for the entire population of DHH adults. The recruitment mode also needs to be looked at critically as most of the recruiting was done via the social media platform Facebook, which bears the risk of selection bias. Moreover, everybody could decide for themselves if they wanted to participate in the study or not. Maybe people who observed a problematic social media usage behavior in themselves did not participate in the study because they felt uncomfortable with this topic.

Data collection might also be criticized. When developing the questionnaire, for example, four scales for the assessment of mental health were used but the language level was not adjusted. Some of the items were highly complex statements and formulations which were probably hard to understand or not understandable at all for people who find it difficult to process written language. To make the participation in the study easier, the survey would also have to be provided in sign language videos and written plain language in addition to the original written version; this is highly recommended for future studies. However, offering the scales in two versions (written and sign language) as well as different difficulty levels of the written modality would have required validation of the questionnaire first, so that without validation the results of this study in different language versions would have been limited.

It should also be noted that the scales used in the questionnaire are originally paper and pencil versions that have now been transferred to an online version. Although attention was paid to ensure that the scales did not differ visually from the paper and pencil versions, it is possible that completing the online version may have resulted in different response effects than completing the paper and pencil version. In an online version, for example, questions cannot simply be skipped, as access to the next page is sometimes only possible once all questions have been answered.

Another limitation refers to the assessment of the daily time of social media use in minutes because the study participants could decide for themselves whether they entered the subjectively estimated time of usage per day or the usage time that appeared on the screen of their smartphones. The self-estimation of daily social media use might result in false estimations.

This study raises further questions on the positive effects of social media on social participation and contribution of DHH people that should be further investigated. Future studies in this research field might be designed in a way that they involve greater samples and people mainly communicating in sign language by means of sign language translations.

Conclusion

The results of this study provide a basis for further studies. As DHH people, especially those who use sign language, are generally more at risk of being excluded than hearing people (Silvestri and Hartman, 2022), new strategies for digital participation are needed, and social media might offer them. Access to digital media for DHH people does not only apply to compensations offered by technology, for example captioning, sign language videos or other techniques, but also opportunities for increasing interaction, for improving language skills, for enhancing learning experiences and motivation while using digital media (Toofaninejad et al., 2017). For DHH school education, this opens completely new possibilities.

A participatory research approach would be desirable, in which digital media are developed and improved together with DHH people. Access can be very different for DHH people, so that, for example, not all DHH people benefit from sign language videos. For others, high audio quality is extremely important, or the captioning of spoken language, or visual support of information, or the use of written plain language, or many other aspects that consider the diversity of the group of DHH people.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. The patients/participants provided their written informed consent to participate in this study.

Author contributions

KS and FM conceived the study and contributed to its conception and design. KS wrote the manuscript. FM collected the data and conducted the data analysis with the assistance of KS. Both authors read and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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EDITED BY
Petra Jaecks,
Bielefeld University, Germany

REVIEWED BY
Hendrik Buschmeier,
Bielefeld University, Germany
Kristina Jonas,
University of Cologne, Germany

*CORRESPONDENCE
Michael Wahl
✉ michael.arnold-wahl@hu-berlin.de

†These authors have contributed equally to this work and share first authorship

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Augmentative and Alternative Communication and digital participation

Michael Wahl*† and Katharina Weiland†

Section Rehabilitation Technology and New Media, Department of Rehabilitation Sciences, Humboldt-Universität zu Berlin, Berlin, Germany

Communication is a basic need for all people to fully participate in life. Persons with disabilities may face particular challenges in developing their communication skills and using them appropriately in different situations. Augmentative and Alternative Communication (AAC) tools and methods can assist individuals in this process. Increasing digitization has changed the way everyone communicates, and this offers opportunities for persons using AAC. This paper briefly outlines what has been achieved in terms of digitalization in AAC. The need for full, adapted access to technology is highlighted and research desiderata are identified.

KEYWORDS

Augmentative and Alternative Communication, digitization, new technologies, participation, barrier, special needs

Introduction

Today's societies are characterized by a high degree of digitization in many areas of life. Accordingly, participation in digitization is commonplace and a natural part of life for many people. The following reflections on participation will focus on the issue of social participation in digital environments (Bernasconi and Terfloth, 2019).

Persons with disabilities are at particular risk of exclusion in digital contexts, as they are particularly affected by the 'digital divide' on the first level: they are statistically less likely to have access to digital devices and the internet, their daily activities in digital environments are correspondingly lower, and surveys show that they feel less included in digital society (Scholz et al., 2017; Johansson et al., 2021; Mason et al., 2021). The extent of the digital divide appears to vary by disability. The group reporting the greatest difficulties in using digital applications and the internet includes people with communication, speech and language disorders (Johansson et al., 2021).

Impairments in speech, language and communication affect a basic human need that is essential for development, empowerment and social participation, as well as psychological wellbeing. Accordingly, the International Classification of Functioning, Disability and Health (ICF) highlights the importance of communication as a core area of activity and participation. It relates to the roles of individuals as receivers and senders of messages, as well as the use of communication devices and techniques (ICF: d3). Participation limitations are threatened when individuals are impaired in their spoken and/or written language skills.

The focus of the further explanation is on social participation with all aspects of social inclusion in everyday environments. Communication and interaction are of great importance in this area, as social participation includes aspects of one's own communicative initiative as well as the role of a person as an addressee of communication. Digital spaces and digitally mediated communication are an essential part of everyday life and therefore the barriers to access for people with disabilities must be considered and reduced. The legal basis for this is the United Nations Convention on the Rights of Persons with Disabilities (CRPD): Article 9 of the CRPD emphasizes the potential of information and communication technologies for the empowerment and participation of persons with disabilities in all aspects of life.

The group of people with limited communication skills–very heterogeneous in their resources and needs–can benefit from Augmentative and Alternative Communication (AAC). The target population for AAC includes all individuals whose currently available resources of natural modes of expression are inadequate for satisfactory communication. This condition may be temporary, prolonged, or expected to be permanent. This group includes neurological disorders such as stroke (Dietz et al., 2020), amyotrophic lateral sclerosis (ALS) (Peters, 2022), people with congenital or acquired physical-motor disorders such as infantile cerebral palsy (ICP) (Hidecker, 2022), people with intellectual impairments such as Down syndrome (Shahid et al., 2022), Rett syndrome (Unholz-Bowden et al., 2023), and people with temporary communication impairments such as those resulting from accidents, surgery, or shock (Cummings, 2023). The use of AAC may be considered, for example, as an aid to language acquisition or as a means of expression for individuals who do not communicate through spoken language. AAC encompasses a wide range of methods and interventions that facilitate successful communication. A mix of methods and procedures is usually used to ensure appropriate expression in a variety of life situations. These may include endogenous methods such as gestures, sounds and facial expressions. In addition, non-endogenous methods are used, such as pictures, symbols, or talking buttons and speech computers (Spreer and Wahl, 2020).

In order to provide a form of AAC that is appropriate to the individual's communicative needs and abilities, it is necessary to look closely at the individual. The Participation Model (Beukelman and Mirenda, 2005) analyses needs and interventions by comparing wants and needs with current opportunities. Patterns of participation vary from person to person, so precise interventions are needed. AAC aims to achieve participation equivalent to that of non-disabled peers. Assessing the person's activities in different areas (work, school, leisure) and comparing them with non-disabled peers helps to set realistic goals. Assessment of current participation and communication skills is essential. The model assumes equal social participation for people with communication impairments. Identifying and reducing barriers to opportunity and access are critical to the successful implementation of AAC. Barriers to access are similar to deficits in contextual factors in the ICF.

The starting point for the following considerations are the issues identified by McNaughton and Bryen (2007) as priorities for research and development in the field of AAC. The focus is on technologies to enable remote communication and connectivity, as well as adapted applications and tools. New developments in recent years, such as those arising from social media, will be addressed.

Digitization in Augmentative and Alternative Communication

Resources available in AAC can be classified according to their technical complexity: "No-tech AAC" are endogenous resources, such as gestures, vocalizations, muscle tone etc., "low-tech AAC" are simple communication aids such as picture boards, etc., "mid-tech AAC" include simple electronic devices such as buttons to display messages. Of particular interest for digital participation considerations are "high-tech AAC" devices, which are dynamic devices that contain page sets of letters, words, phrases, pictures, and/or symbols that the person navigates between to compose messages (Elsahar et al., 2019). As communication tools, high-tech systems can often be used for other functions and usually have interfaces with digital applications e.g., environmental control for windows, doors or E-mail program and consumer electronics (Chen et al., 2021).

High-tech systems have become particularly important since the introduction of tablet computers because they are readily available, inexpensive, and usually easy to use or adapt. The rapid development of these digital technologies has brought great advances in mobility and independence for people who use AAC.

Smartphones and tablet computers are widely used around the world, both to expand communication options and to enable interaction at different levels, such as in social networks. People with disabilities benefit equally from these extensive opportunities, as these technologies allow these groups to interact and access information in the same way as people without disabilities (Isaksson and Björquist, 2021). In their study, Bryen et al. (2017) showed that exactly the same standard applications on devices are used by people with disabilities as by people without disabilities. For example, sharing photos and videos, browsing the web, and sending text messages are just as common. However, a large proportion of the people surveyed in the study say that there is an urgent need to adapt and modify the usability of devices to meet their needs. At the time of the study, however, such adaptations were not standard. In recent years, hardware manufacturers have taken a number of steps to improve usability and accessibility. Features such as reading aloud, voice control, and customization options such as colors, font sizes, fonts, etc. are now standard on devices. They allow for extensive customization of device interfaces and functionality. Persons with disabilities in particular benefit from these customization options (Gandhewar and Mohan, 2022).

In particular, AAC users can benefit from the very generous adaptability of devices and gain broad access to the use of devices, but AAC users sometimes require highly specialized applications and input capabilities that are often not covered by the current adaptability of devices. In recent years, more work has been done to create accessibility guidelines for technology, which aim to design technological solutions so that they can be beneficially used by people with communication disabilities (Saturno et al., 2015). For example, Samuelsson and Ekström (2019) showed that technological aids can be used beneficially by people with dementia by enabling them to talk about important aspects of their lives. In particular, they showed that people with dementia were more likely to take the initiative to communicate using technology, i.e. to create communication opportunities in a self-determined way.

McNaughton and Light (2013) have already shown that the use of new digital devices, especially the iPad, a tablet computer manufactured by Apple Inc., is particularly high among people with disabilities. These devices are potentially less stigmatizing than traditional classic voice recorders and voice computers because they fit in any pocket and (may) lead to greater social acceptance due to their shape, size, and usage options. The introduction of the iPad as a mass market device in 2011 has led to major changes in the AAC community as these devices open up a wide range of possibilities for AAC use. There are a number of requirements that need to be met in order for this to happen. Among other things, it is desirable that manufacturers provide as many options as possible, e.g., for entering commands, text, letters, words, etc., so that individualization can be easily achieved (McNaughton and Light, 2013; Buchholz et al., 2020). In addition, there is a focus on the usability of applications. The design of applications applied to devices is sometimes very creative and thus violates recommendations for the design of online applications, such as the current Web Accessibility Guidelines (https://www.w3.org/WAI/standards-guidelines/wcag/), and is therefore very often not optimally implemented in terms of design, adaptability and control (Du et al., 2022). It is essential that manufacturers work closely with research and development, but also with users, to best understand the needs of the people who will later use the devices (McNaughton and Light, 2013). For a recent review of accessible application design see Zaina et al. (2022).

On the other hand, there is an urgent need for trained individuals who understand the possibilities of using technology in the context of AAC. For example, according to a study by Mackenzie et al. (2016) that examined the provision of digital technologies to patients with ALS, the timing of provision is critical. Patients, who also use the devices primarily for applications such as writing messages, online shopping, searching for information, video telephony, etc., need to be introduced to the possibilities of using the devices beyond traditional input methods such as mouse and keyboard in a timely manner. This requires extensive knowledge on the part of caregivers about the use of alternative input methods, such as eye control. Sebold and Renner (2019) focused their study on the usability of technologies and concluded that different input devices play an important role in the care process of people with physical impairments on the hardware level, but on the software side, features such as word and text prediction positively influence the communication possibilities.

Augmentative and Alternative Communication in Digitization

Digitization has led to profound social changes in recent years. The use of media has become a matter of course in many areas, and it is impossible to imagine life without it. The development of technologies, the collection and storage of data, and the increasing automation of processes have led to lasting changes in people's working and living environments. The age of digitization is characterized by cultural and social realities and ways of life that go hand in hand with digitization, make it possible, and have become the norm for people (Stalder, 2016). This in turn requires that people have the opportunity to use digital technologies. Here, however, especially for people with disabilities, technical barriers mostly arise with regard to the accessibility and usability of digital technologies. As indicated in the previous section, there is an urgent need to open up opportunities for people to use technologies to enable (social) participation. Light and McNaughton (2014) state that the removal of barriers on the one hand and environmental support on the other hand play a very important role in the acquisition of communicative competence for people who use AAC in order to, among other things, increase confidence in one's own abilities so that the necessary communicative competence can be built up at the linguistic, operational, social and strategic levels. Everyone has complex communication needs. Individuals who require and use AAC to communicate exhibit a further increase in complexity. Light (1989) defines a complex dynamic interpersonal construct for this group of individuals that emphasizes functionality and appropriateness of communication and postulates sufficient knowledge, judgment, and appropriate skills as its foundation. In the age of digitization, this construct must also be considered in relation to communication in digital space.

New technologies, such as tablet computers, are opening up new spaces for face-to-face communication by using them as voice computers or talkers. However, people with disabilities are also using them to communicate at a distance. For example, Hynan et al. (2014) show that the use of online social media is a way for people to participate in social life in a self-determined way and to enrich social relationships at different levels through self-expression in the networks. However, according to the authors, support, especially at the technical level, from educational institutions, families and friends is essential in order to be able to use these new forms of communication.

People with disabilities are particularly dependent on support when using digital media (Ramsten et al., 2020). These support needs are particularly relevant for people with intellectual disabilities, learning disabilities, and motor impairments. When appropriate support is provided, the use of digital technologies is possible in a variety of settings, which can have a positive impact on an individual's participation (Darcy et al., 2016). Digitization enables participation and improves quality of life. Caron and Light (2015) interviewed people with ALS in an online focus group about their use of social media. Participants emphasized that social media can strengthen links with communication partners and (other) support networks. Particularly for ALS patients, whose ability to communicate changes significantly over the course of the disease, access to different forms of communication is an essential component of continued independent participation in social life. Digital social networks can be a key component that should not be underestimated. These effects can also be demonstrated for people with motor disorders such as ICP (Caron and Light, 2016).

Very often, however, there are barriers within the technologies that make them difficult for these groups to use, and these need to be addressed first. Once these barriers are overcome, digital technologies are widely used. Hemsley et al. (2015) examined the use of the social network Twitter by people with communication impairments and found that the networks were primarily used to converse with others at the micro (direct communication with individual other users) or meso level (communication with the group of followers), less often to participate in discussions of larger and unknown groups via hashtags (macro level). Users' own social presentation was clearly in the background. A recent study analyzing posts on the social media platform Instagram highlighted its relevance for young adults in terms of identity representation (Tollan, 2022), which seems to be particularly important with regard to the normalization of disability in everyday life. Thus, social media can also play an important role in self-advocacy.

Discussion

The studies briefly reviewed here show that digitization is profoundly expanding the possibilities for interaction between people, and that people with disabilities also want to and do use communication in the context of digitization. The expansion of communication and interaction opportunities through the use of digital technologies is an essential component for the full participation of persons with disabilities in society and is, in principle, already enshrined in law from a human rights perspective. In addition to the use of AAC technologies as communication aids in face-to-face interactions, the potential for their use in digitally mediated communication, such as social networking, is enormous. People who use AAC can benefit from the asynchronous nature of digital communication, which often does not require an immediate response.

A prerequisite for participation in digitization on the part of the person who uses AAC is not only appropriate technical equipment, but also a supportive network of professionals, family members, and peers. All stakeholders need extensive knowledge, which in turn can be improved through training opportunities. Encouraging individual case studies (e.g., Grigis and Lazzari, 2013; King et al., 2020) indicate that the use of high-tech AAC can be learned by different user groups. Professionals should be made aware that communication needs exist beyond the personal, close environment and face-to-face interaction, and appropriate resources need to be provided.

However, the removal of communication barriers should not only be considered at the personal level, but the demand for accessibility of digital offerings (also) for people who use AAC is quite general. Existing laws and guidelines on accessibility provide a basis, but the needs of users with communication impairments are not sufficiently or consistently taken into account. Features that increase the accessibility of digital content [e.g., text-to-speech (TTS), speech-to-text (STT), and the use of objectively understandable communication symbols (CS)] are still too rarely provided, while the rapid development of artificial intelligence suggests great progress in this regard (Elsahar et al., 2019; Sennott et al., 2019). The idea of universal design, which focuses on proactively creating accessibility for all potential user groups, needs to be much more widely adopted as a relevant mandate for stakeholders, policy makers, and society at large. In particular, people with special needs should be involved in the development process. Support networks for people who use AAC also require sustained professionalization and development (Grans and Wahl, 2013; Jacobsson, 2022). Extensive needs have been identified, particularly with regard to the use of modern technology and its implementation in the lives of people who use AAC. Social networks will play a special role in the context of AAC in the future. Waller (2019) states that there is a need to lower the requirements for technology. Both people with cognitive impairments and people with communication disorders need to be empowered to use these technologies, especially social networks (Grace et al., 2019; Waller, 2019). For this to happen, users must be consistently involved in the (further) development with regard to individual physical and linguistic needs (Pampoulou, 2019). This requires further intensive research (Bosse et al., 2020).

Research is also needed to critically examine existing practices of AAC provision in light of the participation model (Beukelman and Mirenda, 2005). In addition to research on needs, attitudes, and barriers, there is a need for presentations of best practices, such as individual case studies. In addition, collaborative projects involving AAC users, researchers, developers, and professionals are needed to jointly explore the potential of digital technologies for AAC and to empower AAC for digitization.

In addition to in-depth research on the perspectives of users, there seems to be a lack of evaluated approaches and studies that address the needs for training and education of professionals and other supporters in the field of AAC care and digitization. Opportunities for inter- and transdisciplinary collaboration may be offered by the discipline of media pedagogy.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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EDITED BY
Hendrike Frieg,
University of Applied Sciences and Arts
Hildesheim, Holzminden, Göttingen, Germany

REVIEWED BY
Guylaine Le Dorze,
Montreal University, Canada
Sam Harvey,
The University of Queensland, Australia

*CORRESPONDENCE
Christina Kurfess
✉ christina.kurfess@oth-regensburg.de

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Peer-to-peer support: digital networking in aphasia to improve quality of life (PeerPAL)

Christina Kurfess[1]*, Sabine Corsten[2], Maren Tabea Nickel[2], Marie Knieriemen[2], Daniel Kreiter[1] and Norina Lauer[1]

[1]Department for Social and Health Care Sciences, Regensburg University of Applied Sciences, Technical University of Applied Sciences, Regensburg, Germany, [2]Department for Health Care and Nursing, Catholic University of Applied Sciences, Mainz, Germany

Background: People with aphasia (PWA) often suffer from reduced participation and quality of life. Nevertheless, there are currently only a few specific interventions that respond to this problem. Participation and quality of life could be increased by interacting with peers who have similar experiences. Digital social networks could stimulate an autonomous interaction. However, digital social networks need to be adapted to the specific needs of PWA. Therefore, a participatory, agile process involving the target group should be chosen to develop such a solution, i.e., an app. The research project consists of a total of three phases. In the first phase—*app development*—the app was developed and programmed including the target group. In the second phase—*app testing*—the usability and user-friendliness of the app were evaluated with four PWA. In the third phase—*feasibility and preliminary efficacy*—that will be described in the article, the impact of the app on PWA will be evaluated.

Aims: The overarching aim of our study is to provide preliminary efficacy of the intervention. Digital social interaction with other PWA can lead to increased social integration. In addition to digital interaction, personal encounters between PWA should be encouraged. As a result, we expect an improvement in quality of life of PWA. Additionally, we focus on identification of the most appropriate measurements to discover changes associated with the intervention.

Methods: The evaluation, which is described in this paper, takes place in a pre-test - post-test design with a total of $n = 48$ PWA. Participants will be recruited in regional clusters to facilitate face-to-face meetings. Half of the participants will be assigned to the delayed intervention group and the other half to the immediate intervention group. Participants in the delayed intervention group will go through a 3-month waiting period before using the app, while the participants of the immediate intervention group will start using the app for 3 months right away. Inclusion criteria are the presence of chronic aphasia (at least 6 months) and possession of a smartphone with internet access. Questionnaires on quality of life (SAQOL-39, GHQ-12), depression (GDS, DISCs), communicative participation (CPIB), and social support (F-SozU) will be conducted at inclusion (t0), after 3 months of app use (t1), and after another 3 months for follow-up (t2). Participants in the delayed intervention group will be assessed twice before the intervention, before the 3-month waiting period (t0a) and after the waiting period (t0b). In addition to the quantitative measures, interviews will take place with 6 to 8 selected participants after 3 months of app use. Responses will be analysed using Thematic Analysis.

Discussion: The app will be the first social network tool that is systematically developed with PWA. Initial indications from the first phases are that the app can be used by PWA, so that the evaluation of this app version can take place in the third phase. Results of this study can provide an initial indication of whether social network support is a suitable intervention. Findings will help provide information on the feasibility of digital connectivity for PWA. Preliminary findings on its impact on the participation and quality of life of PWA could be made available.

KEYWORDS

aphasia, digital participation, quality of life, social network, peer-to-peer support

1. Background

1.1. Introduction

Aphasia is an acquired language disorder due to brain damage. People with aphasia (PWA) show difficulties in producing or comprehending spoken or written language (Orchardson, 2012). Aphasia is a common consequence of stroke. It occurs in about 30% of all stroke patients (Engelter et al., 2006; Flowers et al., 2016). It is caused by cerebral insult in up to 80% of cases (Kolominsky-Rabas and Heuschmann, 2002). Every year around 270,000 people in Germany suffer a stroke (Stiftung Deutsche Schlaganfallhilfe, 2021). The prevalence of aphasia is around 100,000. It will continue to rise due to demographic change and increasing survival rates because of improved medical care (Rothwell et al., 2004).

1.2. Aphasia impacts quality of life and social connectedness

The World Health Organization defines quality of life (QoL) as the perception of the individual's life situation in the context of their environment and value systems (WHO, 2012). Following Hilari et al. (2021), we refer to the construct of health-related QoL in the following. Health-related QoL describes the impact of a perceived health state on the ability to lead a fulfilling life (Bullinger et al., 1993). Health-related QoL comprises the subjective assessment of several components, e.g., physical, mental, emotional, family, and social functioning (Berzon et al., 1993).

Aphasia impacts QoL significantly (Hilari and Byng, 2009) and is associated with difficulties performing everyday activities (Nätterlund, 2010; Alary Gauvreau and Le Dorze, 2022). For example, up to 80% of PWA do not return to work due to the impact of aphasia on their ability to perform vocational activities (Doucet et al., 2012; Musser et al., 2015) and PWA are often unable to maintain hobbies and life roles (Pike et al., 2017; Taubner et al., 2020). Consequently, PWA suffer worse health-related QoL than people living with cancer or Alzheimer's Disease (Lam and Wodchis, 2010).

QoL can be further impacted by a reduced social participation up to social isolation (Hilari et al., 2010; Lee et al., 2015; Santo Pietro et al., 2019). Social participation can be defined as "a person's involvement in activities that provide interaction with others in society or the community" (Levasseur et al., 2010, p. 2148). Social isolation is defined as having a limited network of people to interact with regularly (NIH, 2021). Due to the language impairments, PWA take part in fewer social activities (Cruice et al., 2006; Vickers, 2010). As a result, they are also exposed to the risk of losing contact with friends and their wider social network (Vickers, 2010; Northcott and Hilari, 2011; Fotiadou et al., 2014; Ellis et al., 2019). Consequently, PWA can experience loss of autonomy and social withdrawal (Cruice et al., 2006; Vickers, 2010; Northcott and Hilari, 2011; Le Dorze et al., 2014; Winkler et al., 2014; Musser et al., 2015; Jones, 2017; Konnerup, 2018), which is associated with psychosocial changes including depression. Up to 62% of PWA show signs of depression 12 months after stroke (Kauhanen et al., 2000).

Additionally, PWA often experience mobility issues due to stroke, which further restrict participation and QoL (Lee et al., 2015). In summary, social isolation, psychosocial changes, and mobility issues caused by stroke and aphasia contribute to significantly reduced QoL.

1.3. Peer support for PWA

A distinction can be made between peer-to-peer support within an entire group (typically, e.g., within aphasia self-help groups) and peer-befriending between two peers, i.e., one-to-one peer support. The focus of this study is peer-befriending. Peer-befriending means a social and emotional support through an exchange of experiences between people with similar life circumstances (e.g., living with the same health condition; Solomon, 2004). Support from peers who are experiencing similar life circumstances can be beneficial also in case of aphasia, as PWA can empathise better and share their concerns, fears, and hardships with each other (NHS Improvement - Stroke, 2011). This shared basis of experience and exchange can lead to a deep relationship of trust between PWA.

Increased participation in meaningful activities and greater involvement with family, friends or support groups can have a positive impact on QoL and living well with aphasia (Brown et al., 2012). Brown et al. (2012) conducted a meta-analysis of data from three studies to examine the role of participation on QoL in PWA. They explored the perspectives of PWA, speech-language pathologists, and family members on living successfully with aphasia. According to the data, PWA participated in a wide range of meaningful activities including communication-based activities such as reading the newspaper and non-verbal activities such as gardening. Engagement in meaningful activities was associated with improved QoL.

A professionally guided, peer-befriending approach aiming at depression prevention was planned in a study protocol for PWA (Hilari et al., 2019). In the randomised controlled feasibility study conducted with 56 PWA, Hilari et al. (2021) demonstrated that peer-befriending for PWA resulted in significant long-term improvements in wellbeing. Participants with aphasia were recruited in the acute phase of stroke recovery. They were randomly allocated to receive usual care (control) or usual care plus peer-befriending (intervention). In the intervention arm, participants were age-matched to a peer-befriender (person with chronic mild-moderate aphasia). Participants received six 1-hour peer-befriending visits over 3 months. Wellbeing was measured before and after the intervention with the GHQ-12 (General Health Questionnaire). The intervention group demonstrated greater improvement in GHQ-12 score at the post-test time point providing preliminary efficacy of this peer-befriending intervention. The authors note that PWA who experience low levels of distress in the acute phase of stroke recovery may benefit from this peer-befriending approach in the long term (Hilari et al., 2021).

In another study, patients in the acute phase after a stroke, not all suffering from aphasia, were offered supportive conversations by peers. Semi-structured interviews post-intervention were conducted. Most of the participants perceived the support and peer conversations as emotionally relieving as they gave them hope, provided a sense of validation and reduced feelings of isolation (Kessler et al., 2014).

1.4. Digital solutions

Structural restrictions could make it difficult to participate in peer-befriending approaches. Barriers like reduced mobility, lack of speech therapy provision, especially in rural or underserved areas (Lanyon et al., 2018; Hilari et al., 2021) could be remedied using digital solutions. Digital media can increase autonomous, social participation in the case of health impairments, as Moorhead et al. (2013) found in a review. In this way, contacts and friendships could even be made over distance. This could be helpful especially for people in socially problematic situations. Existing social media platforms such as Facebook are, however, too complex for PWA (Buhr et al., 2017). Moreover, adapted services for PWA so far relate primarily to exchanges via email (e.g., Mahmud and Martens, 2013, 2016; Thiel et al., 2017; Menger et al., 2020). Until now, digital media in aphasia rehabilitation have concentrated mostly on augmented communication in analogue situations and language-specific training as a videoconference (Brandenburg et al., 2013; Bilda et al., 2017; Asghar et al., 2021). Apart from that, there have only been few attempts to develop social networks for PWA. Buhr et al. (2017) found in a feasibility study that an adapted social media tool used for the asynchronous exchange between PWA facilitated interaction among PWA. The social network AphasiaWeb has a linguistically and visually simplified layout and multimodality input/output features (Buhr et al., 2017). However, no activities can be planned. It also lacks the mediating function of "matching" PWA with regard to similar interests, and similar requirements for emotional and psychological support (see Hilari et al., 2021). In addition, chat functions and a platform for appointments, activities, and exchanges are missing. Preliminary concepts use virtual environments to practise specific language skills (Egaji et al., 2019), but also social participation in groups e.g., EVA Park (Galliers et al., 2017; Marshall et al., 2020). In Australia, an app for PWA is also being developed in a participatory approach with the target group (Rose, 2023). As one component of the platform for post-inpatient care, patients with language disorders receive peer support according to the same pattern as in our research project (*Communication Connect*; Rose, 2023). Thus, this project follows a similar concept as we do. However, digital, autonomous peer-to-peer support for PWA to increase social participation has not yet been investigated.

In summary, there is a pressing need to develop digital interventions to improve QoL of PWA (Hilari et al., 2019). It must be noted that aphasia is often associated with other neurological deficits such as hemiparesis or hemianopia (Fisher, 2009). Furthermore, as aphasia is more common among older adults, digital skills are often lacking (Menger et al., 2020). Possible neurological comorbidities and the advanced age of the target group must be considered when designing a digital solution. Based on the findings from the feasibility study by Buhr et al. (2017) and the insights of Hilari et al. (2021), a digital social network should additionally include a peer-matching function as well as enable activity scheduling.

1.5. Introducing PeerPAL

The project "Peer-to-peer support: digital networking in aphasia to improve quality of life (PeerPAL)" involves the development and evaluation of a social network as a smartphone app. A co-design process was used to incorporate the expertise of speech and language therapists and PWA in the app development, i.e., we aimed at a catalogue of requirements for an app solution in collaboration with PWA. To capture the requirements and needs of the target group, a design thinking workshop and focus group meetings took place in **Phase 1** of the research project—the **app development**. The six focus group meetings included the project staff and four PWA. The group meetings took place digitally at monthly intervals. In an iterative process the content, design, and layout of the app went through repeated reviews, tests, and corrections. It was a constant alternating process between focus group discussions and revisions of the app. In addition to the implementation of important functions such as the chat function or text input, it became apparent that a matching function would help the target group identifying participants with similar interests. The app was then programmed for use on mobile devices (iOS and Android). During **Phase 2—app testing—**the app was checked for usage difficulties and problems. Again, four PWA, but different from those who were part of the focus group, tested the app over 2 months. In this paper, we describe the study design of **Phase 3—feasibility and preliminary efficacy—**in which we evaluate the revised app based on findings from Phase 2.

2. Aims

The PeerPAL project aims at:

1) Facilitating digital social networking to prevent depression and social withdrawal, while overcoming physical distances.

2) Encouraging face-to-face meetings and social activities with peers to improve social inclusion.
3) Promoting independent use of the app by PWA.
4) Gaining insights into digital learning under the condition of language limitations to help facilitate digital inclusion of PWA.
5) Identifying the most appropriate outcome measures for evaluating the effects of a digital social networking intervention, which have not been established.

3. Hypotheses

Despite the preliminary nature of our study, we have attempted to formulate initial ideas as hypotheses.

1. We anticipate that the intervention will result in significant improvements in measures of QoL, communication participation, and social participation relative to pre-intervention measures for both the immediate and delayed intervention groups (Babbitt and Cherney, 2010; Hilari et al., 2021).
2. We hypothesise no significant change in measures of QoL, communication participation, and social participation prior to the PeerPAL intervention for the delayed intervention group.
3. We expect approximately constant stable values in the waiting period for the delayed intervention group and significant improvement in QoL, communication participation, and social participation following the intervention period.
4. We hypothesise no significant differences between the immediate and delayed intervention groups on measures of QoL, communication participation, and social participation after the PeerPAL intervention.
5. We expect improvements in measures of QoL, communication participation, and social participation will remain stable for 3 months after the intervention for both groups (Hilari et al., 2021).
6. We expect the level of depression will remain stable in all participants after the intervention until at least follow-up (Hilari et al., 2021).

4. Methods

4.1. Design

The project consists of three phases: App development (Phase 1), app testing (Phase 2), and evaluation of feasibility, acceptability and preliminary efficacy (Phase 3). The first two phases of the study have already been completed, as explained in the background information. Phase 3 uses a pre-post waitlist-controlled comparison design (Figure 1). Participants will be allocated to either the immediate intervention group or the delayed intervention group (3-month waiting period). This allows all PWA to participate in the intervention and still allows any effects found, to be compared with the control period. We will compare the changes during the intervention period with the changes during the waiting period, i.e., our control period. The assessment time points will be at study inclusion (t0), after the intervention (t1) and after follow-up (t2). The delayed intervention group will be tested at study inclusion (t0a) and again after the 3-month waiting period (t0b). They will start the intervention after the second assessment time point t0b. The intervention will consist of two parts. In the first 6 weeks, the participants will receive intensive support in using the app. In the second 6 weeks, only technical support will be provided. Figure 1 shows the study design.

A total of 48 PWA will be enrolled in the main study, 24 in each group. The targeted number of participants was calculated and determined using a power calculation (see Section 4.8.1).

The Template for Intervention Description and Replication (TIDieR) guide (Hoffmann et al., 2014) was used to describe the study interventions (Appendix 1).

Ethical approval to conduct this study with the described study design was sought and received from the Ethics Committee of the German Society for Nursing Science (DGP; 20-032).

4.2. Recruitment

Eligible PWA will be recruited in Germany through various cooperation partners like clinics and language therapy specialist practises as well as regional associations and self-help groups. We will hand out flyers and information material to the cooperation partners describing the inclusion criteria and contact details of the project. PWA, therapists or relatives of PWA could use the material to get in touch if a PWA is interested. By allowing all participants to go through the intervention and thus use the app, we expect that more PWA will be interested in the study resulting in a positive impact on the recruitment rate. When PWA or their relatives or therapists contact us, the project team will check during a phone call if all inclusion criteria are likely to be met (see Section 4.3).

As part of the recruitment strategy, participants are sought in regional clusters. The intervention includes personal meetings. Therefore, it will be necessary to recruit participants in regional proximity so they can meet in person. It is planned that at least six participants per regional cluster will be included and thus it is assumed that about 6 to 8 regional clusters will be needed. For organisational reasons, not all 48 participants can be tested at the same time. However, the participants of a single regional cluster should start the intervention period at the same time so that participants can find as many other participants from their own region as possible in the app. It is planned that the regional clusters will start the intervention one after the other at intervals of 1 month. In the process, the 3-month waiting period will be completed in advance for the first regional clusters. When 24 participants have been found for the delayed intervention group, the following clusters will be recruited for the immediate intervention group. Thus, randomised group assignment will not be used so that participants can use the app in parallel as much as possible. On the one hand, this may lead to differences between groups at baseline, limiting replication and generalisation of this study. On the other hand, non-random group allocation reflects real-world heterogeneity of people with aphasia and the potential impact of heterogeneity on the delivery of this intervention.

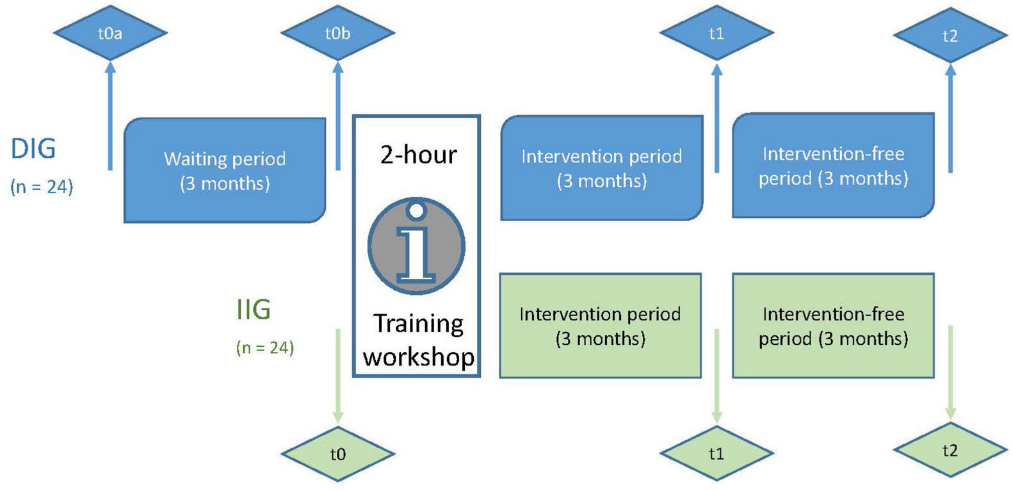

FIGURE 1
Study design. IIG, Immediate intervention group; DIG, Delayed intervention group; Measurement times: t0(a&b), baseline; t1, post-test; t2, follow-up-survey.

4.3. Inclusion criteria for participants

The inclusion criteria for participants are as follows:

- People with chronic aphasia due to a stroke or other injury to the brain (6 months post onset): determined by the Screening of the Aachen Aphasia Test (AAT; Huber et al., 1983). We recruit PWA only from the chronic stage of aphasia onwards, as people in earlier stages of aphasia are more distressed (Hilari et al., 2010). Our method could be used in earlier stages of aphasia, but adaptation to acute aphasia might be required, as PWA in an early stage of aphasia may not yet have realised the impact of the language deficit on their daily lives (Grohn et al., 2012). In addition, social support becomes more important at an advanced stage of adjustment to life after stroke (Hilari et al., 2010).
- Low levels of emotional distress: This is to ensure that participants do not require more complex psychological interventions. To assess depression, the Geriatric Depression Scale (GDS) will be used even if it is not an aphasia-specific measurement tool [such as the Stroke and Aphasia Depression Questionnaire (SADQ; Sutcliffe and Lincoln, 1998)] but it has been successfully used in other studies with PWA previously (Corsten et al., 2015; Lee et al., 2015). As the present intervention is preventive, participants should show only minor signs of depression, operationalised with a score ≤ 8 on the GDS (Sheikh and Yesavage, 1986). For values between five and eight, psychological support is recommended. This will be discussed with the participants in a personal meeting. This conversation is conducted by one of the research assistants with the participants. Both research assistants are qualified speech and language therapists and have therefore also completed several psychology modules. If desired by the participants, relatives may also attend the appointment. If the GDS results in more than eight points, the recruited person must be excluded from the intervention. In this case, one of the research assistants initiates a meeting with the person and his/her relatives and strongly recommends seeking psychological support. Among other things, the participant is strongly advised to go to the general practitioner (GP), who in the German health care system can refer the person to a psychologist or psychiatrist. The GDS test results should be taken to the GP appointment so that the GP can make further decisions based on them.
- Participants should have a smartphone with internet access (WiFi and/or mobile data).
- Vision (with aids) should be sufficient for smartphone use.

No criteria for linguistic abilities are formulated (see Buhr et al., 2017). Thus, the participants could represent a broad spectrum of different levels of aphasia severity. Physical limitations (e.g., hemiplegia) are not an exclusion criteria as long as individuals can operate a smartphone. The aim is to make the app useable for as many PWA as possible. Especially PWA with more severe disabilities, regarding language, mobility, and fine motor skills might benefit from digital inclusion. Persons who do not meet the above inclusion criteria will be excluded from the study.

4.4. Blinding

There is no blinding but there are two rules to improve internal validity. Outcome scorers and assessors are different staff members, but both are involved in the project. Assessors will conduct the quantitative and qualitative outcome measures. Outcome scorers who have experience in administration and evaluation will score the outcome measures. The separation of test administration and test evaluating reduces the risk of individual bias. Participants are not explicitly informed that there is a delayed intervention group and an immediate intervention group. They are only informed about the procedure in their group.

4.5. Training workshop

All participants will attend a 2-h training workshop prior to the intervention period (Figure 1). The training workshop will be based on an action-oriented approach (Pihlanto, 1994). It will take place in a digital setting via Zoom with end-to-end encryption. This is important to protect data privacy of the study participants as best as possible. Small groups of four to eight participants from the same regional cluster will be brought together. Technical and media skills will be trained and knowledge about multimodal communication will be taught. The sections of the app and its functions will be explained in detail and the handling of the app will be practised. Multimodal communication will be explained in more detail and all communication modalities will be tried out in the app. The following communication options are offered in the app: Writing on the keyboard, writing using a dictation function, selection of prepared response options (text modules), emojis and photos.

4.6. Intervention

Following the training workshop, participants will use the PeerPAL-App independently in everyday life over a period of 3 months (Figure 1). The app allows participants to create a profile with name, age, location, interests, and preferred modalities of communication. Using these profiles, PWA can find other users in regional proximity who have similar interests. Contact can be made via text message (chat function) or via phone call. A reduced number of emojis are offered in the chat to not overwhelm with the selection. These are the emojis that are most commonly used by PWA [empirically surveyed and literature-based (Petroi et al., 2014)]. In addition, a selection of text modules is offered, which can be used as response options. Activities can be scheduled. Invitations can be sent to selected friends in the app, or all app users can be invited. All tabs and functions in the app are designed to be as simple and intuitive as possible. Video tutorials explain the functions of the app in plain language and slow speed.

During the first 6 weeks, close support will be provided by the project staff to help users post content and troubleshoot technical issues. The participants will also receive weekly messages via the app's chat from the project team to motivate and remind to use the app. In addition, they will receive individual feedback on their usage behaviour once during this period. This should increase the motivation of the participants to use the app (Zapata et al., 2018). To promote independent use of the app and self-directed learning, participants will be asked in the first 6 weeks of the intervention period to carry out at least two actions in the app each week, e.g., send messages in the chat, schedule activities, or accept an activity invitation. In the second part of the intervention, users will only receive support when having technical problems. Participants will be encouraged to continue using the app after the intervention period has concluded. Technical support will be provided as needed until the follow-up survey.

4.7. Measures

4.7.1. Quantitative outcomes

Based on the aims and hypotheses of the study, the measurements were selected. All tests will be performed at all assessment dates, before intervention (t0), after intervention (t1), and at follow-up (t2). The delayed intervention group will be tested twice before the intervention, once before the waiting period (t0a) and once after the waiting period (t0b). The project staff will conduct the quantitative outcome measures in individual meetings and support participants in case of language difficulties.

As the primary outcome QoL in PWA will be assessed with the SAQOL-39 (Stroke and Aphasia Quality of Life Scale-39; Hilari et al., 2003). The time required for the assessment is manageable, appropriate for the target group and internationally compatible. The test shows good values in internal consistency, test-retest reliability, and construct validity.

GHQ-12 will be used as a second measure for QoL (Goldberg and Williams, 1988). The procedure is the same as that of Hilari et al. (2019). The GHQ-12 was tested in six validity studies and demonstrated high reliability and validity (Goldberg and Williams, 1988).

All other tests are used as secondary outcome measures to learn more about other effects of the intervention and to determine which tests are best suited to detect therapy-specific effects.

Depression will be surveyed with the GDS (Sheikh and Yesavage, 1986). The GDS contains 15 items that are answered with yes or no. The GDS represents a reliable and valid self-rating depression screening scale for elderly populations (Yesavage et al., 1982). Nevertheless, GDS shows good diagnostic sensitivity and specificity even for younger individuals (adults 18 years and older; Guerin et al., 2018).

The intensity of depression will be assessed with the DISCs (Depression Intensity Scale Circles; Turner-Stokes et al., 2005). The DISCs Screening is a simple assessment tool with two questions, specifically for depression in brain injury. It has acceptable convergent validity, reliability, and responsiveness. The research group translated the DISCs from English into German in a scientific translation process ensuring that the internationally used DISCs with a visual scale can be used for this German study with PWA.

Perceived social support and relationships with significant others will be surveyed using the F-SozU (Social Support Questionnaire; Fydrich et al., 2007). The short form of the F-SozU used in this study contains only 14 items and can therefore be completed in a short time. The F-SozU represents a reliable, valid, and economical instrument and can therefore be used effectively in clinical epidemiological studies or related fields (Kliem et al., 2015).

Communicative participation will be assessed with the CPIB (Communicative Participation Item Bank; Baylor et al., 2013). The short form of the CPIB contains 10 items and has been validated for PWA (Baylor et al., 2017). In the study of Baylor et al., the majority of the PWA were able to respond to the CPIB tasks, although most of them needed assistance. PWA, who were unable to complete the CPIB, generally had higher aphasia severity. The research group translated the CPIB from English into German in a scientific translation.

4.7.2. Qualitative outcomes

Semi-structured interviews regarding the social network and living situation will be conducted with seven to eight randomly selected participants immediately after the intervention (t1) and during the follow-up (t2). In order to ensure variance between the clusters and aphasia severity, the participants are divided into the respective groups and randomly drawn from them. On the one hand, this excludes selection bias, but on the other hand, this approach also enables data transferability, by creating variability and gaining different perspectives. Interviews will be held to get a better insight into individually seen advantages and disadvantages of the app, regional cluster dynamics, and perceived effects from app usage, and to learn more about the working mechanism of the intervention. In addition, the interview data will also serve to elicit further suggestions for improving the app. The interviews are based on a guide that includes open-ended narrative-generating questions and specific follow-up questions. This allows the interview to be individually adapted to PWA with different levels of aphasia severity.

4.7.3. Fidelity

To ensure adherence to the protocol and comparability of the implementation, all activities of the participants are recorded in detail (number of posts, number of messages sent, time spent online). This protocol has been developed and defined in advance according to international guidelines.

Training workshop fidelity is monitored by video recordings and with the use of a checklist. The template will be a checklist that was developed and evaluated in the project, "Biography work in long-term residential aged care with tablet support to improve the quality of life and communication" (BaSeTaLK; Corsten and Lauer, 2020). The checklist includes items on observation of the participants and conveyed information on the app. Each training workshop is supervised by an assistant who observes the participants and ensures that the checklist is followed.

4.8. Data analysis

4.8.1. Power calculation

The sample size to detect the efficacy of the intervention was determined based on the research design. Statistical power was calculated using G*Power. With 24 participants each in the immediate intervention group and delayed intervention group, a mean effect size of 0.73 in the primary outcome measure (SAQOL-39) is sufficient to confirm differences between pre- and post-test (for $n = 20$, a mean effect size of 0.82). This is a high effect size. The outcome variable in the calculations is QoL as measured by the SAQOL-39. The calculations were based on a one-tailed test situation, an alpha error of 0.05, and a beta error of 0.2. However, it is meant as a compromise between an achievable number of participants and an expected effect. If we do not achieve such an effect, we may at least be able to see pre- and post-effects. The *t*-test for differences between two independent means was used. The input parameters were one-tailed calculation with an alpha error of 0.05 and a power of 0.8 given the exploratory character of the study. For the G*Power calculation, the *t*-test for two independent samples was again used. The input parameters were one-tailed calculations with an alpha error of 0.05 and a beta error of 0.2, which is common for constructing an RCT.

4.8.2. Statistical methods and qualitative analysis

Inferential statistics of intra-individual changes and inter-individual differences, group differences as well as group differences between the waiting period and intervention period will be evaluated after testing for normal distribution either with non-parametric or parametric procedures (depending on the distribution of the data) with the IBM SPSS 25.0 statistics program. The main objective of the study is to provide evidence of efficacy of the intervention in improving QoL. To prove this, a pre-post analysis will take place. Since we would also like to verify long-term effects, an additional follow-up survey will take place after 3 months. The quantitative outcomes (see Section 4.7.1) will be used as dependent variables. The continuous variables will be analysed according to the distribution characteristics by means of a *t*-test for connected samples or Wilcoxon test. In addition, regression analyses and the Kruskal-Wallis test will be used. The number of factors will depend on the extent to which the recorded group and study periods differences represent a homogeneous or nonhomogeneous construct. Cluster analyses or latent class analyses can be used to identify the subgroups. For example, influencing factors such as age, gender, morbidity, and aphasia severity can be analysed. An alpha level of 0.05 will be accepted as significant. The results of the statistical models will be presented in the form of regression coefficients, their 95% confidence intervals, and effect sizes. Percentage scores will be determined for the checklists for protocol adherence and Kappa statistics will be calculated to determine inter- and intra-rater reliability.

The study uses descriptive statistics to capture numbers on recruitment, treatment fidelity and reasons for dropping out.

Recruitment and retention rates will be used to aid in the calculation of the sample size of future studies with a similar research interest, and to determine the required number of possible recruitment locations (such as clinics and practises). Adverse incidents such as dropouts will be also documented. The course of study will be evaluated with qualitative interviews of the participants. Thematic analysis will be used to explore the interview material (Braun and Clarke, 2006).

4.8.3. Data management

A data management plan has been created via DMPonline (data management plans online; Digital Curation Center, 2023). DMPonline is a web-based tool that supports researchers to develop data management plans. For secure data exchange between the network universities, Synology Cloud Station Drive will be used, which enables data storage on a server of the Ostbayerische

Technische Hochschule Regensburg (OTH Regensburg). Project staff at each university will enter anonymized participant data directly into Synology Cloud Station Drive. Once data collection has commenced, the study's chief investigators will monitor data for completeness and accuracy. They will also continuously monitor the progress of the study, adverse safety events and data accuracy. No formal criteria exist for discontinuing the trial early.

4.9. Trial status

The project started in December 2020 and the first focus group meeting took place in March 2021 (phase 1). A total of six focus group meetings were held by August 2021 to continuously improve the app prototype. The time that followed was all about programming the app, until 4 participants started the app testing in May 2022 (phase 2). In August 2022, the first participants for the main study were enrolled in the delayed intervention group (phase 3). The project is officially registered and can be viewed on the public website of the German Register of Clinical Trials (DRKS00023855) and in the World Health Organization's search portal (http://apps.who.int/trialsearch/). Cooperation agreements have been signed with the following practise partners: "Aphasie Landesverband" (Aphasia National Association) in Bavaria, the "Aphasiker-Zentrum" (Aphasia Center) in Lower Franconia, the Asklepios Klinik Schaufling, the "Berufsfachschule für Logopädie" (Vocational school for speech and language therapy) in Regensburg, the "Logopädische Praxis Brigitte Brauer" (speech and language therapy practise Brigitte Brauer) in Mainz, the "Logopädische Praxis Bruni Zeuner" (speech and language therapy practise Bruni Zeuner) in Idstein and the "Praxis für Logopädie und Neurolinguistik" (practise for speech and language therapy and neurolinguistics) in Regensburg.

5. Discussion

The PeerPAL-App is the first digital social network tailored to the needs and capabilities of PWA. The app is intended to promote social interaction with peers both online and face-to-face, and thereby improve QoL and prevent depression. Consistent and regular use of the app will be facilitated through training, supervision, and support. If effective and integrated into the life of PWA, it may have the potential to improve QoL, communicative participation, and social support, and thereby prevent depression.

App-supported peer-befriending could ease the burden on family members of PWA. Most PWA strengthen ties with immediate family members after stroke, bringing them into focus and making them key contacts (Hilari and Northcott, 2006; Ellis et al., 2019). Interaction with other PWA can improve communication within the family, reduce PWA dependence on family members, and allow family members to have time to themselves (Rotherham et al., 2016).

Future research could more fully implement qualitative outcome measures to better elicit individual factors that contribute to successful intervention such as size of current social circle or personality factors. Transferring the app to other groups, e.g., with neurogenic speech disorders, dysarthria in Parkinson's disease or multiple sclerosis, could be evaluated in following projects. In this way, further benefits can be generated.

5.1. Potential short-term impact

The social network will be open sourced after the end of the project. Thus, the app could be used beyond the end of the project and a continuous, flexible adaptation with low operating costs could take place. In addition, training courses for speech and language therapists, neuropsychologists and social pedagogues are planned to make PWA aware of the app and, if necessary, provide assistance during initial use. Professionals could benefit as PWA will gain more autonomy and rely less on the support of professionals. We are aware that successful use of the app cannot replace personal contacts and professional support. Nevertheless, the interaction with other peers might possibly be an alternative way to get in touch with other people especially for people who live in rural regions with poor infrastructure (Walter and Altgeld, 2000; Keck and Doarn, 2014; WHO, 2016; Roche and Nicholas, 2019), which means e.g., a lack of public transport or reduced speech and language therapy provision. These structural restrictions could make it difficult to keep appointments (without assistance), meet with other people or participate in peer-support approaches such as self-help groups.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Author contributions

CK, MN, and MK elaborated and researched content on the background and hypotheses. Furthermore, they compiled content on the method and wrote the discussion. Significant contributions have been made to the paper as a whole by NL and SC who are both responsible for the research conception design, who contributed to literature search, screening, and editing the paper. DK is responsible for the programming and design of the app. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fcomm.2023.1187233/full#supplementary-material

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Technology use in speech and language therapy: digital participation succeeds through acceptance and use of technology

Juliane Leinweber[1]*, Birte Alber[2]*, Maria Barthel[1], Alexander Sean Whillier[1], Silke Wittmar[3], Bernhard Borgetto[3] and Anja Starke[2]

[1]Health Campus Göttingen, Faculty Engineering and Health, HAWK Hildesheim/Holzminden/Göttingen, Göttingen, Germany, [2]Inclusive Education for Speech, Language and Communication Needs, Department of Education and Educational Sciences, Universität Bremen, Bremen, Germany, [3]Faculty Social Work and Health, HAWK Hildesheim/Holzminden/Göttingen, Hildesheim, Germany

EDITED BY
Kristina Jonas,
University of Cologne, Germany

REVIEWED BY
Michael Wahl,
Humboldt University of Berlin, Germany
Jana Quinting,
University of Cologne, Germany

*CORRESPONDENCE
Juliane Leinweber
✉ juliane.leinweber@hawk.de
Birte Alber
✉ birte.alber@uni-bremen.de

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Introduction: In Germany, as around the world, the use of digital media in speech and language therapy became part of the service during the COVID-19 pandemic. This resulted in a need for empirical studies on the use and acceptance of digital media technologies, to determine users' requirements and concerns regarding the newly mandated technologies, in order to support its expansion in education and training going forward. "Acceptance" has been previously identified as an important aspect behind successful technology adoption. Therefore, two online questionnaire studies were conducted to explore how technology use is accepted among speech and language therapists in Germany.

Methods: Study 1 involved a questionnaire about video therapy with 15 question groupings, examining technology acceptance and competence. From 841 initial respondents, 707 complete responses were included in the analysis. Study 2 involved a different questionnaire, examining technology acceptance and digital media in therapy. In total, 79 individuals participated in the second survey. Study 1 data were analyzed to identify unifying factors underlying respondent attitudes and was followed up with a logistical regression; Study 2 data were analyzed with multiple linear regression.

Results: In Study 1, external inhibiting and facilitating conditions were identified which had an impact on attitudes toward video therapy adoption and its intended future use. In Study 2, the modified model of the Unified Theory of Acceptance and Use of Technology (UTAUT) explained 58.8% of the variability in therapist's Behavioral Intention to Use digital media. Here, Performance Expectancy was a significant predictor.

Conclusions: Both studies investigated facilitating and inhibiting factors for the implementation of digital media including video therapy in future speech therapy services. Results demonstrated that the use is accepted in therapy. Therefore, optimal conditions—both institutional and individual—are needed to enable digital participation for therapists and patients. In future education and training, trainers should focus on the functional aspects of the technologies to be used, in order to positively influence Performance Expectancy in a targeted manner and thus increase the therapists' intention to use digital technology in therapy, which in turn promotes patients' digital participation.

KEYWORDS

technology acceptance, technology adoption, technology use, digital media use, digital participation, speech and language therapy, video therapy, Unified Theory of Acceptance and Use of Technology

1. Introduction

Information and communication technology (ICT) is a growing area of research in health care, including in speech and language therapy (SLT), and its applications are varied—e.g. synchronous and asynchronous telerehabilitation, technology-based interventions and therapy applications, documentation and administration (Alber and Starke, 2021b; Kearns and Kelly, 2022). The use of digital media in speech and language therapy has been repeatedly called for in the past and became part of therapists' everyday life due to the mandate to transition to video therapy during the COVID-19 pandemic in Germany. Speech and language therapists around the world have access to an increasing number of technological resources to support clinical practice, such as electronic devices, software and internet resources, which have been shown to positively impact therapy (e.g. Albudoor and Pena, 2021). ICT is increasingly used in SLT as it comes to be seen as offering efficient and effective options to improve therapeutic outcomes (Jesus et al., 2019; Kearns and Kelly, 2022).

ICT should not be used in isolation—it should be viewed as a set of tools in the therapist's toolbox, as successful integration of ICT into therapy has been shown to confer many benefits. Technology integration in therapy can improve engagement from both patients and therapists (Leinweber and Barthel, 2022; Olszewski et al., 2022). Video therapy technologies make it possible for people to participate in therapy who would not otherwise be able to receive care due to illness, poor healthcare coverage in their region or other factors (Cason, 2009; Tucker, 2012; Hall et al., 2013; Fairweather et al., 2016; Lauer, 2020; Buabbas et al., 2022; Leinweber and Barthel, 2022). With increased integration of ICT in therapy, its use can extend into everyday life and thus enable both independent and supervised practice (Theodoros, 2012; Jakob et al., 2018; Böhm, 2019; Preßler, 2019; Nichol et al., 2022) or facilitate exchange with other people via apps or social media, thus further improving therapeutic outcomes (Welch et al., 2016). In particular, people with language impairments need targeted support in order to successfully participate in both the digital world and in the real world (Steiner, 2023). By including ICT in SLT, it is possible to work on concrete digital participation goals (Steiner, 2023) and to concurrently expand and reshape existing forms of therapy on the grand scale.

ICT represents a very diverse toolkit (Starke and Leinweber, 2019); for example, in the broad variety of software applications (apps). In general use, apps support communication, sometimes by supplementing it—e.g., when a group of people sitting in a café discuss a video playing on someone's phone—or sometimes completely substituting it—e.g., when the same group of people are half a world apart discussing the video while on a messaging forum. Apps can also remove communication barriers, such as social distancing; they can serve as learning aids, e.g., language apps; they can facilitate unlikely connections, e.g., job-seeker apps; they can support motivation, e.g., fitness apps.

In the context of research and therapy, apps can facilitate a similarly broad array of possibilities. In simple terms, apps can serve as a feedback aid for the speech therapist (Wahl et al., 2018). Patients can use apps to practice independently, which can be an effective supplement to their therapy (Böhm, 2019; Nichol et al., 2022). Apps have also been shown to increase the intensity and frequency of therapy (Nordness and Beukelmann, 2010; Hall et al., 2013; Lauer, 2020). The use of apps has been demonstrated to improve therapy motivation (Gačnik et al., 2018; Preßler, 2019). Edwards and Dukhovny (2017) have also noted various advantages in the research and therapy contexts in streamlining data capturing process, cost savings and, most importantly, the benefit of interactive presentation of multimodal therapy, i.e., 3D audio-visual animation. Apps provide all of these benefits and possibilities, regardless of location (Gačnik et al., 2018).

Besides apps, another example of digital media use is videoconferencing systems, such as those which were employed in SLT services in Germany for the first time during the COVID-19 pandemic. Without the possibility of video therapy services, adequate care of patients could not be ensured (Bilda et al., 2020; Schwinn et al., 2020; Bürkle et al., 2021). SLT primarily involves a patient and a therapist engaging in auditory and visual interactions; these interactions can be easily transferred to an online or technology-based environment, provided that auditory and visual cues can be adequately replicated and broadcast over a distance (Theodoros, 2012). While video therapy had already been established internationally in SLT for some years (Rangarathnam et al., 2016; Wales et al., 2017; Sutherland et al., 2018; McGill et al., 2019), it had not been nationally implemented as standard practice in Germany.

Various studies have shown that video therapy is appropriate for use in SLT (Wales et al., 2017; Jung et al., 2020; Weidner and Lowman, 2020). In their meta-analysis, Jung et al. (2020), concluded that the effectiveness of teletherapy and face-to-face therapy may vary depending on the characteristics of the client and the type of therapy, and that it is important to consider the patient's disorder and the type of therapy when choosing between teletherapy and face-to-face therapy. Telepractice does not seem to negatively impact the relationship between speech language therapists and pediatric clients compared to face-to-face therapy (Freckmann et al., 2017; Oprandi et al., 2021), and in various German studies it has been shown that it can be used with patients of different indications and age groups (Bilda et al., 2020; Schwinn et al., 2020; Beushausen and Sippel, 2021; Mörsdorf and Beushausen, 2021).

When considering a patient's digital participation in video therapy, not only the patient's experience but also the therapist's experiences matter. In cases where therapists' early experiences of video therapy were negative, the chance of immediate discontinuation of videoconferencing systems rose considerably (Hastall et al., 2017). In this context, therapists have a stakeholder role—they are concurrently users themselves and they provide patients with access to and guidance in appropriate technologies. Clinician behavior explains much of the variation in the uptake, expansion and sustainability of telemedicine services (Wade et al., 2014)—when therapists integrate ICT into therapy and make it possible for patients to associate ICT with positive experiences, a foundation can be laid for the future use of digital media on the part of patients. The digital participation of patients is therefore strongly dependent on the attitudes and skills of therapists with regard to digital media (Steiner, 2023). Thus, to improve patient usage and therapeutic outcomes, the positive and negative factors influencing therapists must be clearly understood.

To gain this understanding, the current two studies were designed to explore how technology use is accepted among speech and language therapists in Germany. In this context, acceptance refers to the positive decision to utilize and apply an innovation (Simon, 2001). Although a highly subject-specific positive attitude of an individual is usually a prerequisite for acceptance, it alone is not sufficient—acceptance also takes into account the potential or actual use of the new technology in addition to attitude formation (Kollmann, 1999). In the context of video therapy usage, Rettinger et al. (2021) identified that acceptance was one of the two key elements that define the usage of video therapy (the other being regulatory frameworks).

When it comes to the early acceptance of video therapy, the most common obstacle worldwide is technically overstretched staff (Scott Kruse et al., 2018). In order to be able to digitally act safely in the future and to support their patients' digital participation, therapists need to be digitally competent. Unfortunately, digital skills and the use of digital tools are not as yet an integral part of healthcare education in Germany and Europe more generally (European Health Parliament, 2020). The training of digital skills, alongside its underlying acceptance, represents one of the current challenges in professionalization in the field of communication disorders (Lin et al., 2021). Incorporating digital topics and skills into academic and professional development curricula has been well identified as critical to ensure that the field of communication disorders is prepared for the ever-digitizing healthcare environment (Brennan et al., 2010; Theodoros, 2012; Edwards and Dukhovny, 2017; Lin et al., 2021). Understanding the adoption and acceptance of digital media in SLT is crucial for optimizing application selections in therapy itself and educational strategies in training settings (Hastall et al., 2017; Albudoor and Pena, 2021). Thus a clear understanding of the challenges facing therapists can inform educational institutions of any systematic gaps in understanding.

Acceptance, as defined above, is a latent construct (Jockisch, 2010), which is why models are used to explain which facets make up the construct and which factors influence it; one such model is the Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2003). This model was used in Study 2 of this paper. The model, and its supplements and modifications, will be introduced here.

The UTAUT is an empirically tested integrative and global model developed from the main existing technology acceptance theories. Subsequent research has combined or extended the UTAUT model with other theories to examine a variety of technologies in organizational and non-organizational contexts (Venkatesh et al., 2016). The increasing prevalence of ICT applications has led to the UTAUT being widely adopted in a variety of research areas (Williams et al., 2014; Venkatesh et al., 2016). The UTAUT has also been validated in different environments, such as education (Birch and Irvine, 2009; Khechine et al., 2014) and healthcare (El-Gayar et al., 2008; Liu et al., 2015).

In the original UTAUT model, four constructs were identified as predictors of Behavioral Intentions and Usage of ICT: performance expectancy (PE), Effort Expectancy (EE), Social Influence (SI) and Facilitating Conditions (FC). PE is defined as the degree to which a person believes that using ICT will help him or her to attain goals in job performance. EE refers to the degree of ease associated with the use of ICT. SI represents the degree to which a person perceives that other important or influential people believe he or she should use ICT. Finally, FC is defined as the degree to which an individual believes that organizational and technical infrastructure exists to support the use of ICT (Venkatesh et al., 2003). The model used in Study 2 was modified, as in other studies, to also consider Facilitating Conditions (FC) as a direct predictor of Behavioral Intentions to Use (BIU).

In addition to the predictors, there are four moderating variables which can affect the relative influence of the predictors in the original model: gender, age, experience and voluntariness of use (Venkatesh et al., 2003). In addition to the determinant factors, the model uses Behavioral Intention to Use (BIU) as a dependent variable. Behavioral Intention is defined as "the degree to which a person has formulated conscious plans to perform or not perform some specific future behavior" (Warshaw and Davis, 1985, p. 214), in this case the use of technology. Both the original authors (Venkatesh et al., 2003) and future publications (e.g., Lakhal et al., 2013) have suggested enriching the UTAUT model; in order to additionally capture and map specific influences in the field of speech and language therapy, four supplementary UTAUT concepts (impact of peers, familiarity, self-efficacy and attitude) are each presented below.

In outpatient SLT settings, many therapists are part of teams that support and influence each other in terms of content and/or organization. Peer support can enhance users understanding, by providing insight on job relevance, output quality, and result demonstrability of a system (Venkatesh and Bala, 2008). Peer support can also influence the subjective norm and image associated with using digital media. If peers have a positive attitude toward digital media, it is more likely that employees will hold a positive perception (Venkatesh and Davis, 2000; Venkatesh and Bala, 2008). Therefore, the Attitude of Colleagues (AoC) is a relevant supplemental factor.

When people begin to use new digital media in their work, they are likely to experience changes in their intrinsic work characteristics, work processes, routines, and habits (Millmann and Hartwick, 1987). Reactions to these changes are highly individualized and can be positive or negative (Orlikowski, 2000; Boudreau and Robey, 2005). If individuals feel their wellbeing is threatened by these changes, avoidance and rejection are more likely to occur (Beaudry and Pinsonneault, 2005). Comparatively, if digital media are already used in the workplace and superiors have a positive attitude toward ICT use, therapists may feel more comfortable with the next step—accurate perception of a system or a tool is very important before using new ICT (Venkatesh and Bala, 2008). Familiarity with the use of digital media in the direct work environment can have a positive influence on the acceptance of the technology. This is the factor addressed by the model supplement Digitality at Work (DaW).

A related factor is an individual's self-efficacy with a computer; that is, the degree to which an individual believes that he or she possesses the ability to perform a specific task or job using a computer (Compeau and Higgins, 1995; Venkatesh and Bala, 2008). The personal conviction of one's own abilities can influence the intention to use digital media and thus their acceptance of technology (Compeau and Higgins, 1995; Compeau et al., 1999). This construct has been termed the Self-Assessment of Digital Competencies (SAoDC).

Based on different theories of technology acceptance, attitude toward using digital media can also have an impact on acceptance. Attitude is a learned predisposition to respond in a positive or negative way to a given object in a consistent manner (Lakhal et al., 2013). The concept represents a summary of underlying basic constructs of individual theories, e.g., Theory of Reasoned Action (Fishbein and Ajzen, 1975; Davis et al., 1989), Theory of Planned Behavior (Taylor and Todd, 1995b), Combined TAM and TPB (Taylor and Todd, 1995a), Motivational Model (Davis et al., 1992), Model of PC Utilization (Thompson et al., 1991), and Social Cognitive Theory (Compeau and Higgins, 1995; Compeau et al., 1999). Venkatesh et al. (2003, p. 455) summarized the concept as follows: "Attitude toward using technology is defined as an individual's overall affective reaction to using a system". The concept of Attitude and Affect Toward Digital Media Use (AUDM) appeared relevant for the present study. Figure 1 shows the extended model which is relevant for Study 2.

Despite the modifications, the UTAUT follows a relatively simple premise. Venkatesh et al. (2003) assume that the intention to use technology, which is influenced by various factors, has a direct impact on actual use.

More recently, Hastall et al. (2017) criticized such technology acceptance models for ignoring the dynamic and multi-determined process of using technology; this critique is of particular relevance to Study 1. More in detail, they claimed that the attention to the developmental process of technologies, the view of human motivation on technology, the social influences on individuals and the differences between individuals using technologies were all inadequately considered. Therefore, they discussed three approaches through which technology adoption can be promoted: (1) a realistic view about decision-making processes of individuals, (2) sufficient knowledge about different stages of technology adoption, and (3) focus on social, organizational and situational determinants. This results in three dimensions—*individual-related factors*, *environment-related factors*, and *technology-related factors*.

More specifically, *Individual-related factors* encompass approach behaviors and avoidance behaviors. In the case of video therapy, both behaviors can arise simultaneously in a given situation, for example, while the therapist supports the patient verbally during the exercise, the patient needs a hands-on situation to fully engage. *Environment-related factors*, such as social, organizational and situational factors, can express as external supportive or inhibitive influences on video therapy. *Technology-related factors* encompasses the technology itself, including negative complications (e.g., costs, software incompatibility) and rewarding aspects (e.g., increased accuracy, increased efficiency). All factors have implications on the adoption and acceptance of digital media in health care.

Overall, the failure of digital media use in a given setting is underpinned by the non-acceptance and non-usage of the technology by its end users (Standing et al., 2016). In considering the factors that underpin acceptance and use, Niklas (2015) emphasizes that acceptance is a result of a complex decision-making process that is affected by social and situational influences. Thus, to achieve a successful rollout of any digital media technology, different goals must be met; these include: reducing individual barriers, increasing psychological wellbeing, facilitating healthy aging in familiar places and ensuring social participation (Hastall et al., 2017). If technology is assessed and accepted as useful and necessary for professional life, then people are also prepared to deal with future innovations and iterations, and to review and expand their own competencies to match. In this way, it becomes possible to include digital participation as a fundamental goal of SLT work. This results in a need for empirical studies on the use, acceptance and adoption of digital media in SLT in order to be able to determine needs with regard to the expansion of competencies in education and training, but also to increase acceptance.

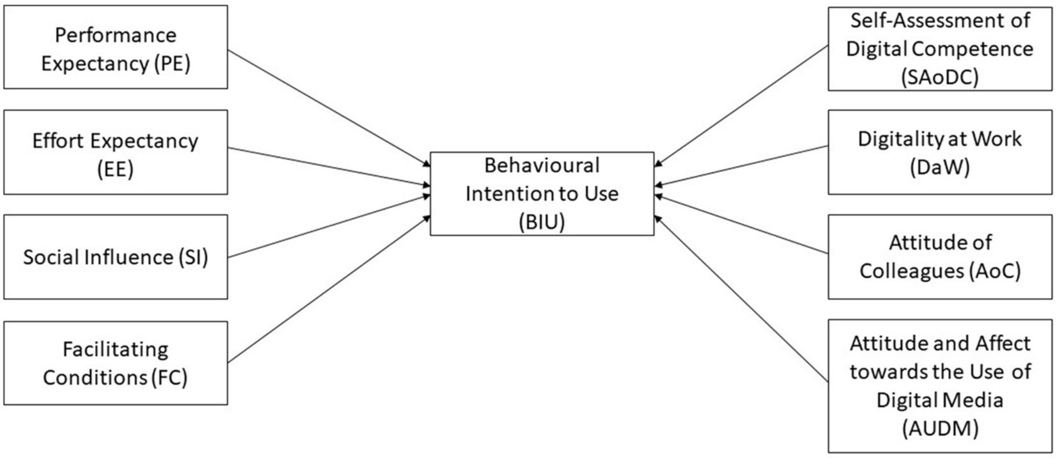

FIGURE 1
Basic UTAUT-model extended by four variables (Study 2).

As ICTs, such as video therapy and apps, are promising innovations in SLT, the current two studies were designed to examine the acceptance of these technologies by German speech and language therapists. Study 1 focuses on positive and negative factors which correlate with the therapist's future use of video therapy and it interprets which factors may thus influence successful implementation of video therapy. Study 2 examines factors influencing the therapists' intention to use digital media in SLT in the future and identifies factors that influence this intention. By identifying supporting and inhibiting factors based on different theoretical assumptions and models, these studies build together to inform the development of training and professional education, to ensure and expand the targeted use of digital media in the future. By inference, these studies would also improve and sustain the future digital participation of patients.

2. Materials and methods

2.1. Study 1

In order to investigate the factors which correlate with successful implementation of video therapy in SLT, Study 1 narrowed its focus on the constructs of acceptance and competence. The authors sought questions from past research on technical acceptance, drawing heavily on Hastall et al. (2017), as well as past key findings in the area of adoption and acceptance especially of video therapy in SLT (Molini-Avejonas et al., 2015; Pitt et al., 2018; Tyagi et al., 2018; Leinweber and Schulz, 2019).

2.1.1. Research questions

The following research questions were investigated by Study 1:

a. What factors correlate with the prospective adoption of video therapy by speech and language therapists?
b. What constructs underlie the attitudes of users toward technology acceptance and technology competence in the context of SLT?

2.1.2. Procedure

An initial questionnaire, made up of 52 question groupings (see Measure below), was developed at the University of Applied Sciences and Arts (German: HAWK Hildesheim/Holzminden/Göttingen) in early 2020. The survey was hosted online from June 3rd to July 1st, 2020, on the online freeware SoSciSurvey website (Leiner, 2019). The data were stored on the SoSciSurvey server until the end of the data collection period, then they were transferred to the university's own server until June 30th, 2030, and deleted from the SoSciSurvey server. Persons outside the project team and temporary staff have no access to the data.

Recruitment was conducted through the German Federal Association of Speech and Language Therapy (Deutscher Bundesverband für Logopädie e.V.), which has about 10,000 members. Respondents were asked to participate if they were providing speech and language therapy in an outpatient setting in Germany at the time of the survey. The participants were informed about the study contents and data privacy and gave their informed consent. Where consent was refused, retracted or could not be ensured, participation was excluded.

2.1.3. Participants

From 841 online responses, 25 were excluded due to denied informed consent ($n = 22$), invalid data ($n = 2$) and a profession outside of SLT ($n = 1$). Subsequently, an inconsistency check was made to proof data validity (Schrepp, 2016). In this context, a time-related test and a content test were made, but no irregularities were found. However, an additional 109 participants submitted substantially incomplete responses, meaning more than 80% missing data, and were therefore excluded from the analysis. Thus, in the end, 707 participant responses were included and analyzed in this study.

From the 707 complete respondents, 671 were female and 36 male (94.9% female). Participants ranged in age from 21 to 68 years ($M = 43.32$ years, SD 11.38 years), with one respondent not reporting their age. Work experience ranged from zero to 44 years ($M = 16.81$ years, SD $= 9.85$ years). Most of the participating therapists were self-employed in their own practice (62.4%), nearly one-third were employed in an outpatient practice (33.1%), a few were working on a fee basis (freelancer) (2.5%) and a few did not respond to this question (2%). A small number of participants indicated "other" (e.g., working as a teaching speech therapist or being in education; 1.7%). Table 1 shows the demographic data.

2.1.4. Measure

The original questionnaire consisted of 52 question groupings (forced-choice, multiple response and free-form response), grouped into seven categories.

TABLE 1 Participants' demographics in Study 1.

Item	Response	Frequency (%)	Mean (SD)
Gender ($n = 707$)	Female	671 (94.9)	
	Male	36 (5.1)	
Age, years ($n = 706$)			43.32 (±11.38)
Years of working experience, years ($n = 703$)			18.81 (±9.85)
Professional status ($n = 816$)	Practice owner	523 (64.1)	
	Employee	259 (31.7)	
	Freelancer	20 (2.5)	
	Other	14 (1.7)	

As the questions were not obligatory to answer, some questions were answered by fewer than the participating 816 therapists. The number of therapists who answered the question is given in brackets after the respective item.

1. Implementation of videoconferencing, as inclusion criteria (2 question groupings),
2. Sociodemographic data (7 question groupings),
3. Resources used for videoconferencing (7 question groupings),
4. Technology use (5 question groupings),
5. Current implementation of videoconferencing (21 question groupings), and
6. Adoption of videoconferencing in future health care delivery (9 question groupings), plus
7. General feedback to the questionnaire (1 question).

The questions were created in accordance with literature about technology use in SLT (e.g., Molini-Avejonas et al., 2015; Pitt et al., 2018; Tyagi et al., 2018; Leinweber and Schulz, 2019). Each grouping was structured as a question with multiple response options, e.g., "in which contexts have you used video therapy". Answers consisted of closed multiple choice options, plus a free text field, e.g., "individual therapy"; "group therapy"; "individual counseling"; "group counseling"; "other (text field)". Respondents could select any and all responses that were relevant. These question groupings were then recoded into unique binary questions for the statistical analysis (see below). The questionnaire used will be published in a separate article.

In preparing the data used for the regression, five of the adoption questions were deemed appropriate and were combined for the dependent variable; these related to: regarding usefulness of video therapy (VT), increased frequency of VT use, making VT standard practice, whether VT is as successful as in person therapy and whether VT affects the relationship with the patient. Seven of the question groupings concerning technology acceptance (TA) and eight groupings concerning technology competence (TC) were selected for independent variables, informed by past literature. The same TA and TC question groupings were then used in the factor analysis.

2.1.5. Analysis

All calculations were performed with the IBM SPSS program version 27 (IBM Corp, 2020). All multi-answer question groupings were dummy-coded into individual binary response questions, to facilitate the use of stronger statistical analyses. No data was lost in this recoding process.

2.1.5.1. Regression

To examine what influences the prospective adoption of video therapy by speech and language therapists, a regression analysis was planned. However, as the dependent variable was found to be significantly non-normally distributed and could not be sufficiently rectified via standard correction methods, a statistically weaker but more robust logistical ordinal regression was performed.

To form the dependent variable, the five questions regarding the participants' views on video therapy adoption (mentioned above in Measure) were recoded into positive (+1), negative (−1) and neutral (0) and summed together to form a general "Opinion of Video Therapy" variable (see Table 2), ranging from +5 (all positive) to −5 (all negative). This resulted in a single variable with a distribution that could be statistically analyzed.

As independent variables, the regression included all binary recoded question items from the factor analysis (89 individual question items in all).

2.1.5.2. Factor analysis and item reduction

To investigate the constructs underlying the attitudes of users toward technology acceptance and technology competence in the context of SLT, the data were analyzed using principal axis factoring with varimax rotation. As one of the 15 question groupings did not load on any factor due to insufficient variance in the responses, it was excluded from further examination. Thus 14 question groupings from the questionnaire were included in the final analysis. See Table 3 for a complete list of included questions, with the excluded item marked in gray.

Although the data were not all perfectly normally distributed, due to the robust nature of the analysis and the use of binary independent variable items, the data was deemed to be acceptable for the analysis. A preliminary factor analysis was originally conducted which was limited to 25 iterations; the resultant Scree plot identified four primary factors before tailing off, thus the final factor analysis was limited to four factors. This four factor analysis is presented in the Results section.

2.2. Study 2

To investigate the technology acceptance of speech and language therapists, the UTAUT was chosen as a basis. The constructs Attitude of Colleagues (AoC), Digitality at Work (DaW), Self-Assessment of Digital Competencies (SAoDC), and Attitude and Affect toward the Use of Digital Media (AUDM) were included as additional variables.

2.2.1. Research questions

The following research questions were investigated by Study 2:

c. To what extent are speech and language therapists intending to use ICT in therapy in the future?
d. To what extent do Performance Expectancy, Effort Expectancy, Social Influence, and Facilitating Conditions, as well as additional factors, predict speech language therapists' Behavioral Intention to Use digital media in therapy?

2.2.2. Procedure

The development of the used online questionnaire took place in the department of Inclusive Education for speech, language, and communication needs at the University of Bremen (Germany). The survey period ran from mid-July to November 2020.

The questionnaire was made available via LimeSurvey (Limesurvey GmbH). Respondents were asked to participate if they were providing SLT in an outpatient setting in Germany at the time of the survey or had done so prior to the COVID-19 pandemic. Use of digital media or delivery of video therapy during the COVID-19 pandemic did not constitute inclusion criteria. Recruitment was conducted through German SLT associations and networks as well as personal contacts of the authors. Participants were informed of

TABLE 2 Question responses informing the independent variable "Opinion of Video Therapy".

Number	Question	Answer	Score
1	Do you see a realistic possibility for the use of video therapy in outpatient speech and language therapy?	Yes	1
		No	−1
		Unsure	0
2	Can you imagine employing video therapy more frequently, if its use facilitated better or faster success therapy?	Yes	1
		No	−1
		Unsure	0
3	Should video therapy be included in standard practice?	Yes	1
		No	−1
		Unsure	0
6	Can you imagine conducting some therapy sessions in the therapy process online, without it impairing the success of the therapy?	Yes	1
		No	−1
		Unsure	0
7	Can you imagine conducting some therapy sessions in the therapy process online, without it affecting the relationship between the patient and you?	Yes	1
		No	−1
		Unsure	0

When summed together, the resultant variable ranged from−5 "fully negative" to +5 "fully positive" opinion of video therapy.

the study content and were required to provide informed consent before beginning the survey. Participation could be discontinued at any time during the survey. The data is stored on the university server and will remain stored until 2030, and only project-internal employees will have access to it.

2.2.3. Participants

In total 79 individuals took part in the survey, of which 75 were female and four male (94.9% and 5.1%, respectively). Respondents ranged in age from 22 to 67 years ($M = 43.37$ years, SD = 10.9). Work experience was reported between one and 40 years ($M = 16.39$ years, SD = 9.6). 69 of the respondents indicated a speech/language therapy practice as their workplace (87.3%). Other places of employment included (interdisciplinary) therapy centers, early intervention centers, and a social pediatric center. Two respondents reported working in three different facilities in combination (see Table 4).

The majority of respondents (64.6%) were self-employed in their own practice. Nearly one-third were not self-employed/employed (31.6%). In addition, two freelancers working on a fee basis (2.5%) and one student worker (1.3%) participated in the survey.

2.2.4. Measure

At the University of Bremen in early 2020, a theory-based questionnaire was created to examine technology use, personal experiences regarding technology use in everyday work, and technology acceptance of SLT. The questionnaire also included a general part with questions on socio-demographic information. The data used for the presented study came from the questionnaire section on technology acceptance and the experience with digital media use.

Different items were used to query technology acceptance. 14 of the items used were German translations and modifications of the adapted UTAUT items validated by Teo (2009, 2010), which have their origin in Venkatesh et al. (2003). They are shown in the Table 5. All items were Likert items which were summarized in 5 Likert scales following past literature (Harpe, 2015). The five response options were: 0 = does not apply at all; 1 = mostly does not apply; 2 = undecided; 3 = mostly applies; 4 = applies fully.

The internal consistency of the 14 used UTAUT items was determined by Cronbach's alpha. With a value of $\alpha = 0.892$, internal consistency was high (Cortina, 1993). The internal consistencies were also calculated for the individual Likert scales of the four predictors of the UTAUT model which also turned out to be high: PE $\alpha = 0.890$; SI $\alpha = 0.813$; FC $\alpha = 0.899$. The value for EE was acceptable: $\alpha = 0.769$.

In addition to the UTAUT items, a total of 25 items were developed for the constructs of Attitude of Colleagues (AoC), Digitality at Work (DaW), Self-Assessment of Digital Competence (SAoDC), and Attitude and Affect toward the Use of Digital Media (AUDM) and included in the questionnaire. The items on these constructs were developed from theory and generated as Likert items (Harpe, 2015) according to the used UTAUT items.

Factor analyses (principal axis analyses; VARIMAX, 50 iterations) were conducted to identify appropriate items related to the constructs developed from theory. The 25 items of the additional constructs as well as the 12 items of the latent constructs Performance Expectancy (PE), Effort Expectancy (EE), Social Influence (SI), and Facilitating Conditions (FC) of the UTAUT were included, while the two items capturing the dependent variable Behavioral Intention to Use (BIU) were not included in the factor analysis. In this way, a total of 37 items were incorporated into

TABLE 3 **Question groupings representing video therapy acceptance and competence in Study 1.**

Question groupings	Literature
Technology competence	
(1) What positive experiences have you had with the technical implementation of video therapy?	Molini-Avejonas et al., 2015; Hastall et al., 2017
(2) What helps you implement video therapy well?	Hastall et al., 2017
(3) How did you deal with the technical problems?	Molini-Avejonas et al., 2015
(4) Do technical problems occur when performing video therapy?	
(5) What caused the technical problems to occur?	
(6) How did you deal with the technical problems?	
(7) How have you dealt with personal difficulties so far?	Molini-Avejonas et al., 2015; Hastall et al., 2017
(8) How have you dealt with patient difficulties so far?	Molini-Avejonas et al., 2015
Technology acceptance	
(1) What are the benefits of video therapy for you as a therapist?	Hastall et al., 2017
(2) What are the benefits of video therapy for your patients?	Molini-Avejonas et al., 2015; Hastall et al., 2017; Tyagi et al., 2018
(3) What difficulties do you personally face when doing video therapy?	Leinweber and Schulz, 2019
(4) What difficulties do patients have when you do video therapy with them?	
(5) In order to perform video therapies optimally, I would need	Hastall et al., 2017
(6) What are the disadvantages of video therapy for you as a therapist?	Tyagi et al., 2018; Leinweber and Schulz, 2019
(7) What are the disadvantages of video therapy for your patients?	Hastall et al., 2017; Tyagi et al., 2018

Question grouping 8 (technology competence) was excluded. Developed following Molini-Avejonas et al. (2015), Hastall et al. (2017), Tyagi et al. (2018), and Leinweber and Schulz (2019).

TABLE 4 **Respondents' demographics in Study 2.**

Item	Response	Frequency (%)	Mean (SD)
Gender ($n = 79$)	Female	75 (94.9)	
	Male	5 (5.1)	
Age, years ($n = 79$)			43.37 (±10.9)
Years of working experience, years ($n = 79$)			16.39 (±9.6)
Professional status ($n = 79$)	Practice owner/self-employed	51 (64.6)	
	Employee	25 (31.6)	
	Freelancer	2 (2.5)	
	Student worker	1 (1.3)	
Workplace ($n = 79$)	Speech/language therapy practice	69 (87.3)	
	(Interdisciplinary) therapy centers	3 (3.8)	
	Early intervention centers	2 (2.5)	
	Social pediatric center	1 (1.3)	
	Outpatient rehabilitation	1 (1.3)	
	Vocational school for speech therapy	1 (1.3)	
	Combination of different facilities	2 (2.5)	

the factor analysis. Data from 63 to 68 participants could be analyzed for this purpose because some respondents did not answer some questions. In the course of the repeated calculation, items that loaded higher on more than one factor were identified and excluded. By excluding nine items for the reason just mentioned, 26 items were finally identified that showed a loading of >0.5 and clearly loaded on one of the eight factors. By the described procedure, the 12 UTAUT items (Teo, 2009, 2010) could be confirmed as well as 14 items could be identified which addressed the four additionally included constructs (see Table 6).

Internal consistency was also checked for these individual scales: SAoDC $\alpha = 0.851$; DaW $\alpha = 0.818$; AoC $\alpha = 0.841$; AUDM $\alpha = 0.918$. These constructs also showed a high value in terms of internal consistency.

2.2.5. Analysis

All calculations were performed with the program SPSS program version 26 (IBM Corp, 2019).

To examine technology acceptance in the form of Behavioral Intention to Use (BIU) among therapists, the calculations and considerations of the mean and dispersion measures of the single variables of UTAUT and the new constructs were performed.

To answer the second question, the respective items of the variables were summarized using their mean values as in other studies on the UTAUT. The recommendations in using the averaged values of Likert scales as interval scaled data were fulfilled (Harpe, 2015). For age and work experience, the response values of the respondents were used (age in years, work experience in years). Multiple linear regressions in a three-block hierarchy (forced entry) were used to test the influence of the different independent variables on BIU. All assumptions for the analysis were fulfilled, including multicollinearity, heteroscedasticity, or nonlinearity (see Results). In order to take into account the possible influence of the variables age and work experience, these were also included in the regression calculations. Due to the

TABLE 5 Technology acceptance items used in Study 2.

Performance expectancy (PE)	Using digital media improves my work.
	Using digital media enhances the effectiveness of therapeutic measures.
	Using digital media increases my productivity.
	Digital media are useful tools for therapy.
Effort expectancy (EE)	I find it easy to use digital media for my needs.
	I find digital media easy to use.
	Using digital media does not require a lot of mental effort.
Social influence (SI)	People whose opinions I value encourage me to use digital media in therapy.
	People who are important to me support me to use digital media in therapy.
Facilitating conditions (FC)	When I need help to use digital media in therapy, guidance is available to me.
	When I need help to use digital media in therapy, specialized instruction is available to help me.
	When I need help to use digital media in therapy, a specific person is available to provide assistance.
Behavioral intention to use (BIU)	I will continue to use digital media in therapy.
	I will use digital media in therapy in future.

Developed following Venkatesh et al. (2003) and Teo (2009, 2010).

TABLE 6 Items used for the four additional influence variables in Study 2.

Self-Assessment of Digital Competence (SAoDC)	I feel competent in terms of using digital media in general day-to-day work.
	I feel competent with regard to the use of digital media within therapy.
Digitality at Work (DaW)	Within my institution, the use of digital media in therapy was widespread.
	My supervisor was open to the use of digital media in therapy.
	I was well supported in incorporating digital media into therapy.
Attitude of Colleagues (AoC)	My colleagues rejected the use of digital media in therapy (reversed!).
	The use of digital media in therapy was viewed critically by colleagues (reversed!).
Attitude and Affect toward the Use of Digital Media (AUDM)	The use of digital media in therapy is a chance to break new ways to go.
	I would be happy if I no longer had to use digital media in therapy (reversed!).
	Contact via digital media is too impersonal for me (reversed!).
	I am motivated to use digital media also in the future in the therapy implementation.
	The use of digital media contradicts my perception of good therapy (reversed!).
	I enjoyed the use of digital media.
	The quality of therapy suffers from the use of digital media (reversed!).

low participation of males ($n = 4$), the gender factor could not be examined.

In a first step, the correlations between all individual variables included were checked. The variable Attitude of Colleagues (AoC) was then excluded from further calculations as it did not show any correlations with the dependent variable BIU or the other predictors.

In the first block of the multiple linear regression, age and work experience (WE) were included in the model. In the second block of the regression, the established predictors of the UTAUT—PE, EE, SI and FC—were included to check the basic model. In the last step, the UTAUT modification variables AUDM, SAoDC and DaW were added. For 12 of the 79 respondents not all values were available, because at the time of the survey they were not undergoing any therapies and therefore certain data were not feasible ($n = 11$) or there were missing values in a part of the included items ($n = 1$). Thus, the data of 67 persons could be used for this analysis. Since collinearity between the predictors Performance Expectancy (PE) and Attitude and Affect toward the Use of Digital Media (AUDM) was found in the last model, AUDM was excluded in a new model calculation to avoid distortions of the model.

In the final step, the same statistical procedure was followed as just mentioned, excluding the variable AUDM.

3. Results

3.1. Study 1

3.1.1. Factor analysis

Numerous factors were initially identified by SPSS due to having eigenvalues <1; however, after examining the Scree Plot of Eigenvalues table (see Supplementary material), it was decided that the first four were legitimate factors and all factors thereafter were the beginning of the tail and could be discarded. Thus, four factors were identified in the questionnaire, accounting for 21.7% of variance in the data. Each factor is independent of all others, as demonstrated by the low correlation scores in the Factor Correlation Matrix (see Table 7).

3.1.2. Regression

As mentioned above, it was not possible to conduct a multiple regression analysis as planned, due to the significant deviations from normality of the independent variable, which therefore violated the assumptions necessary for multiple regression. An ordinal logistic regression was therefore conducted. Significance was determined at the standard p <0.05.

The −2 Log Likelihood model was significantly significant ($\chi^2 = 447.775$, $df = 89$, $p < 0.001$), indicating that the full model was a

TABLE 7 Factor correlation matrix (Study 1).

	(1) Technology-related	(2) Individual-related: emotional processes and risk perception	(3) Individual-related: knowledge and literacy	(4) Environment-related
(1) Technology-related	1.000			
(2) Individual-related: emotional processes and risk perception	−0.238	1.000		
(3) Individual-related: knowledge and literacy	0.303	0.027	1.000	
(4) Environment-related	0.365	0.111	0.316	1.000

significant improvement in the predictive capacity of the full model over the intercept only model. Similarly, both the Pearson ($\chi^2 = 4{,}469.677$, $df = 6971$, $p = 1.00$) and Deviance ($\chi^2 = 1{,}107.218$, $df = 6{,}971$, $p = 1.00$). Goodness of Fit tests indicated that the model was a good fit for the data.

a. What factors correlate with the prospective adoption of video therapy by speech and language therapists?

The regression results indicate a variety of factors which correlate with the adoption of video therapy in the future. Overall, 14 items contributed significantly to the model—see Table 8 for details. Among these items, increased difficulty in any category was associated with a reduced likelihood of a higher adoption score. Technical difficulties [−0.583, Wald χ^2 (1) = 4.947, p = 0.026], a lack of training [−1.594, Wald χ^2 (1) = 6.916, p = 0.009], a lack of prior experience [−0.849, Wald χ^2 (1) = 4.784, p = 0.029] and a perceived limitation of methods [−0.811, Wald χ^2 (1) = 4.846, p = 0.028] all significantly reduced a respondent's opinion of video therapy. Comparatively, perceived benefits like health protection of patients [1.461, Wald χ^2 (1) = 14.533, $p < 0.001$], increased range of therapy options [1.406, Wald χ^2 (1) = 26.750, $p < 0.001$], and new skill acquisition [0.655, Wald χ^2 (1) = 6.823, p = 0.009] all significantly increased a respondent's opinion about video therapy.

Time was variously positive and negative. A reported perception of increased preparation time [0.978, Wald χ^2 (1) = 7.873, p = 0.005] actually improved respondent opinion, as did the reduced travel time for patients [0.557, Wald χ^2 (1) = 3.391, p = 0.047]; however, high follow-up time [−0.916, Wald χ^2 (1) = 5.982, p = 0.014] reduced respondent opinion.

Motivation also seemed to influence respondent opinions—respondents with increased motivation [0.756, Wald χ^2 (1) = 5.025, p = 0.025] reported higher opinions, however those who sought professional help to fix technical problems time [−0.841, Wald χ^2 (1) = 5.020, p = 0.025] and those who gave up on video therapy when faced with technical problems time [−1.268, Wald χ^2 (1) = 4.837, p = 0.028] had a reduced opinion of video therapy.

b. What constructs underlie the attitudes of users toward technology acceptance and technology competence in the context of SLT?

Based on the rotation matrix produced during the factor analysis, the items either loaded uniquely on one of the four factors identified or did not load on any of the four primary factors, with one exception where one item loaded on two factors. All questions contained at least one item that contributed to a factor. Based on the items that contributed to each factor, the four factors were identified as "technology", "emotional processes", "knowledge" and "environment". How these factors relate to previous research will be addressed in the discussion. See Table 9 for a list of which questions contributed to which factors.

3.2. Study 2

c. To what extent are speech and language therapists intending to use ICT in therapy in the future?

With regard to the acceptance of the use of digital media within therapy, a heterogeneous picture emerged among the German therapists. The Behavioral Intention to Use (BIU) scores ranged from 0.5 to the maximum achievable 4 points. The average for the entire group is 2.92 (SD = 0.895), which is within the range of "mostly applies" on the Likert scale used.

All predictors showed average values between 2 and around 3. This corresponds to values between the answer options "undecided" and "mostly applies". The predictors also showed a large dispersion across the sample and thus very different expressions in the individual therapists. The lowest mean value was achieved by the predictor Facilitation Conditions (FC) (M = 2.03, SD = 1.14), the highest mean value was shown by Digitality at Work (DaW) (M = 3.09; SD = 1.08) (see Table 10).

d. To what extent do Performance Expectancy (PE), Effort Expectancy (EE), Social Influence (SI), and Facilitating Conditions (FC), as well as additional factors, predict speech and language therapists' Behavioral Intention to Use (BIU) digital media in therapy?

In terms of the included moderator variables of age and work experience (WE), there were isolated significant correlations found. Age correlated significantly with work experience (WE), Behavioral Intention to Use (BIU), Performance Expectamcy (PE) and Effort

TABLE 8 Significant response items identified for video therapy adoption in Study 1.

Question items	Estimate	Std. error	Wald	df	Sig.	95% CI		Factor
						Lower bound	Upper bound	
To deal with technical problems—I got professional/technical help	−0.841	0.375	5.020	1	0.025	−0.105	−1.577	Did not load on any factor
To deal with technical problems—I stopped offering video therapy	−1.268	0.577	4.837	1	0.028	−0.138	−2.399	Emotional processes
Benefits I see in video therapy for me as a therapist include—video therapy increases my motivation for therapy	0.756	0.337	5.025	1	0.025	1.416	0.095	Did not load on any factor
Benefits I see in video therapy for me as a therapist include—no traveling to the patients	0.557	0.281	3.931	1	0.047	1.107	0.006	Emotional processes
Advantages of video therapy for my patients include—health protection (e.g. no risk of receiving contagious infections)	1.461	0.383	14.533	1	<0.001	2.212	0.710	Emotional processes
Benefits I see in video therapy for me as a therapist include—extension of the range of therapies	1,406	0.272	26.750	1	<0.001	1.939	0.873	Emotional processes
A positive experience I associate with the technical implementation of video therapy is—Acquiring new methodological knowledge	0.655	0.251	6.823	1	0.009	1.147	0.164	Emotional processes
Technical problems occurred during the implementation of video therapy—a lack of previous experience conducting video therapy	−0.849	0.388	4.784	1	0.029	−0.088	−1.610	Knowledge
Technical problems occurred during the implementation of video therapy – a lack of training in video therapy	−1.594	0.606	6.916	1	0.009	−0.406	−2.782	Knowledge
Difficulties I personally faced when conducting video therapy are—of a technical nature (e.g. program crashes, slow internet, etc.)	−0.583	0.262	4.947	1	0.026	−0.069	−1.098	Environment
I have not had personal difficulties to deal with so far (in the context of video therapy)	−0.986	0.448	4.846	1	0.028	−0.108	−1.864	Environment
Disadvantages of video therapy for me as a therapist include—high preparation time	0.978	0.348	7.873	1	0.005	1.660	0.295	Technology
Disadvantages of video therapy for me as a therapist include—a limitation in the choice of methods in therapy	−0.811	0.369	4.846	1	0.028	−0.089	−1.534	Technology
Disadvantages of video therapy for me as a therapist include—high follow-up time	−0.916	0.375	5.982	1	0.014	−0.182	−1.651	Technology

Expectancy (EE), while WE also correlated significantly with EE. All correlations are shown in Table 11.

Model 3, which included all of the variables, explains 58.8% of the variability. The elucidation of variability was increased by including the variables Digitality at Work (DaW) and Self-Assessment of Digital Competencies (SAoDC) into the UTAUT-model but not significantly. Table 12 provides an overview of the multiple linear regression results.

The generalizability of the models is given. The F-statistic shows highly significant values ($p < 0.001$) for model 2 as well as model 3, so both models (basic UTAUT and extended UTAUT) predict BIU significantly.

TABLE 9 Rotation matrix to the factor analysis of 14 question items in Study 1.

Question items	Factor			
	(1) Technology	(2) Emotional processes	(3) Knowledge	(4) Environment
Disadvantages of video therapy for me as a therapist include				
High preparation time	0.673			
High follow-up time	0.487			
A limitation in the choice of methods in therapy	0.688			
A positive experience I associate with the technical implementation of video therapy is—acquiring new methodological knowledge		0.322		
To deal with technical problems:				
I stopped offering video therapy		−0.391		
I got professional/technical help				
Advantages of video therapy for my patients include—health protection (e.g. No risk of receiving contagious infections)		0.700		
Benefits I see in video therapy for me as a therapist include				
Extension of the range of therapies		0.520		
No traveling to the patients		0.443		
Video therapy increases my motivation for therapy				
Technical problems occurred during the implementation of video therapy:				
A lack of previous experience Conducting video therapy			0.581	
A lack of training in video therapy			0.567	
Difficulties I personally faced when conducting video therapy are—of a technical nature (e.g., Program crashes, slow internet, etc.)				0.493
I have not had personal difficulties to deal with so far (in the context of video therapy)				−0.340

Extraction method: principal axis factoring.
Rotation method: Promax with Kaiser normalization[a].
[a]Rotation converged in six iterations.

Table 13 shows the regression coefficients of model 3 (extended UTAUT).

Performance Expectancy (PE) is a significant predictor of Behavioral Intention to Use (BIU) in German speech language therapists. There was no evidence of multicollinearity, heteroscedasticity, or nonlinearity. In addition, no case had an excessive influence on the model and the normal distribution of the residuals was given.

4. Discussion

Study 1 aimed to investigate the use and success of video therapy in German Speech Language Therapy (SLT), based on the technology adoption approach outlined by Hastall et al. (2017). Therefore, the study investigated possible correlations and influences on the prospective attitudes of speech and language therapists toward video therapy as identified via preselected questionnaire items. The significant results included items related to perceived benefits, time and motivation as being impactful to the respondents and therefore for the successful adoption of video therapy in the context of SLT. These factors can have both inhibiting and facilitating outcomes in the adoption and future use of video therapy in SLT, which has also been demonstrated in numerous previous studies (Bilda et al., 2020; Lauer, 2020; Schwinn et al., 2020; Tenforde et al., 2020; Barthel et al., 2021a,b; Eslami Jahromi et al., 2022; Shahouzaie and Gholamiyan Arefi, 2022; Bayati and Ayatollahi, 2023).

Hastall et al. (2017), for example, argued that attention to human-driven factors can promote the adoption of technology—that is, video therapy adoption in SLT in the context of this study. Focusing on the three dimensions of relevant influences from Hastall et al. (2017): (1) *individual-related factors*, (2) *environment-related factors*, and (3) *technology-related factors* provided a good framework for investigating video therapy as an innovative digital medium in German SLT. However, the current analysis identified four factors from among the significant questionnaire items: technology (Factor 1), emotional processes (Factor 2), knowledge

TABLE 10 Descriptive measures of the variables included (Study 2).

	BIU ($n = 79$)	PE ($n = 79$)	EE ($n = 79$)	SI ($n = 79$)	FC ($n = 79$)	DaW ($n = 68$)	SAoDC ($n = 67$)
Mean	2.9241	2.7342	2.5063	2.4304	2.0253	3.0858	2.9403
Std. deviation	0.89546	0.82270	0.79324	1.06438	1.14326	1.08223	0.93551
Minimum	0.50	0.50	1.00	0.00	0.00	1.00	0.50
Maximum	4.00	4.00	4.00	4.00	4.00	4.00	4.00

BIU, Behavioral Intention to Use; PE, Performance Expectancy; EE, Effort Expectancy; SI, Social Influence; FC, Facilitating Conditions; DaW, Digitality at Work; SAoDC, Self-Assessment of Digital Competence.

As the questions were not obligatory to answer, some questions were answered by fewer than the participating 79 therapists. The number of therapists who answered the questions is given in brackets after the respective item.

TABLE 11 Correlations between the included variables (Study 2).

	BIU	Age	WE	PE	EE	SI	FC	DaW	SAoDC
BIU	1.000								
Age	0.251*	1.000							
WE	0.184	0.812***	1.000						
PE	0.706***	0.207*	0.091	1.000					
EE	0.335**	−0.238*	−0.357**	0.422***	1.000				
SI	0.533***	0.113	0.068	0.530***	0.333**	1.000			
FC	0.376**	0.177	0.069	0.303**	0.267*	0.412***	1.000		
DaW	0.376**	0.025	0.112	0.304**	0.113	0.195	0.220*	1.000	
SAoDC	0.463***	−0.032	−0.009	0.453***	0.403***	0.321**	0.403***	0.474***	1.000

Correlation (Pearson) ($n = 67$): *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$ (one tailed).

BIU, Behavioral Intention to Use; WE, Work Experience; PE, Performance Expectancy; EE, Effort Expectancy; SI, Social Influence; FC, Facilitating Conditions; DaW, Digitality at Work; SAoDC, Self-Assessment of Digital Competence.

TABLE 12 Results of the multiple linear regression (Study 2).

Model	R	R square	Adjusted R square	Std. error of the estimate	R square change	F change	df 1	df 2	Sig. F change
1	0.253[a]	0.064	0.035	0.88755	0.064	2.190	2	64	0.120
2	0.750[b]	0.563	0.519	0.62627	0.499	17.136	4	60	0.000
3	0.767[c]	0.588	0.531	0.61852	0.025	1.756	2	58	0.182

[a] Influencing variables: (constant), age in years, work experience in years.

[b] Influencing variables: (constant), age in years, work experience in years, FC, EE, SI, PE.

[c] Influencing variables: (constant), age in years, work experience in years, FC, EE, SI, PE, DaW, SAoDC.

TABLE 13 Linear model of the predictors of BIU (Model 3; Study 2).

	Unstandardized coefficients		Standardized coefficient	*t*	Sig.
	B	Std. error	Beta		
(Constant)	−0.021	0.542		−0.038	0.970
Age	0.008	0.014	0.086	0.550	0.584
WE	0.006	0.016	0.061	0.388	0.700
PE	0.490	0.121	0.470	4.055	0.000
EE	0.062	0.126	0.054	0.494	0.623
SI	0.145	0.089	0.172	1.627	0.109
FC	0.051	0.079	0.064	0.640	0.525
DaW	0.105	0.082	0.127	1.291	0.202
SAoDC	0.087	0.109	0.090	0.801	0.427

Significant results are marked in gray.

(Factor 3) and environment (Factor 4). Following the approach by Hastall et al. (2017) those four factors can give an idea of which human and technology driven factors could impact the use of video therapy. All significant items had at least a moderate impact on the outcome variable here, implying that all four factors are relevant for a successfully implemented adoption of video therapy technology.

With relation to the technology-related factors (Factor 1), therapists indicated the disadvantages of video therapy by the perception of negative aspects. Aspects of time, such as "follow-up time" and "preparation time", are factors that could inhibit the use of video therapy in SLT. This is in line with the literature investigating advantages and disadvantages for the implementation of video therapy in Germany (Bilda et al., 2020; Lauer, 2020; Schwinn et al., 2020; Mörsdorf and Beushausen, 2021; Hecht et al., 2022) as well as in line with international studies (Tenforde et al., 2020; Shahouzaie and Gholamiyan Arefi, 2022; Bayati and Ayatollahi, 2023).

In contrast, the advantages of video therapy were more driven by emotional processes (Factor 2), which compare with the individual-related factors in Hastall et al. (2017). Positive aspects such as travel time, therapy and health protection are in line with the literature and can facilitate the prospective use of video therapy (Lauer, 2020; Schwinn et al., 2020). Following the approach of Hastall et al. (2017) human behavior is driven by emotions in the context of digital media use in health care. More specifically, emotions can play a critically role when being confronted with health vs. sickness (Hastall et al., 2017). In the case of video therapy, the context of health protection seems to be a relevant factor for implementation and was especially relevant during the COVID-19 pandemic (Barthel et al., 2021a,b).

Items related to knowledge (Factor 3) about video therapy seem to stem from negative feelings like insufficiency in knowledge and training. Those who report insufficient training in video therapy or software systems as well as a lack of previous experience in their implementation are more likely to report a low future intention to adopt video therapy. Hastall et al. (2017) emphasized that this factor is not only the missing technology-related foreknowledge but also the access to information about health technology, even of the existence and range of available options. They summarized that not only is appropriate knowledge, experience, and user competences needed in health-related ICT, but likely also knowledge about effective motivating education strategies (Hastall et al., 2017). Both emotional processes and knowledge factors (2 and 3) are highly individual-related and support the technology acceptance literature more broadly (Hastall et al., 2017), with supportive behavior and avoidance behavior combining to influence an individual's attitude.

Factor 4 included items based on environment-related factors, in particular the barriers preventing video therapy adoption that stem from geographical factors. Literature has constantly noted that challenges to video therapy adoption in Germany often include technical difficulties, such as unstable internet connections, service availability or continuity problems (Bilda et al., 2020; Lauer, 2020; Schwinn et al., 2020). Unsurprisingly, an unstable internet connection or intermittent connection failure can make video therapy difficult or even impossible. In many speech and language therapy sessions, high transmission quality is crucial, as the assessment of linguistic or facial aspects can only be accurate with good image and sound quality.

The four presented factors, when taken together, can help to inform those who wish to implement video therapy successfully. Firstly, parties who wish to implement video therapy as a regular and reliable healthcare service should aim to maximize adoption-facilitating conditions, like the personal and emotional benefits to patients and therapists; simultaneously they should aim to minimize rejection-facilitating conditions (Wade et al., 2014), for example by supplementing individual experience with quality training and by supporting therapists in their time investment. All of this requires substantial knowledge about the patients and therapists to bring together.

Study 2 investigated factors influencing the therapists' intention to use digital media in SLT in the future. The results show that German therapists are mostly willing to use ICT in therapy in the future. However, there was a certain heterogeneity within the sample. Thus, while many definitely want to use digital media in the future, there is also a significant minority who does not. Speech language therapists who show little or no interest in using digital media in therapy cannot seriously fulfill their mandate to provide digital participation for patients for whom digitalization is important to their lives (Steiner, 2023).

Of the individual factors, Digitality at Work (DaW) showed the highest mean value. This can be explained by the video therapies performed during the COVID-19 pandemic. These were temporarily the only possibilities to offer therapy for many patients and were therefore integrated in most practices. At the same time, however, there was a lack of support systems, as shown by Facilitating Conditions' (FC) low average score. This is consistent with the results of the first study.

For the purpose of identifying the impact of different influencing factors, six possible influencing factors (four original UTAUT and two supplementary) were included in the full analysis of study 2 along with age and work experience (WE). Age correlated significantly with WE, Behavioral Intention to Use (BIU), Performance Expectancy (PE) and Effort Expectancy (EE), while WE correlated significantly with age and EE. The correlation between age and WE is not surprising, as older speech and language therapists typically have more WE than younger therapists. Beyond this effect, there appears to be an interaction effect of age and WE in parts of the model.

In their meta-analysis, Dwivedi et al. (2019) were able to demonstrate a direct influence of attitude on BIU. Moreover, they found that attitude partially mediated the effects of all UTAUT-predictors on behavioral intention as well. This fits with the overlap, found in this research, between PE and Attitude and Affect toward Use of Digital Media (AUDM). This evidence supports the inclusion of attitude as a mediator in future studies.

While all the results demonstrated a significant relationship between Behavioral Intention to Use (BIU) and all of the checked factors, Performance Expectancy (PE) showed significant and distinct influence in the present study. PE also represented the highest influencing factor on BIU. This suggests that, in their opinions on ICT in therapy, speech therapists are most impacted by the perceived performance outcomes from utilizing that technology. These results match results from past studies (e.g., Venkatesh et al., 2003; Teo and Noyes, 2014). If speech language therapists consider the use of digital media as beneficial for their work, the intention to use digital media in the future increases.

Social influence (SI) on BIU has also been highlighted previously, particularly among women (Morris and Venkatesh, 2000; Teo and Noyes, 2014). Given the very high proportion of female therapists, both in this study and in the field in general, this factor should not be underrated; however, due to this high ratio among the respondents, this study could not isolate the SI effect from the sex effect. The included variables Self-Assessment of Digital Competencies (SAoDC) and Digitality at Work (DaW) could additionally improve the prediction of BIU in the model. However, a significant direct influence on the BIU could not be proven for the present sample.

The results of both studies show parallels. Influencing factors demonstrated for technology use in general (Study 2) can also be shown in the specific area of video therapy use (Study 1). Study 1 provides specific evidence regarding which factors increase acceptance of video therapy among speech and language therapists. Respondents indicated advantages in terms of Performance Expectancy (PE), disadvantages in terms of Effort Expectancy (EE), training (SAoDC, FC), and experience (DaW) as supporting and negative influencing factors, respectively. These determinants are also found in the UTAUT and were surveyed in Study 2 for general media use in therapy. The parallels noted are not surprising, as both studies looked at technology acceptance of speech and language therapists (see Figure 2).

Across the two studies, one of the biggest factors influencing future ICT adoption was support—especially in the form of education and training. A lack of training and experience can lead to frustration with the technology (De Joode et al., 2012; Liu et al., 2015; Gagnon et al., 2016), while an increase in troubleshooting knowledge and experience can improve satisfaction (Tucker, 2012). Professionals themselves have frequently highlighted the importance they place on training and the availability of support (Hill and Breslin, 2016; Burke et al., 2022; Kearns and Kelly, 2022). This highlights the importance of education in the industry going forward.

This change in education is multifaceted. With regards to the education of new practitioners, there is a need to integrate both theory-based content and practical digital skills in the curricula (Edwards and Dukhovny, 2017; European Health Parliament, 2020). In the spirit of lifelong learning, other training concepts should be tailored to suit currently active therapists—to expand their digital skills in a professional context and to implement them in their everyday practice (Lin et al., 2021). These are essential prerequisites to be able to advance professionalization in speech therapy in line with current developments (Theodoros, 2012). The implementation of the aforementioned content and factors faces the additional challenge in Germany that there are different training paths (e.g., vocational school vs. university) and professional groups (e.g., speech language therapists or academic speech therapists). Therefore, the authors provide concrete factors to consider and ideas for implementation that can be applied in all education and training contexts of speech language therapy.

From one perspective, therapists must have specific digital competencies in order to responsibly and meaningfully incorporate ICT into therapy. For example, the suitability and adaptation of programs must be tailored to the individual patient, their embedding must be planned and implemented in a goal-oriented manner, and their use must be continuously reflected upon and subsequently evaluated (Brennan et al., 2010; Alber et al., 2020; Alber and Starke, 2021a; Wirths et al., 2022). Further education and training should also focus on dealing with questions on Performance Expectancy (PE), as this could promote a positive Behavioral Intention to Use (BIU). Therapists should receive information and gain experience in this context, which would show them how ICT can improve and support the fulfillment of individual tasks in therapeutic work. This includes, among other things, focusing on the benefits and opportunities that the technology can bring to the therapy situation itself. To ensure that the technologies being taught, including video therapy, will be meaningfully incorporated into the therapists' repertoires, educators should focus in particular on the deeper functional aspects with a high proportion of practical exercises.

Besides the consideration of PE, educators should be aware of the importance of Social Influence (SI), as the valued opinions of other respected individuals have an impact, often serving as role models of technology use. These role models can include other students or educators in SLT-training (Teo and Noyes, 2014). Digitally supported didactics should be practiced and play an essential role in case management in the area of context assessment, goal setting, therapy planning and implementation, and evaluation and modification (Steiner, 2023). Possible approaches could include the use of case studies or therapy videos in which the use of ICT is exemplified, collegial case consultations with a focus on ICT-supported therapy, or problem-based learning, which brings the use of ICT into the trainees' focus. Additionally, education and training could include formats for exchange between speech and language therapists, e.g. through videoconferencing. In this way, positive experiences can be shared with peers, awareness can be raised and people can also benefit from the experiences of others.

By trying out digital media independently in a protected setting, the expectation of effort can be lowered and the therapists' self-efficacy of dealing with technology can be experienced. Thus, technology acceptance can be promoted within the consideration of both Effort Expectancy (EE) and Self-Assessment of Digital Competence (SAoDC). Practical exercises in video therapy could thus reduce inhibiting factors for video therapy in the area of technology, as well as knowledge and skills. Appropriate training and educational content must first be specifically designed, piloted, made easily accessible, and continually updated. To further support EE and reduce inhibiting factors at the emotional and knowledge levels, it may be useful to focus on therapy-relevant programs and devices and to use applications with easy-to-use interfaces that hide the complexity of the hardware and software. These considerations should also be taken into account when developing specific software for use in therapeutic settings (Teo and Noyes, 2014).

Beyond education, Facilitating Conditions (FC) and Digitality at Work (DaW) are factors that need to be supported more on a structural level. The development and expansion of support systems for the use of digital media in general, and for video therapy in particular, in everyday speech therapy is a challenge.

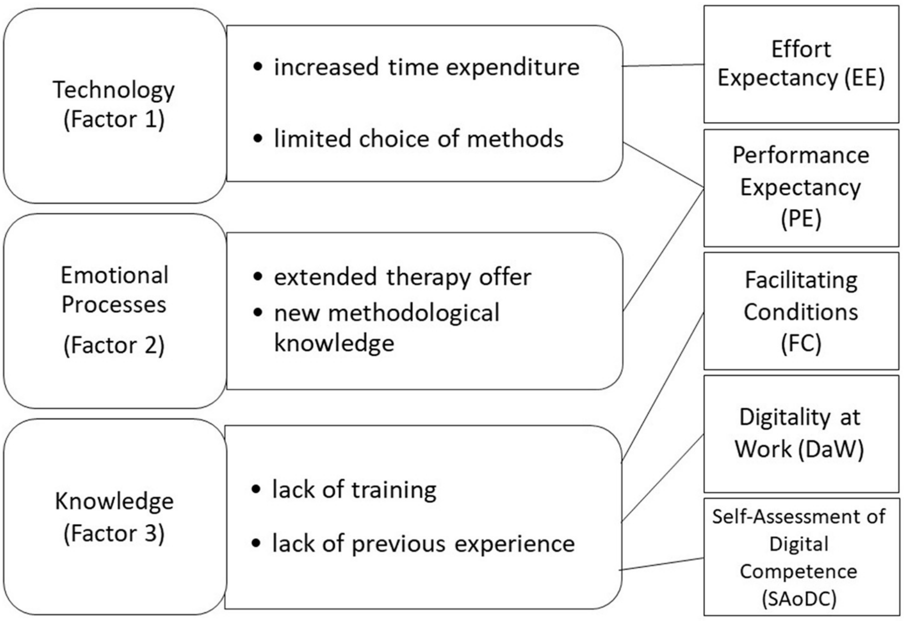

FIGURE 2
Comparable constructs of both studies underlying the attitudes of users toward technology acceptance and technology competence in the context of SLT.

On a structural level, the possibility of billing for video therapies introduced in Germany during the COVID-19 pandemic led to an improvement in the conditions for the use of digital media (Bilda et al., 2020). However, the therapeutic use of video therapies was an uncertain factor during this period; one that was allowed for a certain period of time with a couple of extensions and therefore inhibited the further development of sustainable hybrid (face-to-face therapy in combination with video therapy) or virtual (full video therapy) telepractice offerings (Lauer, 2020). Since September, 2022, video therapy is again possible in Germany due to a transitional arrangement, but it is still not implemented in the regular speech and language therapy service. In line with the literature, unstable reimbursement policies by insurance companies present a barrier to teletherapy implementation (Rettinger et al., 2021). The challenge of purchasing and maintaining suitable hardware and software is also financial. Until now, these costs have been shouldered predominantly by the practices themselves or the individual therapists.

The provision of paid working time for ICT familiarization and implementation is thus another facet of FC. In Germany, speech therapists are paid individually by health insurance companies for each hour of therapy provided. The level of remuneration is also low. Further education and training, as well as familiarization with new technologies is usually voluntary, so that a high level of motivation and personal commitment appears necessary to advance digitalization in a professional context (Hilbert and Paulus, 2018), because the introduction of ICT is often time-consuming, even though the use of ICT can save time in the long run (Gagnon et al., 2016; Burke et al., 2022).

In addition to FC and DaW, other structural factors can also have an impact. The lack of widespread, reliable availability of high-speed Internet can influence the use of digital media in SLT negatively (Schwinn et al., 2020). However, this will not be presented in more detail here, as it was not specifically investigated in the studies presented. Similarly, previous papers (e.g., Alber and Starke, 2021b) found that although German speech and language therapists increased their use of digital technology during the COVID-19 pandemic, this was largely concentrated in the use of video therapy; the use of apps or educational software in therapy did not significantly change over the COVID-19 pandemic period. These factors could be considered in future investigations.

Maximizing facilitation triggers and reducing inhibiting conditions should be the intention, for an optimal health service delivery to patients. A better digital participation for patients is only possible if technology acceptance in speech and language therapists increases by the described possibilities of individual-related, social and environment-related as well as technology-related factors and therefore allows a satisfying health technology adoption in SLT.

5. Limitations of the studies

The results of both studies presented here are based on an online survey of therapists. The samples were obtained from SLT professionals working in outpatient settings in Germany, so it was consciously accepted that therapists working in other contexts, like hospitals or non-German therapists, would be excluded. In addition, both studies used an online questionnaire for the survey, which means that it cannot be ruled out that therapists were more likely to participate who had a minimum level of affinity for and competence in technology. Accordingly, a certain bias in the results cannot be discounted. Due to the pandemic situation and the associated restrictions at the time of the studies, a different procedure was not possible.

The results of Study 1 demonstrated facilitating and inhibiting factors for video therapy adoption based on a high number of participants. However, on a structural level, data did not allow for a more acute examination due to failing certain statistical assumptions, which means that a more precise relationship between the constructs cannot be defined, only trends. Additionally, due to the large test size and breadth of analysis, the cumulative variance accounted for by the factor analysis was low. A follow-up study with fewer but more precisely keyed questions would help. Regarding the interpretation, the results were not as highly interrelated as other literature (e.g., Hastall et al., 2017). This could be due to the methodological limitations, or due to the structure of the questionnaire questions selected, but this limits the connections that can be drawn with the three factors (individual-related, environment-related and technology-related factors) derived from the technology adoption approach of other models.

The generalizability of results of Study 2 is not given due to the sample size. Structural equation modeling was also not possible due to the limited sample size. The moderating variables "age" and "work experience" of the original UTAUT model were therefore included as predictor variables to take their influence into account. The uneven distribution of respondents with regard to gender did not allow this factor to be considered. However, the proportion of male respondents is not surprising, as more than 90% of speech and language therapists in Germany are female (Gesundheitsberichterstattung des Bundes., 2022). Because of the occasional proven correlations between age/work experience and other variables there seems to be moderating effects in parts of the model. These effects should be investigated in more detail in future studies.

Due to statistical evidence, two additional factors derived from theory had to be excluded from the final analysis (Attitude of Colleagues and Attitude and Affect toward the Use of Digital Media). This was the only way to ensure a methodologically adequate procedure.

Despite the limitations mentioned above, it was possible to obtain initial indications regarding the technology acceptance among SLT professionals in Germany, which can be used for future studies in this area. First hints for possible supporting factors emerge, which can be applied for practice and planning of further education and training.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

This study was approved by the committee for research ethics of the University of Applied Sciences and Arts (HAWK) Hildesheim/Holzminden/Göttingen. On the first page of the online-survey, all participants were informed about the study contents and data privacy and gave their informed consent. No data was collected without prior consent. Likewise, all participants of Study 2 were informed about the study content and data privacy on the first page of the online-survey and gave their informed consent. The survey itself and its evaluation were anonymous, and it was not possible to draw conclusions about the respondents at any time during the survey or the evaluation.

Author contributions

JL, MB, BB, and SW designed Study 1. MB, JL, and SW oversaw data collection. MB and AW performed the statistical analysis from Study 1. BA and AS designed Study 2 and oversaw data collection. BA performed the statistical analysis from Study 2. All authors contributed to writing the manuscript, read, and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fcomm.2023.1176827/full#supplementary-material

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Understanding the experience of users of communication aids and applications through focus group discussions with people with aphasia and family members

Nancy Azevedo[1,2,3]*, Guylaine Le Dorze[3,4], Gonia Jarema[2,3,5], Christine Alary Gauvreau[3], Tatiana Ogourtsova[1,3], Stéfanie Beaulieu[3], Christel Beaujard[6], Marc Yvon[6] and Eva Kehayia[1,3]

[1]School of Physical and Occupational Therapy, McGill University, Montréal, QC, Canada, [2]Department of Linguistics and Translation, Université de Montréal, Montréal, QC, Canada, [3]Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Montréal, QC, Canada, [4]School of Speech-Language Therapy and Audiology, Université de Montréal, Montréal, QC, Canada, [5]Research Centre of the Institut Universitaire de Gériatrie de Montréal, Montréal, QC, Canada, [6]IBM Europe Human Centric Innovation Center, Paris, France

The present study sought to identify the communication needs of persons with aphasia (PWA) and of their spouses, that could ultimately be addressed with current communication aids or applications (CA/A). Among users of CA/A we solicited their opinions and experiences with current CA/A. In contrast, among those not using CA/A, we explored why they did not use CA/A. A qualitative experiential research design was used through two in-person focus groups, one in English and one in French, at a large rehabilitation hospital in the Greater Montréal region (Canada). Participants' responses were recorded, transcribed and analyzed. The thematic analysis that ensued allowed the identification of four main themes. The first theme reflects participants' observations and experiences when communicating with aphasia. The second theme regrouped responses related to successful communication with the help of CA/A. The participants' challenges and dissatisfaction with CA/A were grouped into the third theme. Lastly, a fourth theme included participants' general views about CA/A and their wishes for further development. Participants' experience with communication difficulties following aphasia and the barriers and potential facilitators to adoption of CA/A were brought to the forefront. They also highlighted those features necessary to ensuring functional uptake of CA/A by those who would benefit from it. Finally, the importance of providing training to the communication partner and sensitizing the public to the impact of aphasia on people's daily lives and on the potential benefits of using CA/A were raised as necessary future actions.

KEYWORDS

aphasia, family member, focus group, AAC, communication aids and applications

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EDITED BY
Hendrike Frieg,
University of Applied Sciences and Arts Hildesheim, Germany

REVIEWED BY
Elisabeth Meyer,
Hochschule für Gesundheit, Germany
Miriam Abel,
University of Cologne, Germany

*CORRESPONDENCE
Nancy Azevedo
✉ nancy.azevedo@mail.mcgill.ca

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1. Introduction

Aphasia is an acquired language impairment that occurs as the result of a trauma to the brain. In Canada, approximately one-third of stroke survivors, or more than 100,000 people, are living with aphasia (The Heart and Stroke 2017 Stroke Report). This number is expected to double over the next 20 years with the aging of the population. While stroke is the most common cause of aphasia in people seen in the rehabilitation setting, it can also be caused by a traumatic head injury (TBI) or brain degeneration such as primary progressive aphasia (PPA). Aphasia symptoms can include varying levels of impairment in understanding or producing speech, in reading, or in producing written language (Koul, 2011). As a result, a person with acute-onset aphasia or PPA will often struggle when communicating with others.

Although one may take the use of language for granted, when the ability to easily communicate with others is compromised it can lead to devastating effects on interpersonal relationships and access to services in the community (Brown et al., 2006; Simmons-Mackie and Damico, 2007). The ability to communicate with others is essential in practically all aspects of a person's life since it underpins most interactions with others and permits people to express their feelings and to express decisions that affect their lives (Goldbart and Caton, 2010). Furthermore, communication promotes a person's autonomy in everyday life and is fundamental for participation in society (Morreale et al., 2000; Goldbart and Caton, 2010).

Given the importance of communication, living with aphasia can negatively affect a broad range of aspects in the person's life. For example, people with aphasia (PWA) can have more difficulty accessing support and health care (Carragher et al., 2021), their quality of life can be reduced (Lam and Wodchis, 2010; Bullier et al., 2020), their mental health may be affected (Baker et al., 2020; Azios et al., 2022), their relationships can suffer (Howe et al., 2012), and return to work can be challenging (Graham et al., 2011).

Moreover, having few interactions with others can reduce social participation in daily activities (Parr, 2007; Simmons-Mackie and Damico, 2007; Dalemans et al., 2010; Le Dorze et al., 2014). Social exclusion and the consequent loss of autonomy has also been shown to negatively impact the quality of life of PWA and often elicits emotional stress and psychosocial disturbance (Code et al., 1999; Code and Herrmann, 2003). According to Lam and Wodchis (2010), aphasia has an even more negative impact on a person's quality of life than many other diseases, including cancer.

Aphasia can also affect family members, especially the person's spouse, because they need to deal with multiple problems related to the consequences of aphasia, their concerns regarding the PWA, as well as dealing with their own unmet caregiving needs (Le Dorze and Brassard, 1995; Michallet et al., 2003; Le Dorze and Signori, 2010). Furthermore, family members should be considered and involved in aphasia interventions because of their role as a communication partner who is also affected by aphasia.

A central goal of speech and language therapy is for PWA to be able to communicate as effectively as possible in their day-to-day lives (Thompson et al., 2008; Wallace et al., 2017). This focus on functional communication (i.e., communication in real-life situations) has led speech-language therapists (SLPs) to try to improve not only the person's ability to talk but also to attempt to help facilitate communication by other means, including with the help of augmentative and alternative communication (AAC) methods.

AAC aids can range from basic communication boards to high-technology communication aids or applications. Low technology-based AAC strategies, i.e. picture boards, spelling boards, photo albums, drawings, and cue cards (Chavers et al., 2021) do not include any method of speech output when a message is selected (Koul, 2011). While these allow the PWA to express themselves by pointing to the relevant choice, these tables are reduced to a few basic ideas or messages and cannot sustain even a basic conversation. In response to the limitations of low-technology tools, various dedicated communication aids and applications (CA/A) have been developed to better support communication. Such applications can enable a computer or hand-held multipurpose electronic device (e.g., Apple iPad™, Google Android™) to be used as a communication aid. While there exists a large body of research showing that both low- and high-technology based communication strategies can facilitate communication for PWA (Koul and Harding, 1998; Koul and Lloyd, 1998; Koul et al., 2005, 2008; Nicholas et al., 2005; McKelvey et al., 2007; Wallace et al., 2012; Ball and Lasker, 2013; Dietz et al., 2018; Mooney et al., 2018; Alam et al., 2023), many high-technology devices and applications require that PWA be able to use a keyboard to express themselves or to be capable of navigating through sets of pictograms to build messages. In addition, although PWA can make use of these types of CA/A, there are drawbacks to their use as well.

Two scoping reviews have been published on the use of high-technology communication aids (including mobile devices and communication apps) by PWA (Baxter et al., 2012; Russo et al., 2017). In a review of studies investigating the usefulness of high-technology communication aids to enhance communication abilities in adults with aphasia following a stroke, Russo et al. (2017) found that individuals generally showed improvements in communication when these technologies were employed. However, they noted that while the use of these aids could be useful in improving communication and social participation, the practical application of interventions using a form of high-technology communication aid as a compensatory tool was still in the developmental stage. Baxter et al. (2012) explored the potential barriers and facilitators associated with high-technology communication aids with the aim of better understanding the factors that underpin use rather than effectiveness, from the point of view of users and of providers of these aids. They found that implementation of high-technology communication aid interventions was affected by many factors that could become barriers or facilitators to successful outcomes. These included the device's ease of use, reliability, availability of technical support voice/language of the device, decision-making process, time taken to generate a message, family perceptions and support, communication partner responses, service provision, and knowledge and skills of staff. Additionally, Pampoulou (2019) looked at factors influencing CA/A acceptance or abandonment by interviewing SLPs. While their findings do not relate specifically to PWA only, they do suggest that the process of accepting a CA/A is complex with many factors influencing acceptance, including time since onset and acceptance of disability, the person's attitude toward communication facilitators, and the perceptions of family members and people with an acquired communication disorder about CA/A.

2. Study aim

While some or even many PWA have communication aids at their disposal, clinical experience suggests that the learning process is arduous, and inconvenience associated with their use sometimes outweighs potential benefits. The goal of this study was to identify communication needs of PWA that could ultimately be addressed with current CA/A or with newer versions, considering the points of view of both users and non-users. Given the importance of family member support in the successful use of CA/A, we also wanted to include their opinions and experiences. Among users of CA/A we sought to solicit opinions and experiences with current CA/A. In contrast, among people not using CA/A, we were interested in exploring why they did not use CA/A, as well as their communication needs.

3. Methods

3.1. Study design

A qualitative experiential research design was used to explore users' experience and attitudes toward CA/A (Braun and Clarke, 2013). We held two in-person focus groups, one in English and one in French, at a large rehabilitation hospital in the Greater Montréal region (Canada). Despite communication issues, PWA have been shown to be able to participate in focus groups and we chose this method of data collection because it can allow for the observation of non-verbal communication, and also encourages participant interaction and calls attention to areas of agreement and or lack thereof in the group (Barbour, 2005). The study was approved by the research ethics board of the Center for Interdisciplinary Research in Rehabilitation of Greater Montréal (CRIR, REB # CRIR-1333-0518). All participants signed informed consent forms. Researchers and participants pledged to preserve the anonymity of participants and to not divulge personal information that was shared during the discussions.

3.2. Participant inclusion criteria

Two types of participants were recruited: people with aphasia (PWA) and a family member, speakers of English and/or French. To be included in the focus group, participants had to be at least 18 years old, capable of giving informed consent, have aphasia resulting from stroke, or traumatic brain injury, or exhibit progressive primary aphasia. PWA could be receiving or could have previously received speech-language pathology services at a CRIR facility. The family member also had to be at least 18 years old and be a primary caregiver of a PWA.

3.3. Data collection

Each of the two focus groups was facilitated by a speech-language pathologist (SLP) with experience in leading focus groups with PWA (CAG) with the support of a second SLP with expertise in communication aids (SB). The facilitator had previously followed the "Supported communication for adults with aphasia" training from the Aphasia Institute. Most other members of the research team (NA, EK, GJ, MY, CB) were present to witness and take notes during the French focus group and many (NA, EK, GJ) were present for the English group as well. Each group session lasted ∼1.5 h and participants were compensated for their participation. The goal was to obtain feedback from both the PWA and family members through questions regarding their communication needs, their opinions regarding CA/A, and, for those who used CA/A, their individual experiences. The facilitator used a semi-structured question guide to ensure the coherence of the questions across the two groups (see Appendix A).

The SLP with CA/A expertise brought the following devices for demonstration purposes: an *iPad*^{TM}, a *Panasonic Toughbook CF-19* (https://na.panasonic.com/us/computers-tablets-handhelds/computers/laptops/toughbook-19) and a *Lightwriter* (https://www.abilia.com/en/our-products/communication/lightwriter-sl50). Participants were encouraged to bring their devices and tablets as well. Information regarding what CA/A they used (or had used), if any, is presented in Table 3. We note that while some of the technologies might have been sought out by the PWA or their family member, CA/A is prescribed by a specialized SLP assigned to the Technical Aids program as part of a treatment plan that includes training on the device and follow-up.

The sessions were video recorded and then transcribed verbatim by an individual who was not involved in data collection. Both transcripts were verified by the first author to ensure the accuracy of the transcription. Participants were assigned codes, PWA-X and SP-X to protect their anonymity. Moreover, in this paper we elected to use the gender-neutral pronouns "they/them" when referring to participants to further protect their anonymity.

3.4. Data analysis

In order to organize the data, the transcripts were uploaded to the NVivo 11 qualitative data analytic software (QSR International). The English and French transcripts were treated together and content analysis procedures were applied to both, using the six phases of thematic analysis proposed by Braun and Clarke (2006, 2013). Two members of the research team (NA, main researcher present at both discussions and TO, experienced in qualitative analysis and in using NVivo software), who are fluent in French and English, completed the initial stages of the thematic analysis and coded the transcripts independently. First, they each read the two transcripts to obtain a sense of the whole and familiarize themselves with each transcript. Then they each independently coded the data from both focus groups. Initial codes were generated in an inductive manner. As such, all segments of the data that were relevant to our research goals and questions were coded. Once this was completed, the two researchers met to discuss these codes and their meaning, and disagreements were resolved through discussion. Once a list of codes had been generated from the two transcripts, the researchers collaboratively identified potential categories and subcategories. Categories were predominately descriptive, i.e., they described patterns in the data that were pertinent to the research questions and goals. At the completion of this first analysis, we had created four major descriptive categories that allowed us to include all codes and extracts. The categories were: barriers, benefits, facilitators and optimal features of CA/A. Each category was defined and was further broken down into sub-categories. All of the information was included in an Excel file that organized all relevant extracts by category and subcategory.

Once this initial classification of extracts was complete, a process of member-checking was set up. Two couples, one from each discussion group, were sent a document by email describing each category and subcategory with detailed descriptive statements summarizing the information obtained from the transcriptions pertaining to the categories and subcategories. The document was created in French and English. Participants were asked their opinion as to whether we had understood the thoughts that were shared the day of the discussion. They were asked to respond to the email by indicating their agreement or disagreement, and whether something else should be added to the information. We obtained one response from one couple who agreed with the information that we sent them. The other couple did not respond even after a follow-up email.

We then undertook a second analysis in order to represent the participants' experience with CA/A and to derive themes. The following researchers were part of this process: NA, who had conducted the initial analysis and was present at both discussions and, GLD, a researcher in qualitative approaches with people with aphasia and family members with over 25 years of experience. They worked in a collaborative manner. GLD provided descriptions of the essential meaning of each extract. Together, they examined each extract and description with the aim of ensuring common understanding of the meaning of each extract as it had been spoken at the focus group. They also examined and coded anew each extract and proceeded to group together extracts that were similar in meaning. Codes, a synthetic and short description of the meaning across one or several extracts, were created to describe each extract, paying attention to how participants related their experience. All information was then grouped into Tables with tentative themes and subthemes. Initially there were eight themes that were merged into four, over time.

When writing up the results of this analysis, verification of the codes and extracts was often necessary. In this step, EK, GLD and NA chose extracts that would illustrate some of the codes for each subtheme and theme. The final selection of extracts was made collaboratively and these are included in the Results Section. At this point, verification of the extracts was conducted as needed to ensure truthfulness the citation and findings are summarized in Tables 4–7.

4. Results

The groups involved both PWA and spouses (SP), with experience with different communication aids or applications that ranged from "beginner" to "extensive." It is worth noting that, since all were recruited from a rehabilitation hospital, participants' experience with communication aids or apps was limited to those that were eligible for reimbursement by the Quebec Healthcare system at the time of the focus group. Three participants (1 couple and 1 PWA who came alone) did not have previous experience with communication aids or applications. In total, 10 people participated in the focus groups. The first group discussion held in French comprised three PWA and two SP: one couple and three individuals who came alone. The English group discussion had two PWA and three SP: two couples and one individual who was alone. Additional participant demographic information is presented in Tables 1, 2.

Furthermore, participants can be described in terms of their degree of experience with CA/A and available information regarding the types of CA/A that were prescribed by a SLP is included in Table 3 and described in the paragraphs below. However, while some participants also used applications of their phone or tablet that they had sought out themselves; information regarding these is not included in Table 3. Information regarding participants' experience with CA/A was provided by the collaborating SLPs.

TABLE 1 Demographic information for the five PWA.

Variable	Count
Gender	
Men	2
Women	3
Age	
45–64 years	2
65+ years	3
Type of aphasia	
Non-fluent following stroke	3
Fluent following stroke	1
Non-fluent primary progressive aphasia (PPA)	1

TABLE 2 Demographic information for the five spouses.

Variable	Count
Gender	
Men	3
Women	2
Age	
45–64 years	2
65+ years	3
Spouse of a PWA with	
Non-fluent aphasia following stroke	2
Non-fluent aphasia following non stroke neurological event	1
Non-fluent primary progressive aphasia (PPA)	2

TABLE 3 Description of participants' experience with communication aids or applications (CA/A) and their attendance with or without their spouse.

Experience with CA/A	Who attended		
	Couple	PWA alone	Spouse (SP) alone
Beginner			SP4: PWA has the *Grid Player* application on their tablet. Spouse encourages use but both report significant difficulties
Experienced	PWA2: Has applications (a dictionary application and a text-to-voice application but we are unaware of the specific application names) on their tablet but does not know how to use them effectively. The spouse would like the applications to be more tailored to spouse's challenges; seems to use them little	PWA1: Used a *Lightwriter first* that they did not like. Now uses two tablet applications, *Grid Player and Proloquo4Text*	SP7: The PWA has a very simple application on their tablet with a few choices of words and pictures (we are unaware of the specific application name). Not useful because of limited choices
	PWA5: Uses the *Grid Player* application on a tablet that appears to be ineffective. Also, they employ the word predictor on their cell phone. The spouse states that the application is not always effective		
Non-users	PWA6: Does not use any communication aid. The spouse admits to not being familiar with communication aids from the outset, but expressed interest	PWA3: No experience with communication aids but expressed interest. Uses word prediction when sending text messages to family members	

As shown in Table 3, two spouses came alone. One mentioned the PWA was a beginning user of the *Grid Player* app on a tablet (https://thinksmartbox.com/product/grid-player/). They both had significant difficulties in using the application. The second spouse who came alone spoke about their relatively negative experience with CA/A. They had however found that pictures worked the best to support their communication.

Two PWA came alone to the discussions as mentioned in Table 3. One was an experienced user of CA/A. This PWA had previously employed a *Lightwriter* that they later discontinued using and was now employing the *Grid Player* and *Proloquo4text* (https://www.assistiveware.com/products/proloquo4text) apps with a certain degree of satisfaction. The other PWA had no experience with communication aids but employed word prediction with a tablet when sending text messages and was quite interested in using CA/A.

Three couples attended as per Table 3. Two of these were experienced users of CA/A and one couple was a non-user. One experienced couple had various apps (including a dictionary and a text-to-speech application) on their tablet but none seemed to meet their needs. The spouse used them infrequently and wanted apps more tailored to the PWA's needs. Similarly, the other experienced couple had the *Grid Player* app on their tablet but it seemed ineffective. They had found other ways to communicate using pictures and had developed a seemingly good collaboration. They used word prediction on their cell phone with success.

The last couple who came to the discussion had no prior experience with CA/A. The spouse admitted they were unfamiliar with CA/A and, at the onset, was reticent about the PWA using CA/A to communicate. The PWA had PPA and believed they did not need CA/A.

4.1. Themes

During the analyses, we noted that participants had spoken about aphasia and described the difficulties they ran into when engaging in communication. We were sensitized to the idea that they viewed their experience with CA/A in the context of the difficulties that aphasia created for them. This insight is reflected in themes 1 through 3.

Another meaningful distinction that became apparent to us was how PWA were attentive to their own process of communicating and how SP were both observers of how the PWA was doing when they were trying to communicate and experiencers of changes affecting communication with their family member who had aphasia. Some spouses also had a third role, helping the PWA communicate with and without CA/A. In the Tables we distinguish the data provided by SP from that of PWA.

As mentioned above, four (4) themes were identified, each is represented in a Table below. Each theme is described with related subthemes and codes (i.e., short expressions representing the essential meaning of the extract), for both types of participants. Representative extracts are included in the text below, at least one from each participant has been included. Extracts produced by French-speaking participants have been translated for the purpose of this publication.

The first theme reflects their observations and experiences with communicating with aphasia. The second theme regroups codes related to successful communication with the help of CA/A. The participants were not always successful in using their CA/A and experienced difficulties and dissatisfaction. These challenges were grouped into theme 3. Lastly, theme 4 includes participant views about CA/A and their wishes for further development.

TABLE 4 **Subthemes and codes for theme 1: participants experience and observe communication and communication difficulties in daily life.**

Subthemes	Codes	
	PWA	Spouse (SP)
Experiences of word finding difficulties and associated negative emotions	Experience of word finding difficulty, the word is in my mind but does not come out of my mouth. (PWA1; PWA2; PWA3; PWA5)	Observation of word finding difficulty. (SP2; SP4; SP5)
	Self-reported word-finding difficulties exacerbated by fatigue. (PWA6)	Sadness felt by spouse when PWA can't find the word they are looking for and the communication breaks down. (SP2)
	Frustration felt by PWA associated with words getting stuck in their mind. (PWA3; PWA5; PWA3; PWA1)	
	Anger and sadness felt by PWA when words don't come out. (PWA2; PWA2)	
Experiences when the PWA needs to understand something	PWA no longer understands the newspaper; attributes it to lack of interest can still understand TV. (PWA3)	Severe aphasia, cannot understand simple things. (SP7)
	When PWA reads text and doesn't understand a word, they search for the definition. (PWA2)	
Strategies when communicating together as a couple	Taking a break to stop, PWA needs to listen to the questions spouse is asking to get to what they want to say. (PWA3)	In the past, by using pictures around the house. (SP5)
		Trying again later. (SP2)
		Not correcting PWA's errors. (SP4)
		Goes along with what PWA is asking even though it is frustrating for both of them. (SP7)
		Have had to change how they communicate with spouse (SP7): • Using pictures or brand names and logos that PWA recognizes • Communication intent has to start with PWA, spouse can't start an interaction and expect PWA to understand but if PWA initiates then they can understand what PWA is saying • PWA cannot reliably use yes/no response but spouse continues to check with PWA • Spouse needs to call 4–5 times before PWA answers the phone, PWA can follow a simple message (e.g., go get their son)
When the PWA communicates with other people including strangers	Self-reported comprehension difficulties in a group setting worsened in their second language. (PWA2)	Spouse shares their experience of difficulties experienced in everyday life when in the presence of others. (SP4)
	PWA need to speak more slowly but others also need to speak more slowly for PWA to better understand. (PWA1; PWA2)	Spouse notes that PWA chooses to stop talking when with strangers. Embarrassment with communication breakdowns can lead the PWA to leave off communication, or becoming resigned to being silent. (SP4)
	Anger felt by PWA associated with having to speak well at all times. (PWA3)	Partner uses humor to diffuse the awkwardness that they perceive other people are feeling related to aphasia and to calm distress felt by PWA. (SP4)

4.1.1. Theme 1. Living and communicating with aphasia

Within theme 1, we grouped together participants' descriptions of their experience and observations about communication and communication difficulties in daily life when they communicated together as a couple and, when the person with aphasia interacted with other people including strangers (see Table 4). Participants described communication difficulties, i.e., expressive and word-finding problems and comprehension difficulties. These often led to communication breakdown and participants shared what they did to resolve difficulties. The solutions they tried depended on the specifics of the situation they were involved in and on what they believed was required. Word-finding difficulties were central to most participants' experience of aphasia.

4.1.1.1. Subtheme: experiences of word finding difficulties and associated negative emotions

As can be seen in the extracts below, participants with aphasia described how they had a word in mind, that it got stuck there and would not come out of their mouth. Both participants with aphasia and caregivers also expressed negative emotions, such as frustration, anger and sadness, that were associated with not being able to find words or observing such a phenomenon. Others also had negative emotions associated with their perception of having to speak well at all times, and with the underlying problem of saying the right word.

> *PWA3: It's going to be difficult. It's going to keep me uh keep...it's going to stay in my throat...in my brain a little bit.*
>
> *FAC: Hmmm.*
>
> *[...]*
>
> *PWA3: It's very frustrating. Because it exi- it exi-exists, it's there. But how do I do that I can't use it?*
>
> *FAC: Hummm.*
>
> *PWA3: That annoys me.*
>
> *FAC: I understand, I understand.*
>
> *[...]*
>
> *PWA2: I too have uh... like PWA3. A problem [gestures]. [a lack of words] Yeah [nods].*
>
> *FAC: And what does that create?*
>
> *PWA2: Ah... angry.*
>
> *FAC: It makes you angry?*
>
> *PWA2: Yes.*
>
> *FAC: What makes you angry?*
>
> *PWA2: It's uh... crying too, why, why doesn't it come out?*

One participant conveyed that word-finding difficulties were exacerbated by fatigue. Spousal participants had a shared understanding of the word-finding problems experienced by the PWA.

> *FAC: So, what do you do when you don't understand what they want to tell you? Or when you see that they can't say their word. What is your reflex?*
>
> *SP2: Well, it makes me sad, because they can't say that word, so I don't understand it either. Sometimes I ask, I ask simple questions, but no, they tell me no.*

4.1.1.2. Subtheme: experiences when the PWA needs to understand something

One participant reported occasionally needing to look up definitions of words in order to understand reading materials. A spouse commented on the fact that the PWA did not understand simple things, which made their communication difficult but not impossible because they found ways to ensure that they were correctly understanding what the PWA wanted to communicate. Another PWA mentioned how they now had a limited interest in reading their favorite newspaper and that they were more successful understanding television newscasts.

> *FAC: You're talking about TV, right?*
>
> *PWA3: Yes. I watch programs.*
>
> *FAC: You watch TV, you're interested in politics, sports, all that.*
>
> *PWA3: I have, I have all that, but I have this too. But I'm not able to buy [read] a newspaper. It doesn't have the same interest for me anymore.*
>
> *FAC: Hmmm. Okay, hard to understand what you're reading?*
>
> *PWA3: I have it, I still have it, but it m- ... I don't like it as much.*
>
> *FAC: Okay.*
>
> *PWA3: I don't like it as much. I like it, I don't like it, eh, I have a newspaper called Le Devoir, for example I have Le Devoir in front of me, it interests me, but much less.*
>
> *[...]*
>
> *PWA3: So, it's too much. So the whole reading is too much. Could reduce it, make it a bit more.... That's how I see it. That's how I see it. I don't want it!*

4.1.1.3. Subtheme: strategies when communicating together as a couple

Participants described various communication strategies. However, although it is essential for families to know strategies to help palliate aphasia and word-finding problems, not all spouses knew how to help the PWA. One spouse mentioned how they did not correct the aphasic person's speech especially when they succeeded in understanding them. Participants described how they needed to take a break when they experienced communication breakdowns. For one PWA this allowed them to better understand their spouse's questions so that their spouse could help them (the PWA) in what they wanted to say.

> *PWA3: That's so true. Because we misunderstand what-, I said something and it's misunderstood by me. It frustrates me because I say to myself "it doesn't make sense, yet I said it well." How is that possible? Then I learn how I do it. And I feel like I'm having a hard time understanding that. That they understand, and then I ask for a break. Give me a break. Explain. So, I say to my spouse: "Stop [name,] I can't do it, I can't do it!" So [gesture: points to themselves and to another person] it makes a difference for me, with my spouse.*

Another spouse described at length how the PWA had great difficulty to understand what was asked, for example: yes-no questions, simple requests, or when they (the spouse) initiated a conversation. This PWA had limited language and the spouse provided examples of how the PWA communicated. The PWA often only said the word "no" even though one could tell they meant "yes." Also, the PWA once made the spouse understand what was wanted by directing them to drive to a specific location, which unfortunately happened to be closed when they got there. The spouse thought this means of communication was too frustrating for both of them and too demanding. This individual described how instead they used pictures and logos for better communication.

> *SP7: Not so much using... cause I think... that it depends, it's personal, to their head PWA knows what they want... And no no no I tell you, look. You want to check uh. I go always to the pictures that you make uh XXX ...*
>
> *FAC: Yeah, yeah. Oh! The paper pictures, wow!*
>
> *SP7: Yes. And then they goe "no no no no no." To PWA, they know what they want. It's clear to their head, but not clear to me you know, so... Then, they start again and starts the guessing.*
>
> *FAC: Yeah*
>
> *SP7: Go there, go there. no.*
>
> *[...]*

> *SP7: That's it, yes that's what I tell you. No, no, no. "Tell me," and I go in my head and , "you want Dollarstore?" and all the things, put an order so...*
> *FAC: Ok, so you give a choice.*
> *SP7: We learn, we learn like [points to SP5 and PWA5] PWA learns, we learn to...*
> *FAC: To communicate*
> *SP7: Yeah, too communicate but no.. pictures, they work for us...*
> *[. . .]*
> *SP7: ...as long as they will point by themselves. Not when I ask PWA, it's more like uh... PWA knows what they want. But when I ask them the question then.... but for them to show me, yes ... go to...*

4.1.1.4. Subtheme: when the PWA communicates with other people including strangers

One PWA mentioned that speaking in another language, especially in a group setting, was challenging. Another PWA emphasized how they needed to speak more slowly to be successful in communication and how their speaking partners, other than family members, also needed to slow down in order for them to better understand.

> *PWA2: Also, slowly. Talking slowly is better for me. To understand better.*
> *FAC: So, you like it when people talk slower.*
> *PWA2: Yes.*
> *FAC: So that you understand better.*
> *PWA2: Yes.*

A spouse also described how the PWA was resigned to being silent in the face of negative emotions and communication breakdowns, especially in the presence of strangers. The spouse used humor to diffuse the awkwardness that they perceived other people were feeling when faced with the distress the PWA was displaying.

> *SP4: PWA can say the opposite, they will say the opposite. Like yesterday, the example, they wanted to talk about a dog, a big dog. They said it was small and had no hair. I knew that they wanted to talk about a big dog, a big dog full of hair. So they do the, they say the opposite. ... I know it, but for the others it's not obvious. Yeah, like I was saying yesterday, well no, that's not it, you know. So, uh, it's difficult, and sometimes I let him go because I want to, I realize sometimes that it's not necessary to make PWA understand that they are saying the opposite because it doesn't go well..*
> *FAC: So, if I understand correctly, you were with other people, you weren't alone?*
> *SP4: No, that's right. That's right.*
> *[...]*
> *SP4: It's not, it's not obvious. But I, my XXX. I try to play it down.*
> *FAC: Yeah.*
> *SP4: With crazy things. Like yesterday, I said, "Oh, I brought the wrong [spouse]!"*
> *ALL: (Laughter)*
> *SP4: So, you know, that's right, I do crazy things like that "phew..."*
> *FAC: To lighten the mood.*
> *SP4: To relax PWA a bit.*

4.1.2. Theme 2: successful communication with CA/A

Using CA/A did help with communication, be it within the couple, or with family members, such as adult children (see Table 5).

4.1.2.1. Subtheme: pathways to communication using CA/A when together as a couple or with a family member

Participants said that they employed CA/A because it did help them communicate better even though sometimes the quality of communication was not optimal. One individual used voice and word recognition functions to write and send text or email messages to her spouse. Some reported not using their cell phones to speak but to send text messages instead. Even though they knew there may be errors in the messages, they still reported a preference toward employing the texting function with word-prediction.

> *PWA1: Uh XX...the keypad. The keypad*
> *FAC: The keypad on your phone? Of your iPad^{TM}?*
> *PWA1: (gestures: points to iPad^{TM}) Yes, my phone.*
> *FAC: From your phone*
> *PWA1: Because I send my messages to XXX (my spouse?) to to ... to my two sons.*
> *FAC: To your two sons, to your spouse.*
> *PWA1: Yes.*
> *FAC: You send them text messages? ...*
> *PWA1: Yes*
> *FAC: ...and you use the word predictor?...*
> *PWA1: Yes, yes*
> *FAC: ... Does it work well?*
> *PWA1: Well, not all the time.*
> *FAC: Not all the time?*
> *PWA1: Sometimes, sometimes, they are..., I have it, but I don't know any more how to write.*

Several reported ingenious ways they used for word prediction when stuck with word-finding problems. For example, one spouse stated that they used word prediction to solve communication breakdown when face-to-face as it improved their "guessing game." One PWA used texting to send the word they could not say while talking over the phone with their daughter.

> *SP5: But PWA5 find ways, because they called our daughter a little while ago and was trying to tell her something on the phone, but on the phone it's difficult.*
> *PWA5: Yeah! Me I can't when, to I can't, so I go... [frustrated]*
> *SP5: So then they texted her, and... there was no way they would have been able to spell "razors" but they sent her a message*

TABLE 5 Subthemes and codes for theme 2: successful communication with CA/A.

Subthemes	Codes	
	PWA	Spouse (SP)
Pathways to communication using CA/A when together as a couple or a family member	Uses voice/word recognition function to write and send messages (text or email) to spouse. (PWA2)	Description of how they communicate in daily life, with help from the app to provide cues for the guessing game. (SP5)
		Uses word prediction to solve communication breakdown when face to face (improves guessing game). (SP5)
		Observes that PWA uses word prediction to solve communication breakdown when talking over the phone (looks up and texts the word that the predictor helped them find). (SP5)
		Word definition feature works well if the partner is assisting the PWA (when alone cannot always use it). (SP2)
	Use word prediction to send text messages, despite some errors they still use it even though they are not always understood. (PWA-1; PWA-3; SP-5)	
Pathways to communication using CA/A with other people, including strangers	Uses CA/A with partner and at the Aphasia Association only. (PWA1)	Description of how they communicate in daily life on Facebook in a novel way. (SP5)
	Can communicate better over the phone than in person. (PWA1)	
	Uses pre-made lists of words and names that they created that are personally relevant. (PWA2)	
	Cannot use the cell phone to talk but uses it to send text messages to adult children. (PWA3)	
	Description of how and where they use their device with others. (PWA1)	
Benefits of using CA/A	General acknowledgment of CA/A usefulness. (PWA2)	Couple use CA/A to practice language skills. (SP5; SP6)
	Uses CA/A to find words when they have word finding difficulties. (PWA1)	Observations of overcoming word finding difficulties in another (less dominant) language. (SP5; SP6)
	PWA and spouse believe that using iPad has helped improve communication. (PWA5; SP5)	
	Feels that they can communicate better since they have their CA/A. (PWA1)	Personally relevant pictures are helpful when they cannot find the word. (SP5)
	Pictograms occasionally work, this is positive for the PWA on these occasions when it does work. (PWA3)	

> *"razors," so it had to have been the predictor and it was exactly what they needed. They needed "razors" and since she was out at the pharmacy ...*

Some spouses stated that they were quite involved in using CA/A to help the PWA communicate. In fact, they expressed that needed to help the PWA because they could often not use the device or app on their own. One spouse assisted the PWA to use a word definition feature on the CA/A device.

4.1.2.2. Subtheme: pathways to communication using CA/A with other people, including strangers

One individual said that they used their CA/A device with their partner or when at Aphasia Association meetings, where such devices are common among attendees. Another individual noted that they could communicate better over the phone rather than in person, so this was a preferred mode of communication. Another had listed family member names on their iPad^{TM} that they could easily access in conversation.

One PWA used Facebook to communicate with others. To express themselves, they initially copied messages that others were sending and, over time, they were able to send messages more easily without having to copy other messages.

> *SP5: Yes or no I think because PWA5 will look, like say they want to say something about someone's picture like, on Facebook, they will look at other people's comment, and retype somebody's comment. But from that we have noticed, like certain words like "happy b-day" they now do it automatically because they have copied it so many times.*

A spouse was able to describe how the PWA used several ways to support communication with others by using texting and by having personally relevant pictures on their phone.

> *SP5: A couple of letters, or like, you know, they know Walmart it's the "w," they know the "pa" they doe the "p," you know so we have adapted as well so we know. And umm... they find other ways. They use the phone a lot as well. So, the phone helps them. Because, like there's pictures of their truck on there and stuff. So, when somebody doesn't understand this and they can't get the word "truck" out, they go in their phone and find the truck.*

TABLE 6 Subthemes and codes for theme 3: communication difficulties and dissatisfaction with CA/A.

Subthemes	Codes	
	PWA	Spouse (SP)
Dissatisfaction using CA/A when communicating with other people including strangers, do not use outside the home	Do not want to use the CA/A outside of home because it is too complicated and causes shame. (PWA1; SP5)	
	Negative experience when interacting with strangers while using an app on their tablet to communicate. (PWA3)	
Mismatch between what the PWA needs and what the CA/A can provide	CA/A does not always work for them, reveals language problems, or requires abilities that are no longer present. This causes frustration and therefore they do not always use it. (PWA1; PWA2; PWA5; SP4; SP5; SP7)	
	CA/A does not always work for them, reveals language problems, or requires abilities that are no longer present. This may cause frustration however they do still use it because it is somewhat useful in certain situations. (PWA2; SP4; SP5)	
	Difficulty finding or recognizing the correct pictograms (PWA3; PWA5) or confined to the list of pictograms available which is not always the one for the word they are looking for. (PWA3)	iPad app does not support conversation because spouse guesses what PWA wants to say before they can find the message with the iPad. (SP4)
Limitation of the general design of CA/A	CA/A device is too big and cumbersome. Size inappropriate and not useful. (PWA1)	
	CA/A is difficult to use: PWA cannot use the CA/A, does not understand why (PWA5); technical issues with CA/A (PWA2)	
	Prefers to use the male voice output, uses the app successfully but quality of communication may be impacted. (PWA1)	

4.1.2.3. Subtheme: benefits of using CA/A

Participants believed that using CA/A provided opportunities to practice and overcome word-finding difficulties. CA/A had helped them improve their communication, and that they now communicated better. In this extract the spouse recognizes that the CA/A helped and provided practice opportunities

> *SP5: So, yes, it's something to help, but if it can have a dual purpose of also helping...*
>
> *SLP: Practicing*
>
> *SP5: Exactly. And we see that with certain things already, like the repetition of writing the words, because of the repetition they are sticking and... yeah, I just lost my train of thought*
>
> *SP6: Thank you for saying that, because I think that sometimes we tell ourselves "no, I cannot do a certain thing, no I can't XXX. We told ourselves that she couldn't speak English anymore." Sometimes we tell ourselves "No I cannot do something" but my god, yes we can!*
>
> *[. . .]*
>
> *PWA5: Because, me I can't... I don't know, better, I talk. But uhh...*
>
> *FAC: You know more than you can say, right?*
>
> *PWA5: Well, me I, me I can't. NO uh, no It's... good, it's good. Before, euh, me, euh, like that. Am, can, euh... am... I'm [sigh] When I first like that. I go like, First like, little bit, but now, I'm get better and better. And also, me and you, is good.*
>
> *[. . .]*
>
> *FAC: You can talk much more.*
>
> *PWA5: Ya ya ya.*
>
> *FAC: And that's why you need that less and less. That's what I understood from your spouse. [Observer note: they are referring to the communication device they were given]*
>
> *PWA5: Yes, I know I know, and also...this one too [pointing to an iPad^{TM}], like 1,2 ok.*
>
> *FAC: The reading?*
>
> *PWA5: But now it's 1,2,3,4,5*
>
> *SP5: Yes, you're getting better by reading.*
>
> *PWA5: Ya.*
>
> *FAC: The reading is getting better too.*
>
> *PWA5: When I first, like that, when I first like that [gesturing a flat line] it's maybe. But then, after like that. [gesturing the motion of "up"]*
>
> *FAC: Much better.*
>
> *PWA5: And now, after here, like that. [gesturing the motion of "higher up"]*

One PWA specifically used CA/A when they had word-finding difficulties and thought that the device had helped them speak better.

> *FAC: Okay. In what circumstances do you use your communication aid?*
>
> *PWA1: When I feel—I am searching for my words.*
>
> *FAC: Yes*
>
> *PWA1: And I can't find them.*
>
> *FAC: Hmmm ok.*
>
> *[...]*
>
> *FAC: Okay. And what is, uh, what is a communication aid for you?*
>
> *PWA1: Oh my God, it helps- helps me a lot!*
>
> *FAC: It helps you a lot?*
>
> *PWA1: Yes. Erm, if er, if er I mark.*
>
> *FAC: Okay.*
>
> *PWA1: Uh... Let's say I want to... uh, nothing, uh, no, uh, no. Uh, dentist.*
>
> *FAC: Yeah, for example.*
>
> *PWA1: Everything uh. Like everything is... [showing an app on their device]*

> *[...]*
> *PWA1: There's a lot, a lot. Since I got it, I speak much better.*
> *FAC: Yes? So, do you find that it has really helped you?*
> *PWA1: Yes. Yes, yes*

Although many participants had found pathways to communication using CA/A, CA/A did not always work for them and frustration and dissatisfaction were expressed, as presented in theme 3.

4.1.3. Theme 3: communication difficulties and dissatisfaction with CA/A

Three subthemes were created for this theme and include circumstances when participants did not use CA/A, experiences of mismatch between what the PWA needs to communication and what the CA/A provides as well as comments referring to limitations of the design of CA/A (see Table 6).

4.1.3.1. Subtheme: dissatisfaction using CA/A when communicating with other people including strangers, do not use outside the home

Some individuals spoke about their negative experiences, such as shame and a feeling that CA/A was very complicated to manage when outside their home. Some had decided to not employ CA/A outside their home. Moreover, most participants reported dissatisfaction and frustration with how CA/A did not work for them all the time. Some CA/A devices revealed further language problems or required abilities that were no longer present exposing a mismatch between what the PWA needed and what the CA/A could provide.

> *FAC: That's perfect, because I was naturally turning to you,*
>
> *FAC: so if you want to tell us about your spouse's communication assistance.*
>
> *SP4: Uh, well [NAME] there's been a tablet for about 1 month, but there's a lot of difficulty using it because they are not able to read or write anymore. Uh, talking is starting to be difficult, like PWA3 said, it's there [point to head], but it's not getting there.*
>
> *SP4: It's true that at the beginning PWA didn't use it, but I said, you're going to sit with it and you're going to listen to [them], you're going to pitch, you're going to concentrate on it, but still, their sight is not sufficient. Well, in fact, it's that they don't recognize the images. You can see a bottle there [touches the bottle on the table], I say look for the bottle, it's there, it's all alone, but their brain misses it. So for PWA, for the moment, as I said to SLP, let it be for the programming because for the moment I don't see any improvement.*
>
> *SP4: To the rest of us, PWA has deteriorated, it's difficult for them and it's doubly frustrating because it's hard for them to see things and to recognize things on their tablet. So, they use it more or less.*

4.1.3.2. Subtheme: mismatch between what the PWA needs and what the CA/A can provide

Difficulties with CA/A that participants talked about included not knowing how to overcome a problem, experiencing a technical issue, difficulty in finding the correct pictogram to express their idea and, sometimes, the pictogram did not even exist. Another individual spoke about the resources required to actually find what they wanted to say and how they would forget the word they were looking for while scrolling through pictograms.

> *SP5: We worked with [SLP], to come up with this, it was a couple of years ago. And at that point, PWA5's language and comprehension were not at the level it is now. So, what we found is, um like...They would know something, like if they wanted to eat an apple, by the time they got through the first screen, they had forgot what they were searching for. So, we ended up stopping this and then, you know, we used a lot of pictures around the house and a lot of, you know, the hands gestures and things like that. And honestly, we haven't come back to it.*

4.1.3.3. Subtheme: limitation of the general design of CA/A

One female PWA said she preferred the male voice for spoken output, because it was easier to understand compared to the female voice, impacting the quality of communication. While the PWA preferred the male voice option, people often responded negatively to this because the voice did not match the person's gender. The PWA would have preferred to have more choices in voices instead of just one female option. Some participants described CA/A devices they no longer used consequent to difficulties experienced. For example, when a PWA used an app provided on their tablet for conversation, the PWA had such difficulty finding the words they were searching for in a timely manner that the spouse was able to guess what the PWA wanted to say before they were able to find the words. Those who had abandoned their device said they had found other options. One spouse spoke about using pictures and pictograms in the home.

One individual pointed out another source of dissatisfaction, i.e., the large size of their device (a *Lightwriter)* that led to them to abandoning it.

> *PWA1: I used to [points to the Lightwriter]. Oh, my goodness.*
>
> *FAC: You used to have that?*
>
> *PWA1: Oh, God! [rubs head].*
>
> *FAC: No?*
>
> *PWA1: Yes, yes, I had that [hand gesture of discouragement].*
>
> *FAC: And why wasn't it good?*
>
> *PWA1: Well, oh, [gestures with hand of discouragement], there's uh... [gestures to wait with hand]. Because I didn't have uh...to spell.*
>
> *FAC: It was more difficult you couldn't spell the writing?*
>
> *[...]*
>
> *FAC: It wasn't helpful at all?*
>
> *PWA1: No. T-t-t at all. Much t- too big.*
>
> *FAC: Way too big?*
>
> *PWA2: Okay. Did you ever used it?*
>
> *PWA1: A little bit.*
>
> *FAC: A little bit.*
>
> *PWA1: XXX no... I didn't like it.*

TABLE 7 Subthemes and codes for theme 4: views and expectations about CA/A.

Subthemes	Codes	
	PWA	Spouse (SP)
Negative views related to CA/A	Has a negative attitude to using CA/A in public and believes it's best to try to speak in public without CA/A because they have the words. (PWA1)	SP believes that the CA/A will become a crutch for PWA. Afraid of it because they do not know about it. (SP6)
	Having a CA/A would not help them to talk faster. Communication required them to talk slowly and others too (a device cannot do that in their opinion). (PWA1)	
	CA/A would be difficult to use because information there is not organized like they are used to. (PWA3)	
Positive views about CA/A	Learn about a new CA/A they may want to try. (PWA2; PWA3; PWA6; SP2; SP6)	
	Interest in learning how to use an app to compose messages. (PWA3)	Changed their perspective on CA/A and now are open to trying one. (SP6)
	Positive perception of premade messages that were demonstrated by FAC. (PWA2)	CA/A can be good for someone who does not speak at all. (SP7)
		SP believes that having a CA/A could help PWA be less frustrated and more autonomous. (SP4)
		SP believes that a word predictor could help PWA with a blockage with not being able to say the word in their mind. (SP6)
Wishes for CA/A development	More pictograms or pictures that are meaningful enough to convey a variety of ideas and that are personally relevant. (PWA3; SP7)	
	Pictograms organized in groups in a personalized fashion that are meaningful to the person, according to interest. (PWA3)	More public awareness of aphasia and CA/A. (SP4)
	For the world to communicate in pictograms instead of only words. With more pictograms in the world, the PWA would be able to communicate better because pictograms can convey a lot of information without the need for words. (PWA3)	Premade message programmed to be used in stressful situations explaining that they have aphasia (SP5)
	CA/A that allows ideas to be conveyed with short messages. (PWA3).	
	Would like an app that conveyed precisely what they wanted to say and can correctly interpret what is being said. (PWA3)	
	Having CA/A find the missing word or wrong word for them. (PWA1)	
	CA/A that translates a voice message to text because they cannot write the message but can speak it. (PWA2)	

Considering these experiences and their dissatisfaction, participants expressed their views about CA/A, which are presented in theme 4.

4.1.4. Theme 4: views and expectations about CA/A

Overall, participants expressed both positive and negative views about CA/A (see Table 7).

4.1.4.1. Subtheme: positive views about CA/A

All participants expressed that they could see how CA/A could be useful for someone who had aphasia and could help reduce frustration and increase autonomy. They also mentioned that CA/A could be helpful for someone who did not speak at all and could help with word blocks, when a word in mind could not be spoken.

One participant expressed an interest in learning how to use an app to compose messages and another thought premade messages could be useful. Many participants, i.e., two couples and one PWA, expressed interest in trying a new CA/A they learned about during the discussion. One spouse changed their opinion regarding CA/A as a result of participating in the group discussion. They initially stated that they were afraid that CA/A would become a crutch for the PWA, but that they had no knowledge and experience with CA/A. The following extract shows their change of mind.

> *SP6: I have an impression, uh and that's new for me, and I am learning here, a lot! A thousand times by the mile. I am sure that this machine over there, I don't know how you call it...*
>
> *SLP: This one, the Lightwriter?*
>
> *SP6: Yeah, I think that that one might be useful to PWA6, because they may have lost their..., part of their vocabulary and uh, this is made to measure. This is really made to measure. If PWA6 wants to say something, they only have to type it and out it comes really. Isn't it?*
>
> *FAC: [nods]*
>
> *SP6: So that might be helpful.*
>
> *PWA6: Yes, I write euh... everyday, everyday, my euh...*
>
> *FAC: Diary*
>
> *PWA6: Journal.*
>
> *FAC: Diary. Yes, I know, you're good.*
>
> *PWA6: And euh... I can write euh..*

4.1.4.2. Subtheme: negative views about CA/A

One PWA explained that having a CA/A could not help them because going slowly was the best strategy they employed for communication and one they needed other people to adopt when speaking with them. Thus, the PWA did not believe that having a CA/A could help them speak more quickly, an aim they would not try to pursue in the first place. The PWA also believed that in public situations it was preferable to speak, rather than use CA/A. The same individual mentioned that they wanted to speak to people instead of using CA/A.

> *PWA1: Look, well... Before the C-V-which a- a- XX [stroke] [points to arm].*
>
> *FAC: Your stroke.*
>
> *PWA1: I was talking very fast!*
>
> *FAC: Ahhh.*
>
> *PWA1: And then, not at all! I have to speak very, very slowly.*
>
> *FAC: Ok, so, now you speak more slowly.*
>
> *PWA3: Yes.*
>
> *PWA1: Yes!*
>
> *FAC: Would a communication aid help with the speed at which you speak?*
>
> *PWA1: No, not at all*
>
> *FAC: No?*
>
> *PWA1: ...because to get to the reality and XXX the... the [picks up, gestures to stop]. Wait*
>
> *FAC: Take your time.*
>
> *PWA1: To get there, it's good to talk quickly- no. Slowly.*
>
> *FAC: Okay.*
>
> *PWA1: Slowly*
>
> *FAC: In order to make yourself understood, you mean?*
>
> *PWA1: Yes, to understand, I don't understand anything (?).*
>
> *FAC: To understand people, people have to speak slower?*
>
> *PWA1: Otherwise yes*
>
> *FAC: Okay, so it goes both ways. You speak slower, but you also need people around you to speak slower.*
>
> *PWA1 Yes, yes yes*

4.1.4.3. Subtheme: wishes for CA/A development

Participants were also asked what they wished for in future apps. Spouses were mindful of the difficulties that the PWA had when interacting with others and with the general public. One spouse wanted more public awareness about aphasia and CA/A, as well as premade messages the PWA could use for specific and potentially difficult situations, i.e., such as interacting with the police when pulled over.

> *SP5 And uh... but I think it's something, cause now PWA5 has uh, they got their licence back by the way.*
>
> *FAC: Wow!*
>
> *SP5: Their car had to be adapted.*
>
> *FAC: Congratulations!*
>
> *SP5: But, I always got a fear, that if they are pulled over by police, and you know ...*
>
> *PWA5: No. Not me.*
>
> *SP5: I know. But you never know, just a spot check, whatever...*
>
> *FAC: Oh yeah...*
>
> *SP5: You know, So if PWA5 had this [pointing to the iPad™] with them, so, like the first thing is "I'm [says their name], I suffer from aphasia," you know, it would be something that-*
>
> *FAC: It would be good to at least have this as a backup plan as you say. Mm, ok.*
>
> *SP5: Yeah, because in stressful situations the, you know...*
>
> *FAC: Sometimes the speech is not coming.*
>
> *SP5: Yeah.*

PWA had several suggestions concerning pictograms and mentioned the following: (1) a greater variety of pictograms, (2) more pictograms that are personally relevant, (3) pictograms that conveyed a variety of ideas, (4) pictograms organized according to the interests of a person and (5) pictograms that conveyed a lot of information without the need for words. One individual also wanted a voice-to-text app that could help her send texts, because she could speak better than write. They wished for CA/A that could be more succinct in expressing what they intended to say and could correctly interpret what was being said to them. They wanted CA/A that could help them find the words they wanted to say and provide feedback if the word produced was not the right one.

> *FAC: ...what would you like it to do for you, a communication aid?*
>
> *[PWA2 does not respond after a few seconds]*
>
> *PWA1: Let it speak for me! [Laughter].*
>
> *FAC: That it speaks for you? All the time?*
>
> *PWA1: No no no!*
>
> *FAC: Because earlier you told us...*
>
> *PWA1: No, but when I don't know... XXX XXX... but it didn't do it then [pointing to their iPad™].*
>
> *FAC: Okay, so, as soon as you block, when you don't know, let it speak for you, just. Let it fill the hole.*
>
> *PWA1: No, not, not that much.*
>
> *FAC: Not that much. Well, explain it to us.*
>
> *PWA1: Because when I don't understand it, it writes another word.*
>
> *FAC: Let's put it this way, you said another word.*
>
> *PWA1: Well, say another word, then I'm- I'm trying to [makes fist gesture] then I, the more I think about it the more there [gestures to take out a word] not.*
>
> *FAC: The more you think about it, sometimes you can't find it.*
>
> *PWA1: Lord [gesture deep breath and stop]*
>
> *FAC: So, it's maybe at that moment, when you got the word wrong, that you would like it to correct you, for example.*
>
> *PWA1: Yes*
>
> *FAC: Is that what I understand?*
>
> *PWA1: Yes.*
>
> *FAC: Okay.*
>
> *PWA1: But, I shouldn't correct it too hard, because when I (laughs).*
>
> *FAC: You shouldn't try too hard to correct yourself?*
>
> *PWA1: Yeah.*
>
> *FAC: So it could be the communication aid correcting you.*
>
> *PWA1: Yes.*

5. Interpretation and discussion

The present work sought to identify communication needs of PWA (both users and non-users of CA/A) and family members that could ultimately be addressed with CA/A. Our study responds to a gap identified by Pampoulou (2019) that underscores the importance of capturing the views of CA/A users of their family when reflecting upon CA/A acceptance and abandonment.

Among users of CA/A we sought to solicit opinions and experiences with current communication aids while among people not using CA/A, we were interested in exploring their opinions regarding CA/A, as well as their communication needs. In two focus group discussions, users and non-users of CA/A provided their perceptions and experience of living and communicating with aphasia with and without CA/A.

The interview outline included three topics related to the participants' degree of familiarity with communication aids, their experiences with communication aids and what they wanted in future aids. Transcriptions of participants' discussions responses were analyzed using a qualitative thematic analysis. Codes of extracts were grouped into four themes. The first theme describes the experience of living and communicating with aphasia, the second presents successful communication with CA/A while the third theme discusses difficulties and dissatisfaction with CA/A. Finally, the fourth theme presents view and expectations from CA/A.

While we centered the focus group discussion on communication aids, across all themes PWA spoke about their word-finding difficulties as the most central feature of their experience of living with aphasia. This was also emphasized by their partners. CA/A was experienced as a facilitator for overcoming word-finding difficulties. When confronted with word-finding difficulties and searching for a word on their device or app, some individuals were dissatisfied due to the lack of results, leading them to abandon the CA/A. Finally, when discussing what they expected future aids to do for them, they imagined that a CA/A could speak for them when they blocked or correct errors they might have made. The next sections discuss the major findings, as outlined above, in light of available literature.

5.1. Word-finding difficulties, a basic challenge

The focus group participants spoke mainly of word finding problems as the source of difficulties in communication and the main reason for which they needed communication assistance. They had varied types of aphasia as well as diverse levels of severity. Some participants had sudden onset aphasia while others had PPA and their experience of aphasia ranged from relatively recent to several years. Given the qualitative nature of the study and our interest in participants' subjective experience, we did not try to make associations between their experience with CA/A and aphasia type and severity, the latter considered objective elements. Consequently, all participants interested in the topic were included in one of the discussion sessions, without specific exclusion or inclusion criteria or intent to represent the different types and degree of severity of aphasia. However, not having an easy access to the words they wanted to say was their main problem, which we found to be both surprising and not surprising.

Word-finding difficulties have long been reported in the literature (Le Dorze and Nespoulous, 1989) and the experience of aphasia as told by those who have it does include word-finding problems (Mooney et al., 2018). However, having aphasia also includes other dimensions that touch on how communication limitations affect relationships and curtail them (Mc Menamin et al., 2015). Moreover, the lived experience of aphasia is often described, but only in part, as a problem with speaking (Le Dorze and Brassard, 1995), and more generally experienced as various limitations in conversation and changed speaker and listener roles with new negative emotions not normally present in communication (Croteau et al., 2020). An international study conducted by Wallace et al. (2019) found that, in addition to findings related to life participation, societal attitudes, wellbeing, and health and support services, having better word finding abilities was only one of several wishes concerning communication that PWA and SP wanted to change about how aphasia affected their lives. In other words, people living with aphasia and their spouses do not usually put forth word-finding problems as the main impact of aphasia on their lives. As such, our result concerning the central role of word-finding difficulties in the participants' experience was not anticipated. Within the qualitative design and the conduct of focus group discussions, we did not anticipate and therefore did not explore the reasons why word-finding problems were highlighted to the extent that they were. One possible explanation is that their experience with communication aids may have highlighted this particular difficulty. For example, an app such as *Grid Player* presents a repertoire of illustrated concepts associated with content words. Also, a word-corrector on a smart phone proposes potential words as letters are typed in, which may help them finding the word that they want to express. Consequently, participants using such CA/A may deduce that their main difficulty is with finding the correct words when expressing themselves.

5.2. Communication aids and apps do help with communication

In speaking about the positive effects of CA/A, both PWA and spouses spoke of the usefulness of CA/A and of how communication and word finding difficulties were lessened through CA/A. One PWA uses voice/word recognition function on their tablet to write and send messages while another uses word prediction to solve communication breakdown and in face-to-face communication. In spite of occasional errors, word prediction is still useful in communication as per several PWA. Spouses describe how the app provides cues and facilitates the "guessing game" and how word prediction can solve communication breakdown over the phone. Some spouses had developed their own low-tech CA/A using pictures and pictograms around the house when their devices or apps had not fulfilled their needs. These findings underscore the role of family members, in this case spouses, in successful communication with the PWA using CA/A (Rayer et al., 2022). Although none of the spouses had been involved in a specific communication partner training program, it was obvious that several of them had become positively involved in communicating in a manner adapted to the PWA's limitations. One individual with aphasia who came to the focus group discussion alone recalled their spouse's unsuccessful attempts to assist them when they were searching for a word. This created stress and frustration and required that they remove themselves from the situation before trying again. This finding is also consistent with the idea that the main communication partner is critical to successful CA/A use and that this individual should participate in a training program where they would learn to facilitate communication through CA/A (Mc Menamin et al., 2015).

We note that PWA were reticent to use their CA/A outside their home or a protected environment where such aids were common, like attending an Aphasia Association activity. Participants did not like to feel shame or feel the discomfort of other people who were unacquainted with CA/A, leading them to use CA/A mainly in facilitating environments such as their home and with their spouse but adopting a silent posture in many social situations. Most comfortable users of CA/A were supported by their spouse who was quite involved in making communication work for both of them (Rayer et al., 2022).

A couple in the group uses CA/A to practice language skills. Some participants note that CA/A helped them beyond the singular moment of overcoming word-finding problems. They believed that using CA/A had improved communication over time and helped the PWA recover language skills after the neurological incident causing aphasia. This observation is in line with Dietz et al. (2018) who indicated that AAC treatment assist in compensating for language loss in communication situations and also, can support language recovery.

Facilitating features of CA/A mentioned by PWA and spouses are the word corrector, having a word definition feature, pictograms as well as contextually and personally relevant pictures and pre-made word lists. These comments support Rayer et al. (2022) conclusions that AAC interventions using individualized visual screen displays are more effective for several reasons, including the biographical and contextual organization of the information and reduced cognitive demands associated with traditional semantically-organized grids.

Finally, it is also possible that coaching provided by the specialized SLP was critical in helping participants successfully adopt the specific CA/A devices. Although not directly discussed during the focus group, it is possible to imagine that users of CA/A had not found the devices and aids they liked to use on their own, except for those who had extrapolated what their devices did for them to other situations. Findings from an ongoing study with SLP participants who were interested in discussing this topic will help us further explore the role and issues that SLPs encounter when suggesting devices and software and when training PWA and family members with CA/A.

5.3. What happens when CA/A do not work for them

All of the above notwithstanding, PWA also spoke of their negative experience when using CA/A. When confronted with problems in word-finding compounded by difficulties in having to search for a word with their device or app, some individuals were dissatisfied with the lack of results. This often led them to abandon the CA/A. The major issue with some CA/A was the difficulty of mobilizing the necessary linguistic or other cognitive resources, such as working memory and attention, required to make efficient use of the CA/A. There were moments when a mismatch was obvious for them, when using the app required them to keep in mind their idea while scrolling through pages of pictures or not knowing which semantic category was the one they should look up to find the specific word they were looking for. Sometimes, the provided pictograms were not relevant, also causing dissatisfaction. Other reasons for abandoning a CA/A was the less than desirable design, such as the size, which made the use of the device cumbersome and ineffective. A spouse also mentioned that they would sometimes end up guessing what the PWA wanted to say before them finding their word with the CA/A, again underlining the importance of the involved partner or spouse in using CA/A. In this particular case, the spouse had to find other ways to improve communication with the PWA. Pampoulou (2019) found that AAC systems that require too much effort and lost abilities, such as motor impairment related to hemiparesis, may be abandoned. Other factors such as attitudes toward CA/A, other caregiving demands, acceptance of disability, and the high cost of the CA/A may also contribute to negatively influence CA/A acceptance and use (Pampoulou, 2019). Some CA/A users may be dependent on a partner initiating the use of the device or app and supporting them in successful identification of the words they want to say. Such dependent users and their partners may require feedback to acknowledge the albeit limited, benefits of CA/A use (Taylor et al., 2019).

The reluctance to accept and adopt CA/A is also mentioned in the literature (Taylor et al., 2019). Factors such as attitudes toward CA/A, other caregiving demands, acceptance of disability, and the high cost of the CA/A, may also contribute to negatively influencing of CA/A acceptance and use (Pampoulou, 2019). In the case of a couple who participated in the focus group, the spouse was quite negatively disposed toward CA/A use. The spouse felt that CA/A was a replacement for their partner's speech and would become a crutch for the PWA. However, when confronted with the potential benefits of CA/A as discussed by some users of CA/A, they recognized that a CA/A could potentially help, especially if personalized, and assist with word finding. They met with the facilitator and specialized SLP after the discussion to further explore CA/A options for them. Despite the limitations in CA/A, we found that hearing about how CA/A can help people communicate directly from PWA, and not just from an SLP, can change people's negative outlook toward CA/A and promote their acceptance.

Finally, the group approach where different people share their experiences appears to have allowed participants to go beyond their specific experience and offered both PWA and spouses the opportunity to see perspectives that they may not have previously contemplated. The group approach also offered the opportunity to learn from one another and to feel at ease to express their views. The exchange of experiences, needs, obstacles and facilitators, demystified CA/A and their use.

5.4. What would an ideal future communication aid be for PWA and their spouses

In the context of this study and the existing stipulations of the healthcare system in which the participants and clinicians interacted, the CA/A presented were part of the pool of those eligible for reimbursement. Options that would need to be paid out of pocket at the time the focus group was conducted were not included. Based on all of the findings to date and those specific to this theme it is clear that one must think outside the box as one attempts to conceptualize functional and usable CA/A. It has been clear for a while that, just like with other interventions, "one size does not fit all." Rather, CA/A needs to be personalized to the user's profile, interests, leisure activities and life roles. It should also be versatile and dynamic, with the possibility to change over time to reflect changes in the user's abilities. It would be preferable to organize words by conversational topics that are relevant to the user, and not by semantic categories. To address PWA's word finding difficulties, CA/A should act as a cue, offering a feature like the "word predictor" that may be written or spoken. Furthermore, it would be desirable if the CA/A would also identify and correct mistakes that the user is making. Going beyond the word level, it would be preferable if CA/A would use short and simple sentences for input as well as for output. The inclusion of pictures/pictograms is also thought to be a helpful feature. Regarding speech output, having the option of choosing speed of vocal output as well as different accents and voices (various male/female) was desired. Thinking outside the box also applies to the physical appearance of a CA/A that needs to be light weight, small in size, and take into account that a PWA may have left or right upper limb paresis or paralysis. Lastly, PWA requested that CA/A could be programmed to be used as a tool in their aphasia rehabilitation.

While to date, the CA/A the participants currently used did not incorporate many of the features appearing in the participants' wish list above, rapid advances in artificial intelligence (AI) and its integration in aphasia rehabilitation can bring us closer to the realization of what appears, at the moment, to be a "dream" or "utopia" (Azevedo et al., 2023). Although it is possible that some of these features are already available in one or several CA/A, in our current setting in Quebec (a province of Canada) these were not available through provincial financing. Any advances in CA/A need to pass through the slow process of government approval as this is the only way to receive compensation or reimbursement. Further research on this topic can contribute to promote uptake of recent and performant CA/A for PWA and their family, including those that could use AI.

Furthermore, in line with the current research topic of this special issue, our findings may indicate that people living with aphasia had limited digital participation, meaning that their participation in society through the use of digital media and modern technologies such as smartphones was restricted for most, if not all, important life areas. Nevertheless, there was evidence that some participants who employed a smartphone for texting and social media wished to maintain relationships with family members not living with them, a notable aspect of participation. We did not uncover other digital participation goals that participants pursued with CA/A. Further studies with other participants who recently completed rehabilitation may provide a more optimistic and compelling portrayal of the digital participation of PWA, presuming that pre-aphasia digital participation will increase in the general population of older adults, i.e., aged 60 years or more at the time of aphasia onset due to brain injury or PPA. We also conclude that within aphasia rehabilitation, be it focused on language recovery or on employing CA/A to compensate for language limitations, the overarching and ultimate goal should more explicitly focus on participation (Laliberté et al., 2016; Alary Gauvreau et al., 2019; Alary Gauvreau and Le Dorze, 2022; Escher et al., 2022), despite significant challenges with this population (Berg et al., 2019). Re-learning to use CA/A to enable PWA to successfully access social media and to compose and read e-mail and text messages may be worthy rehabilitation goals leading to PWA being more independent and better able to participate in significant aspects of their social and community digital lives.

6. Limitations and further research

The findings we report were obtained from 10 participants, both spouses of a PWA and PWA. Although we emphasized depth of understanding when conducting the time intensive analyses, considering the small sample size, it is important to consider the present findings as preliminary. Further validation through studies with larger samples and more information regarding aphasia type and severity, conducted in other countries, can help determine the extent to which the results presented here are similar or different to those experienced elsewhere. Clinical practices related to CA/A probably differ according to geographical region, thus potentially influencing the experience that PWA and their families have regarding when CA/A is presented to them as a potential therapeutic tool. In the province of Quebec, where this study was conducted, PWA could have access to an iPad with specific language apps or to a dedicated CA/A device as part of their treatment plan. However, this required a referral to the Technical Aids program, consulting with a specialized SLP, and then finally obtaining a CA/A, steps each of which incur important time delays. This time-consuming process may differ in other Canadian provinces and in other countries. Furthermore, the inclusion of participants who had access to newer CA/A, including those not reimbursed by provincial financing, could enrich our understanding of the usefulness and limitations of CA/A as experienced by people with aphasia and their family members.

As is common in studies with PWA, recruitment was another limitation. Potential participants who were users of CA/A were sought to be recruited if they were no longer receiving rehabilitation at the time of the study. However, one PWA included in the study was still receiving rehabilitation services. Furthermore, while we initially sought to recruit only users of CA/A, we finally included one PWA and one couple who were non-users of CA/A. This was because these three had initially refused to consider CA/A as a treatment option for the PWA and we were interested in understanding their experience and reasons for refusal. One of the difficulties in recruitment had to do with the fact that within the clinical facility where participants were recruited, the CA/A program is separate from other programs such as stroke and neurological rehabilitation. Therefore, referral to CA/A occurs after rehabilitation ends, if it occurs at all. Moreover, at the time this study was conducted, potential clients entered a wait list, sometimes as long as 1-year long, before accessing CA/A services. Hence, most CA/A users had waited several months before accessing their device. For people who had PPA this was a greater problem because their abilities declined over time while waiting to access their CA/A, thus running the risk that having a CA/A was no longer optimal for the person and their particular linguistic and cognitive abilities. We believe this may have influenced their experiences and perceptions about CA/A. Had they received CA/A early, as part of their rehabilitation plan, the results would have been different, but from our understanding, such a practice may not be generalized to all areas of the world (Dietz et al., 2020). In addition, in future studies, it would be useful to have additional information regarding how PWA receive training in using their CA/A once they receive it.

We did not assess general media competence or comfort with technology, as part of the study but this is generally done by the SLP as part of the treatment plan and when determining whether a CA/A should be prescribed. Thus participants who were using a CA/A had been deemed able to learn how to use it and could use it, potentially with assistance from a family member. In future research about CA/A, it may be useful to report digital media competence of both PWA and the family member. Despite the belief that aging can negatively affect digital media competence, we did not observe variations in their experience that could be attributed to aging.

7. Conclusions

In this study, the PWA and spouses' experience has brought to the forefront the barriers and potential facilitators to use of CA/A. It has also highlighted those features necessary to ensure functional uptake of CA/A by those who would benefit from it. In parallel to improving currently available devices and software, it is important that training be provided to the communication partner and that the public is sensitized on the impact that aphasia can have on people's daily lives and on the potential benefits of using CA/A not only for improving language and word-finding difficulties but more importantly, for access to digital participation in their life and society.

Data availability statement

The datasets presented in this article are not readily available because no dataset will be made available for the focus groups. Requests to access the datasets should be directed at: nancy.azevedo@mail.mcgill.ca.

Ethics statement

The studies involving humans were approved by the Research Ethics Board (REB) en Readaptation et en Déficience Physique (RDP). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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Conflict of interest

MY and CB are employed by IBM France.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Appendix A

Question guide for focus group.

Question guide

Question 1—Are you familiar with communication aids? In your opinion, what is a communication aid?

Sub-questions:

- What do you know about communication aids?
- Have you ever used one? If yes, how have you used it? If no, why not?
- Did using a communication aid help you speak with someone (ask them to specify the communication partners; caregivers/family, strangers, friends, children, at the shopping center, etc.) In what context?
- How well does this work in everyday life?

Question 2—What are your experiences with communication aids? Sub-questions:

- Give concrete examples
- If you do not use communication, why is this the case?
- Give me an example of a time when it went well and an example of a time when it did not go well.
- Are there contexts that are more enabling for using a communication aid and others that are less enabling? (at home, at the store, with a family member/caregiver, with strangers?) Why?
- Do you use an application, word prediction on your phone, speech recognition, etc?

Question 3—What would you like your—or a—communication aid to do for you that it currently does not do? Sub-questions:

- What would an ideal communication aid be like? We can dream here, what is your wish list when it comes to communication aids?
- How could we improve the communication aids that you currently use or that you are familiar with? For you and for your family/caregiver.
- If you do not use one, what would you like a communication aid to do for you and for your family/caregiver?

Note for facilitator: Points to consider, if necessary: Speech recognition, artificial intelligence for word prediction, possibility of learning a person's vocabulary, dynamic processing, application for a phone, etc.

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Improving lexical retrieval with LingoTalk: an app-based, self-administered treatment for clients with aphasia

Judith Heide[1*†], Jonka Netzebandt[2†], Stine Ahrens[1], Julia Brüsch[1], Teresa Saalfrank[1] and Dorit Schmitz-Antonischki[1]

[1] Department Linguistics, University of Potsdam, Potsdam, Germany, [2] Lingo Lab, Berlin, Germany

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EDITED BY
Kristina Jonas,
University of Cologne, Germany

REVIEWED BY
Jean K. Gordon,
The University of Iowa, United States
Anna Rosenkranz,
University of Marburg, Germany

*CORRESPONDENCE
Judith Heide
✉ jheide@uni-potsdam.de

†These authors have contributed equally to this work and share first authorship

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Introduction: LingoTalk is a German speech-language app designed to enhance lexical retrieval in individuals with aphasia. It incorporates automatic speech recognition (ASR) to provide therapist-independent feedback. The execution and effectiveness of a self-administered intervention with LingoTalk was explored in a case series study.

Methods: Three individuals with chronic aphasia participated in a highly individualized, supervised self-administered intervention lasting 3 weeks. The LingoTalk app closely monitored the frequency, intensity and progress of the intervention. Treatment efficacy was assessed using a multiple baseline design, examining both item-specific treatment effects and generalization to untreated items, an untreated task, and spontaneous speech.

Results: All participants successfully completed the intervention with LingoTalk, although one participant was not able to use the ASR feature. None of the participants fully adhered to the treatment protocol. All participants demonstrated significant and sustained improvement in the naming of practiced items, although there was limited evidence of generalization. Additionally, there was a slight reduction in word-finding difficulties during spontaneous speech.

Discussion: This small-scale study indicates that self-administered intervention with LingoTalk can improve oral naming of treated items. Thus, it has the potential to complement face-to-face speech-language therapy, such as within in a "flipped speech room" approach. The choice of feedback mode is discussed. Transparent progress monitoring of the intervention appears to positively influence patients' motivation.

KEYWORDS

aphasia, anomia, lexical retrieval, oral naming, app-based intervention, self-training, automatic speech recognition (ASR), LingoTalk

1 Word-finding disorders in aphasia

Aphasia is an acquired disorder of language processing that occurs after language acquisition has been completed. The most common cause of aphasia, responsible for more than for 80% of cases, is stroke (Engelter et al., 2006). While aphasia can affect all four modalities of language – reading, writing, oral production, and auditory language comprehension – the most prevalent symptoms involve difficulties in word retrieval (Goodglass and Wingfield, 1997; Nickels, 2002). The severity of the impairment can vary greatly, ranging from difficulties to formulate even single words to mild uncertainties in selecting the appropriate word. Word-finding disorders often lead to an enormously high level of despair: they severely limit everyday communication (Blom Johansson et al., 2012) and have a significant impact on the quality of life (Hilari et al., 2016). Word-finding disorders are observable in everyday conversation as well as in tasks requiring oral word production, such as picture naming, storytelling or word fluency.

Typical symptoms of word-finding difficulties include hesitations, the use of empty phrases, rephrasing or paraphrasing, as well as zero responses, phonological or semantic paraphasias or neologisms. Sometimes individuals with aphasia can retrieve partial information of a word, such as the number of syllables or the initial sound of a word (Goodglass et al., 1976; Anusuya and Shyamala, 2021). They might also have access to grammatical information, such as gender, without being able to retrieve the word form (Badecker et al., 1995).

Both neuro- and psycholinguistic research have developed models of language production that can explain word retrieval disorders in aphasia [see Nickels (2001) for a comprehensive discussion]. A fundamental distinction can be made between serial-modular and connectionist models. Connectionist models assume a continuous flow of information, leading to multiple processing steps being active in parallel and mutually influencing each other. This information flow can be either strictly feedforward (Plaut and Shallice, 1993a) or interactive, allowing feedback from later processing steps to earlier ones (Dell, 1986). On the other hand, serial-modular models propose autonomous modules that process incoming information independently and sequentially. For the neurolinguistic diagnosis of word retrieval disorders, serial-modular models are highly suitable as they allow for a very precise localization of the underlying impairment (Lorenz, 2004). Examples of serial-modular models include the Logogen model (Patterson et al., 1987) and Levelt's two-stage model (Levelt, 1993). These models differ in their stance on whether lexical access and phonological retrieval constitute a one- or two-step process. The Logogen model (Patterson et al., 1987) posits a direct link between a semantic concept and the corresponding phonological word form, rendering lexical access a one-step process. In contrast, Levelt's model (Levelt, 1993; Levelt et al., 1999), assumes two distinct steps within lexical access, distinguishing between accessing abstract lexical representations (lemmas) and the retrieval of the phonological word forms (lexemes). In the context of this study, we rely on the Logogen model (Patterson et al., 1987), which describes the oral and written production as well as auditory and visual comprehension of monomorphemic words and neologisms. Figure 1 illustrates the modules that are relevant to oral picture naming.

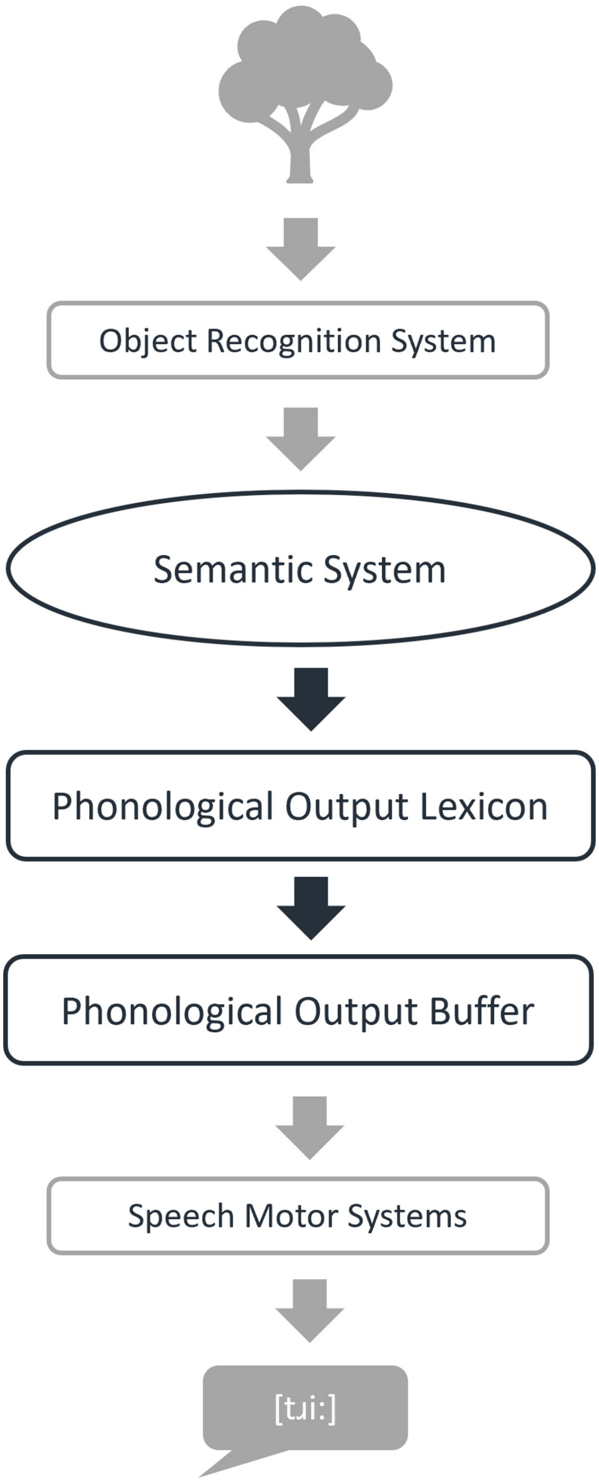


FIGURE 1
Lexical retrieval in oral picture naming according to the Logogen model (based on Patterson et al., 1987).

The recognition of an object leads to the activation of the item's semantic features in the semantic system. This semantic activation is forwarded to the corresponding entries in the phonological output lexicon (POL). The target word, which receives the highest activation, is then retrieved, while competing word forms are inhibited. In the next step, the target word is briefly stored in the phonological output buffer (POB) before it is articulated. The modules involved in lexical retrieval may be disrupted selectively or in combination (Hillis and Caramazza, 1994). Thus, impairments in oral word production can be due to semantic and/or post-semantic disorders (Ellis et al., 1992), namely

1. Faulty or insufficient activation of semantic knowledge.
2. Impaired access from the semantic system to the corresponding lexical entry in the POL.
3. Missing or underspecified lexical entries in the POL; i.e., deficient knowledge about the phonological word form.

4. A limited capacity of the POB which leads to deficits in maintenance and assembly of phonemes.

Various (psycho-)linguistic parameters are known to influence word production in aphasia, as well as in neurotypical individuals. For instance, concrete words and typical members of a semantic category are retrieved more easily than abstract words and atypical members. Both the concreteness effect (Plaut and Shallice, 1993b) and the typicality effect (McRae et al., 1997) are attributed to the word's semantic features and their representation in the semantic system. Frequency effects – where high-frequency words are easier to retrieve than low-frequency words – are associated with lexical disorders. In the framework of two-step models, Kittredge et al. (2008) argue that word frequency affects both stages of lexical retrieval, i.e., access to both lemmas and lexemes. In the Logogen model, word frequency effects arise from the POL, as representations of high-frequency words require less activation to be retrieved than representations of low frequency words (Morton, 1969). Also, the influence of part-of-speech and lexical neighborhood density is attributed to the lexicon (Harley and Bown, 1998; Laiacona and Caramazza, 2004). Whether effects of age of acquisition originate at the lexical or at the semantic level is still under discussion (Morrison and Gibbons, 2006). Word length has an impact on phoneme maintenance and sequencing and is associated with post-lexical processes, i.e., the phonological output buffer (Baddeley et al., 1975; Haluts et al., 2020). Contrasting performance for morphologically complex vs. simple words is attributed to morpho-lexical processing of complex words (Lüttmann et al., 2011).

These parameters and their specific impact on cognitive components should be considered when compiling materials for an intervention aimed at facilitating lexical retrieval. A substantial body of research has demonstrated the effectiveness of repetitive word retrieval training (Hickin et al., 2002; Boyle, 2004; Renvall et al., 2013a). Patients with post-semantic word-finding disorders appear to benefit from tasks that require both phonological and semantic processing (Lorenz and Ziegler, 2009). Effective cueing techniques include phonological, semantic, auditory, and visual hints (Sze et al., 2021).

When addressing word retrieval deficits, the aim is typically twofold: On the one hand, the goal is to enhance naming performance for treated items. On the other hand, there is an aspiration for generalization to untreated items and/or untreated tasks, as this would result in a broader improvement beyond therapy. Generalization to untreated items requires that they share semantic or phonological features with treated items, and that these features are targeted during intervention. In this case, spreading activation within the semantic system or the POL may lead to improvement of untreated semantic concepts or untreated word forms (Webster et al., 2015). However, if the word retrieval deficit is due to an impaired connection between semantics and the POL, generalization to untreated items is not expected: as the association of a semantic concept with a particular word form is, in most cases, purely incidental, each connection must be rebuilt in its own right (Miceli et al., 1996; Howard, 2000). Consequently, the selection of the items to be practiced is of great importance. The items should be meaningful for the client and have relevance in everyday contexts (Renvall et al., 2013a). Corpus analyses conducted by Renvall et al. (2013a) showed that the 100 most frequent English words include verbs, pronouns, adverbs, and prepositions. Similarly, in the German corpus "Wortschatz Leipzig" (Universität Leipzig, Institut für Informatik, Projekt Deutscher Wortschatz, 1998-2023), the 50 most frequent German words consist mainly of function words (determiners, prepositions, pronouns) and various forms of the light verbs "to have" and "to be." This underscores the importance of incorporating words other than nouns in an intervention aimed at facilitating lexical retrieval (Renvall et al., 2013a). Generalization to untreated tasks may occur within the same linguistic level, e.g., if naming by definition improves after the treatment of oral picture naming. Even more meaningful are across-level generalizations, where improved lexical retrieval extends to sentence production, connected speech or everyday communication (Webster et al., 2015).

2 Apps in speech-language therapy

The dosage of speech-language therapy plays a crucial role in its effectiveness (Bhogal et al., 2003). A recent review conducted by the RELEASE collaborators [The REhabilitation recovery of peopLE with Aphasia after StrokE (RELEASE) Collaborators, 2022] found that the most significant improvements in language and functional communication occurred when the intervention was administered 5 days a week. Breitenstein et al. (2017) demonstrated that receiving ten or more hours of speech-language therapy per week led to sustained improvements in aphasic communication disorders after a stroke. German guidelines for the rehabilitation of aphasic disorders after a stroke (Deutsche Gesellschaft für Neurologie, 2011) recommend daily speech therapy as the minimum dosage. However, the reality in outpatient speech therapy facilities differs (Bürkle et al., 2022). In Germany, the standard practice typically involves one to two therapy sessions per week (Asmussen et al., 2013). Therefore, therapeutic homework is employed to increase the frequency of the intervention through complementary self-training (Wendlandt, 2002). In this context, patients bear a high level of responsibility, as they need to complete their assignments regularly, comprehensively, and in the desired manner. Digital applications, such as apps and computer programs, can provide the necessary guidance and support that individuals with aphasia, in particular, may require (Braley et al., 2021). Participation in digital technologies – in the case of aphasia rehabilitation, the competent use of a high-quality speech language app – can therefore contribute to the self-determined pursuit of individual health goals.

2.1 Advantages of app-based approaches

While therapeutic homework can increase the frequency of interventions, it lacks the interaction between the client and the speech-language therapist (SLT). Most notably, traditional "paper and pencil" tasks do not provide any feedback. Consequently, clients remain unaware of their performance until their next session with their SLT. In contrast, digital applications, can offer immediate feedback that is independent of the therapist, objective, and reliable. Outcome-oriented feedback which visualizes the learning progress is motivating (Kurland et al., 2014). Clients are encouraged to practice more frequently, thereby achieving the intended intensive treatment (Stark and Warburton, 2018; Leinweber, 2021). At the same time, clients assume greater (shared) responsibility for their therapy (Palmer et al., 2019), as app-based learning fosters personal responsibility and self-determination (Kurland et al., 2014).

The availability of high-quality speech-language applications is still limited in German-speaking countries. Only a few apps are specifically designed for adults with aphasia. These apps usually focus on training reading comprehension, writing, or auditory comprehension – tasks where the app can easily provide feedback. In contrast, oral naming tasks require the clients to self-assess their own production, such as by comparing their answer to the target word that is presented auditorily and/or visually by the app. Obviously, this self-evaluation can be error-prone when self-monitoring is impaired. Therefore, there is a demand for external feedback in word production tasks as well. Achieving therapist-independent training for verbal speech production necessitates the use of automatic speech recognition (ASR) technology to recognize and assess spoken words. There is initial evidence suggesting that digital speech recognition technologies utilizing ASR can improve verbal word production in individuals with aphasia and apraxia of speech (Ballard et al., 2019).

2.2 LingoTalk – a speech language app with automatic speech recognition

LingoTalk (© LingoLab 2021–2023) is a German speech-language app designed to enhance word retrieval in individuals with aphasia. The app has been available in the Google and Apple app stores for tablet computers and large smartphone displays since spring 2021. LingoTalk focuses on training lexical retrieval through cued verbal picture naming. The design and objectives of LingoTalk are based on the ICF framework (World Health Organization, 2001). Training with the app is intended to facilitate lexical retrieval from the POL, ultimately enhancing communication in everyday life.

LingoTalk's linguistic database covers words that are highly relevant to everyday life and topics of general interest, allowing for a patient-oriented selection of word materials. As of April 2023, this database contained over 3200 words, categorized into 28 topics. Each word is represented by a color photo. The items are classified based on 17 linguistic parameters and divided into four levels of increasing difficulty (easy, medium, demanding, hard). The difficulty level of an item is determined by various linguistic criteria, including word frequency (high vs. medium vs. low; derived from Digitales Wörterbuch der Deutschen Sprache Universität Leipzig, Institut für Informatik, Projekt Deutscher Wortschatz, 1998-2023, word length in syllables (ranging from 1 to more than 4 syllables), morphological complexity (simple vs. complex), syllable complexity (absence vs. presence of consonant clusters), and stress pattern (trochaic vs. non-trochaic). If norm data are available (see Schröder et al., 2012), age of acquisition (early vs. late) and familiarity (high, medium, low) are taken into consideration. Shifts in place of articulation (none, few, many) and phoneme-grapheme regularity (regular vs. irregular) are considered if the other criteria result in an inconclusive classification. Easy words, for instance, are of high or medium frequency, acquired early, morphologically simple, have one or two syllables, do not contain consonant clusters, and two-syllable words have a trochaic stress pattern. In contrast, words that are morphologically complex (e.g., compounds and or reflexive, prefix, or particle verbs) or consist of four or more syllables are classified as demanding or hard. Further details on how these different criteria correspond to the four levels of difficulty can be found in the Supplementary material.

The words to be practiced can be selected either based on a specific topic (e. g., "city life and traffic") or according to psycholinguistic variables (e.g., "two-syllable high-frequency nouns with /n/ or /m/ in the initial sound"). In both cases, one can choose not only content words but also items from the core vocabulary. The core vocabulary includes high-frequency function words (e. g., "more," "not") that are not tied to a particular topic but are applicable in various contexts (Boenisch and Sachse, 2020). LingoTalk's items encompass 11 part-of-speech (nouns, different verb forms, adjectives, adverbs, perfect participles, pronouns, numerals, prepositions and interjections), including both concrete and abstract concepts.

LingoTalk is the first German speech-language app to incorporate ASR, enabling app-based evaluation and feedback in a verbal picture naming task. When ASR is employed, the app assesses the response and indicates whether the item was named correctly or not. LingoTalk's ASR relies on the speech recognition software provided by Apple (SIRI) and Android-based devices (Google Speech). Data protection regulations are strictly adhered to and the use of ASR requires explicit consent from the clients. To determine the accuracy of the app's ASR functionality, we analyzed 1801 utterances from ten neurotypical native German speakers (six men, four women, aged 20–70). Each speaker named 50 pictures depicting nouns, verbs, and adjectives up to six times on two different days. We tested the quality of Google Speech's ASR with 15 Samsung tablet computers (Galaxy Tab S2 or Galaxy Tab S6; Android 7.0) and Apple's SIRI ASR with five devices (iPad Pro and iPad Air; PadOs 14.1.1). The correctness of the utterances was assessed by both the ASR and two experienced SLTs. There was a high level of agreement in the ratings between ASR and the SLTs, reaching 98.05% for Google Speech (1259/1284 utterances) and 99.26% for SIRI (508/517 utterances). Google Speech rejected 24 responses that the SLTs rated as correct and accepted one response that the SLTs rated as incorrect. SIRI rejected 9 responses that the SLTs rated as correct. With both Google Speech and SIRI operating with an accuracy rate of over 95%, we consider the feedback provided by the app to be reliable. Moreover, ASR offers the opportunity for feedback-driven learning outside of face-to-face sessions. This enhances clients' independence from their SLT and strengthens their sense of competence, responsibility, and self-efficacy in rehabilitating their language skills. As an alternative to ASR, the correct/incorrect rating can also be performed by either the SLT or by the clients themselves. For self-evaluation, clients can play an audio file containing the target word and then reveal the written word form to compare their reaction with the target item.

The app is designed in a tandem version, allowing the client's and therapist's applications to be linked via an encrypted code. The SLT can compile patient-oriented and linguistically tailored materials, define the type of feedback, and choose from ten evidence-based cues (Sze et al., 2021). Linked accounts also allow the therapist to monitor the patient's treatment routine and their progress. LingoTalk records the date, time and duration of each practice session, as well as the number of correct responses (with and without cueing), naming latencies, and the cues that were most frequently employed.

During the training session (Figure 2), the patient is presented with the picture to be named and hears the instruction "Please name the picture!" or "What can be seen here?" On the right side (or optionally on the left side), cues are displayed, offering phonological, semantic, and graphemic support in a hierarchical sequence. Additionally, an audiovisual articulation video is provided. When ASR is enabled, the patient presses the microphone button while uttering the word and the app responds with outcome-oriented feedback. Successful naming is indicated by a green flag along with a confirming sound, while incorrect responses are marked with a gray tag and an error sound. The patient is granted three attempts to name the item correctly and can make use of cues if necessary. After three unsuccessful attempts, the client receives corrective feedback, and the target word is presented auditorily and in written form beneath the picture. Then the next picture is presented. The progress of the exercise, including the number of remaining items, is displayed in a progress bar at the top.

When the exercise is completed, the evaluation screen (Figure 3) shows a pie chart that summarizes the current session (naming accuracy with and without cues) and a bar chart that shows the therapy progress (naming accuracy with and without cues, average naming latencies). A table displays date, time and duration of a practice session. It also includes average naming latencies, the most frequently used cues, and naming accuracy with and without cues.

3 Research questions

The aim of our case series study was twofold. Firstly, we monitored if and how participants with aphasia were able to carry out the self-administered training with LingoTalk and asked:

1. Can participants with aphasia manage their app-based treatment independently and adhere the treatment protocol as instructed?

Secondly, we investigated whether intensive training with the LingoTalk app leads to improved oral naming in aphasia. We aimed to answer the following questions:

2a. Does treatment with LingoTalk result in improved oral naming of treated items?
2b. Does this improvement generalize to (a) untreated but similar items and/or (b) treated items in an untreated task that is similar to the treated task (naming by definition)?
2c. Is there a transfer from the highly structured practice sessions to spontaneous speech and everyday communication?

4 Materials and methods

The research presented in this paper was conducted in the context of three Bachelor's projects (Schmitz-Antonischki, 2021; Ahrens, 2022; Saalfrank, 2023) carried out at the University of Potsdam and the P.A.N. Center for Post-Acute Neurorehabilitation in Berlin. The research was conducted in accordance with the relevant institutional guidelines, including the EU General Data Protection Regulation (GDPR) and the Brandenburg State Data Protection Law (BbgDSG) as well as the German Research Foundation's Guidelines for Safeguarding Good Research Practice. The project was approved by the research coordinator of the P.A.N Center.

4.1 Participants

An intervention with LingoTalk is appropriate for native speakers of German who have impaired lexical retrieval due to aphasia. For the present study, the participants had to meet the following criteria:

Inclusion criteria
- Native speaker of German
- Chronic aphasia, at least 6 months post-onset
- Word-finding difficulties and impaired oral naming due to a post-semantic deficit, i.e. preservation of basic semantic knowledge
- Written informed consent
- Interest in working with a speech-language therapy app and informal commitment to practice on a daily basis
- Ability to use a tablet computer and the LingoTalk app without assistance
- Completion of a test trial
- Access to a stable Wi-Fi connection at home

Exclusion criteria
- Moderate or severe speech motor disorder
- Severely impaired auditory comprehension that might compromise the understanding of instructions

The diagnosis of aphasia was established using either the ACL (Kalbe et al., 2010) or the AAT (Huber et al., 1983). In the ACL, participants needed to score below the cutoff, i.e., <135 points. The outcome of the AAT had to indicate "aphasia." Additionally, participants' performance in the Wortproduktionsprüfung [WPP/subtest 3 (Blanken et al., 1999)], where they were required to orally name 60 nouns, had to be < 90% correct. As LingoTalk does not allow for semantic treatment, participants had to score above cutoff in subtests 1–3 of the Bogenhausener Semantik Untersuchung (BOSU, Glindemann, 2002), which require thematic and taxonomical semantic knowledge to judge on situations and features. Participants were also required to demonstrate the ability to initiate, turn off, and recharge their tablet computers. After receiving an extensive demonstration of how to use the LingoTalk app and the ASR, participants had to successfully complete a test trial with five to ten items without assistance.

Three participants (P1, P2, P3), who met all inclusion criteria and none of the exclusion criteria were recruited in the P.A.N. Center for Post-Acute Neurorehabilitation (Berlin) and through University of Potsdam's Patholinguistics patient database. The participants were provided with information

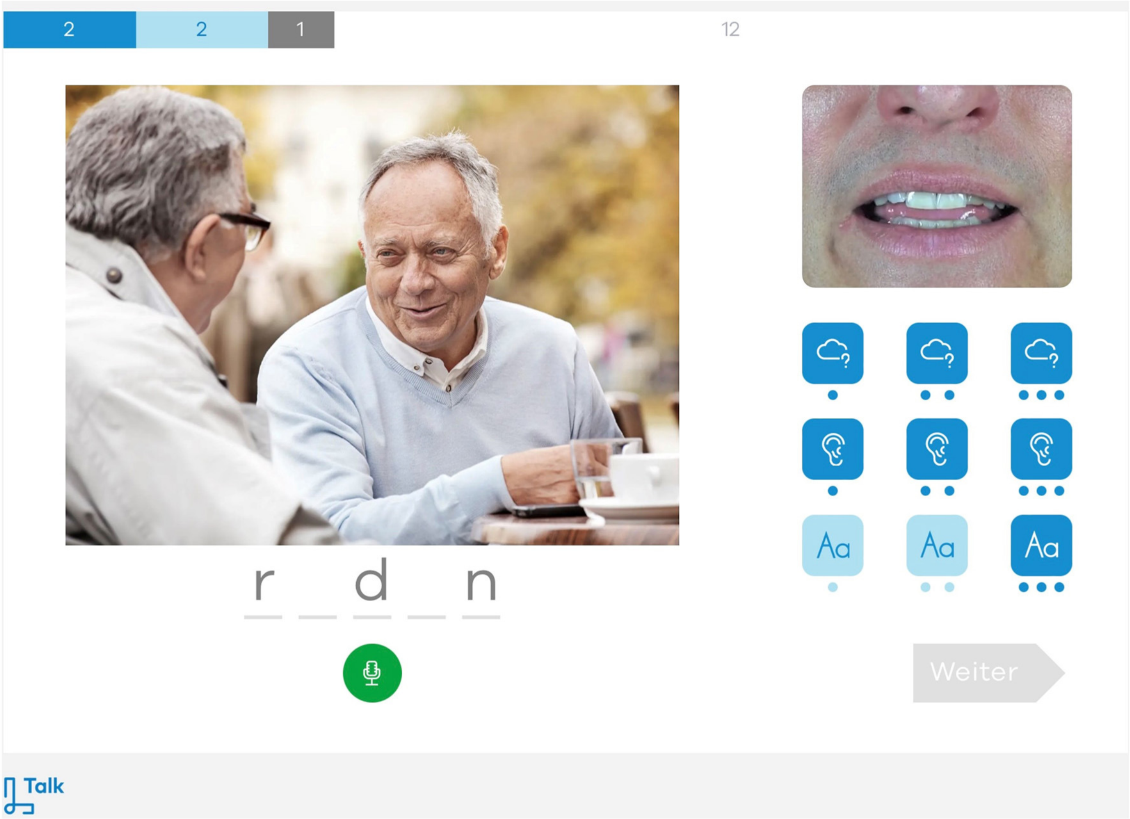


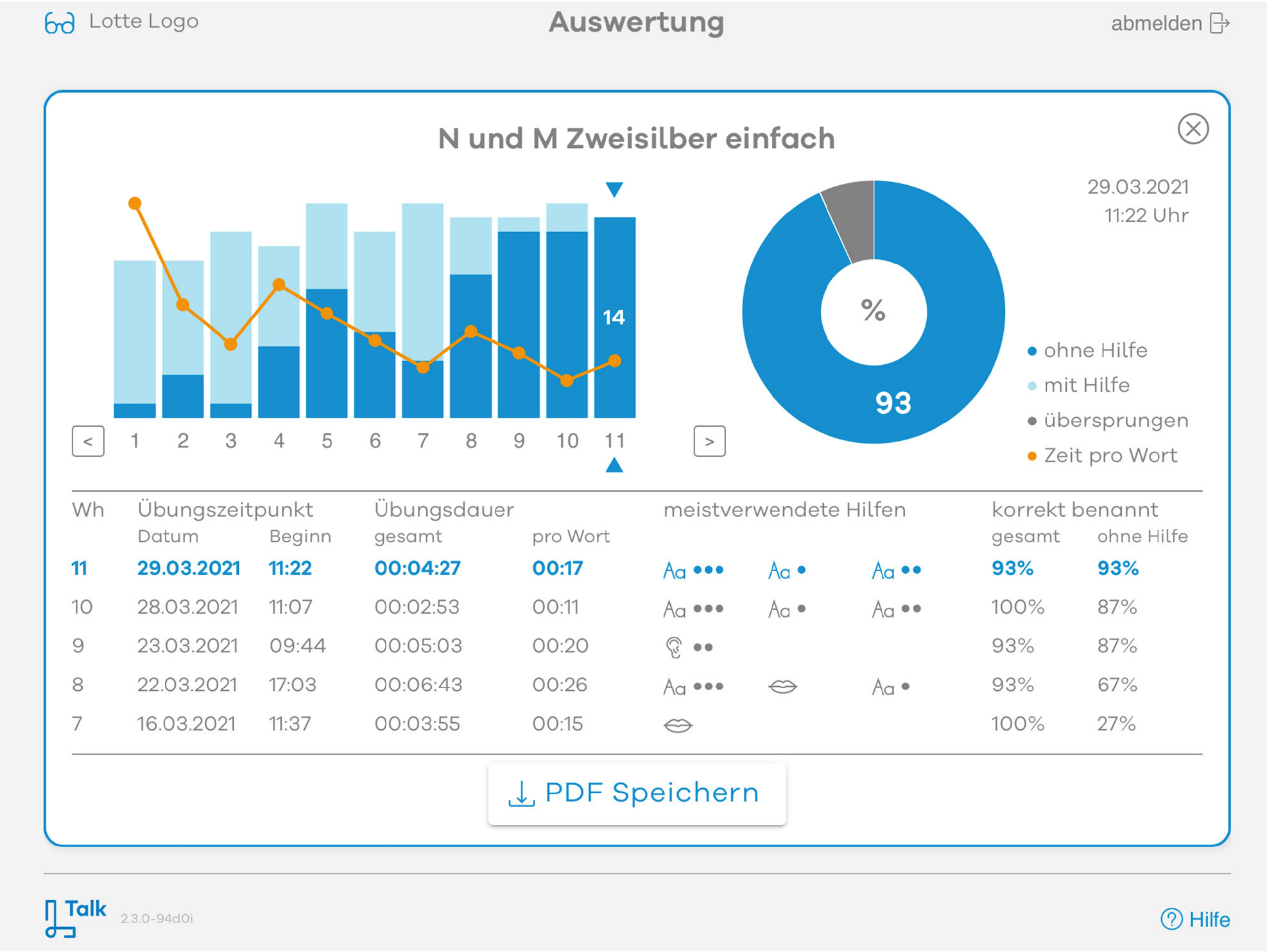
FIGURE 2
Target item "reden" (to talk) with semantic, phonological, orthographic cues and the articulation video. The green button allows ASR-based feedback on the spoken response.

about the study's purpose, procedures, collection and use of data and the potential risk of an unsuccessful therapy outcome. They provided written consent to participate in the study and they could withdraw from the study at any time and without giving any reason. All participants had received speech-language therapy before their involvement in the study, but no additional speech-language treatment was administered during the intervention with LingoTalk. P1 and P2 already owned tablet computers, while P3 was provided with a loan device for the duration of the study. Table 1 shows the demographic information for each patient and their language profiles.

The purpose of the neurolinguistic assessment was twofold: to confirm that the participants met the inclusion criteria and to examine the severity and the nature of their word-finding difficulties. Using the WPP (Blanken et al., 1999), we investigated the participants' overall naming performance and examined the influence of word frequency, word length, and articulatory complexity on lexical retrieval. The BOSU assessment (Glindemann, 2002) ruled out severe semantic impairment. Comparing oral naming to oral reading performance [either WPP subtest 3 vs. 6 (Blanken et al., 1999) or LEMO 2.0 T13 vs. T8 (Stadie et al., 2013)] provided insight whether impaired oral naming was caused by damaged access from semantics to POL and/or impairment of representations in the POL.

P1 was a 23-year-old German-speaking woman with 16 years of education. She had suffered a traumatic dissection of the left carotid artery and an occlusion of the internal carotid artery (ICA) due to an accident 1.5 years prior to this study, resulting in damage in the entire left ICA territory. At the time of the study, P1 resided in a center for post-acute neurorehabilitation and was highly motivated to maximize her rehabilitation potential. P1 used a smartphone on a daily basis and had recently acquired a tablet for Augmentative and Alternative Communication (AAC). Assessment with the AAT (Huber et al., 1983) confirmed a global aphasia, although clinical observation was more indicative of Broca's aphasia. Her spontaneous speech was non-fluent and agrammatic, characterized by frequent word-finding difficulties, and displayed mild symptoms of apraxia of speech. Neurolinguistic assessment revealed impaired oral naming [50% correct in WPP (Blanken et al., 1999)] with no effects of word frequency, word length, or articulatory complexity. Errors included semantic, phonemic, and formal paraphasias. According to BOSU (Glindemann, 2002), basic semantic knowledge was preserved, whereas oral reading of regular and irregular words was impaired [23% correct in LEMO 2.0/subtest T8 (Stadie et al., 2013)]. Therefore, the naming disorder was attributed to the access from semantics to the POL and/or the POL itself.

P2 was a 39-year-old woman with 9 years of education. 1:6 years prior to this study, she suffered a left carotid ischemic stroke. P2



Wh	Übungszeitpunkt		Übungsdauer		meistverwendete Hilfen			korrekt benannt	
	Datum	Beginn	gesamt	pro Wort				gesamt	ohne Hilfe
11	**29.03.2021**	**11:22**	**00:04:27**	**00:17**	Aa •••	Aa •	Aa ••	**93%**	**93%**
10	28.03.2021	11:07	00:02:53	00:11	Aa •••	Aa •	Aa ••	100%	87%
9	23.03.2021	09:44	00:05:03	00:20	👂 ••			93%	87%
8	22.03.2021	17:03	00:06:43	00:26	Aa •••	👄	Aa •	93%	67%
7	16.03.2021	11:37	00:03:55	00:15	👄			100%	27%

FIGURE 3
Evaluation screen.

resided in a center for post-acute neurorehabilitation and received treatment there. She was an enthusiastic computer gamer and proficiently used a laptop and a smartphone. She also owned a tablet for AAC but did not actively use it. Assessment with the ACL (Kalbe et al., 2010) confirmed the diagnosis of aphasia. Her spontaneous speech was non-fluent, characterized by incomplete sentences due to word-finding difficulties. Oral naming was impaired [65% correct in WPP (Blanken et al., 1999)], and performance for high-frequency words was significantly better than for low-frequency words (24/30 vs. 15/30, $p = 0.029$; Fisher's exact test). Word length and articulatory complexity did not influence naming performance. There were few phonological paraphasias, but most errors were semantically related to the target. As basic semantic knowledge was preserved [cf. BOSU (Glindemann, 2002)], the latter errors were attributed to insufficient activation of the lexical entry in the POL, resulting in the retrieval of a semantically similar response. Since reading and oral naming were equally affected [cf. LEMO 2.0 (Stadie et al., 2013), T13 vs. T8, 17/20 vs. 41/60, $p = 0.25$], the impairment was localized within the POL itself, rather than in lexical access.

P3 was a 69-year-old German-speaking man with 15 years of education. He had suffered a left carotid ischemic stroke more than 20 years prior to this study. After a pause of several years, P3 requested the resumption of speech language therapy and was included in the study in an outpatient setting. P3 showed great interest in working with an app but had never used a tablet computer or a smartphone before. The ACL (Kalbe et al., 2010) confirmed a persistent mild to moderate aphasia. His spontaneous speech was fluent but marked by various symptoms of word-finding difficulties, including hesitations, rewording, empty phrases, and repetition of words and phrases.

Oral naming was impaired [70% correct in WPP (Blanken et al., 1999] and affected by word frequency (high: 25/30 correct vs. low: 17/30; $p = 0.047$) and word length (1 syllable: 17/20 vs. 3 syllables: 10/20, $p = 0.041$). Both semantic and phonologic errors occurred. Articulatory complexity did not influence the naming performance. Basic semantic knowledge was preserved [cf. BOSU (Glindemann, 2002)], and the WPP (Blanken et al., 1999) showed that oral reading was significantly better than naming of the very same words (59/60 vs. 42/60, $p < 0.001$). Therefore, the naming disorder was attributed

TABLE 1 Patient demographic information and language profiles.

	P1	P2	P3
Demographic information			
Gender	f	f	m
Age (years)	23	39	69
Educational level/former profession	High school/student	Secondary school/shop assistant	Bachelor's/retired CEO
Etiology	Traumatic dissection LCA and occlusion ICA	Ischemia left MCA	Ischemia left MCA
Time post injury (months)	17	18	248
Neurolinguistic assessment			
AAT Overall result	Aphasia (global)	—	—
ACL Overall result	—	Aphasia (79/148)	Aphasia (114/148)
Severity of aphasia (clinical observation)	Severe	Moderate	Mild
BOSU (subtests 1–3)	26/30 all subtests above cut-off	27/30 all subtests above cut-off	29/30 all subtests above cut-off
WPP (subtest 3) oral naming	30/60	39/60 frequency effect	42/60 frequency effect length effect
WPP (subtest 6) oral reading	45/60	—	59/60
LEMO 2.0 (T13) oral naming	16/20 impaired	17/20 impaired	18/20 impaired
LEMO 2.0 (T8) oral reading regular/irregular nouns	14/60 impaired	41/60 impaired	51/60 impaired

LCA, left carotid artery; ICA, internal carotid artery; MCA, middle cerebral artery; AAT, Aachen Aphasia Test (Huber et al., 1983); ACL, Aphasie Check Liste (Kalbe et al., 2010); WPP, Wortproduktionsprüfung (Blanken et al., 1999); LEMO 2.0, Lexikon modellorientiert (Stadie et al., 2013); BOSU, Bogenhausener Semantik Untersuchung (Glindemann, 2002).

to an impaired access from semantics to the POL while semantic and lexical representations were intact.

4.2 Materials

LingoTalk allows for an individual selection of items that takes into account both the patient's needs and interests as well as the degree of language impairment. PlanBe (Pfeiffer and Leisner, 2016) was used to identify the patients' interests and hobbies, their interlocutors and the communicative topics and situations they engage in. Involving patients in the item selection process and developing individual item sets makes the materials relevant to everyday life and usually increases motivation for the intervention (Renvall et al., 2013b). Based on the information from PlanBe (Pfeiffer and Leisner, 2016), topics of interest were selected in LingoTalk individually for each participant. In addition, the difficulty of the items (easy, medium, demanding, hard) was adjusted to the severity of the oral naming impairment. To investigate item-specific effects as well as generalization, Brüsch (2022) suggests to use three item sets for each participant: (1) treated items, (2) untreated items from treated topic, (3) untreated items from untreated topic. Each set should contain 20–30 items and preferably different part of speech. Table 2 shows the item selection for each participant. A full list of items can be found in the Supplementary material.

Using PlanBe, P1 identified six topics relevant to her daily life, with four of them being treated and two remaining untreated. The intervention comprised 120 items that were divided into three sets: Treated items ($n = 50$), untreated items from the treated topic ($n = 30$), and untreated items from an untreated topic ($n = 40$). Each set contained the same proportion of nouns (60%), verbs (20%), and adjectives (20%) and the same number of low, medium, and high frequency items. Treated and untreated sets were matched for item difficulty. As P2 was about to move into an assisted living facility, the treated items were chosen from topics related to living at home. Untreated items were chosen from other topics that were relevant at that time. All item sets (treated items, untreated items from treated topic, untreated items from untreated topic) comprised 20 nouns, 10 verbs and 10 adjectives. Each set contained the same number of low, medium, and high-frequency items. Treated and untreated sets were matched for item difficulty. P3 is an avid sailor and therefore identified summer holidays and weather as relevant topics. As previous interventions had revealed a specific deficit for morphologically complex words (Wegener et al., 2010), only low frequent compound nouns were treated. Compounds of low and medium frequency, belonging to the same topic as the treated items, served as untreated control items.

4.3 Planned treatment and procedure

The overall aim of the intervention was to facilitate lexical retrieval for items that were chosen according to the participants' needs and interests. The treatment was planned within a multiple

TABLE 2 Items individually selected for each participant.

	Item difficulty (LingoTalk classification)	Treated topics	Untreated topics	Part of speech	Treated items	Untreated items treated topic	Untreated items untreated topic
P1	Medium Demanding Hard	• Family • Grocery shopping • In the kitchen • Climate and weather	• City life and traffic • Nature and environment	Nouns Verbs Adjectives	$N = 50$	$N = 30$	$N = 40$
P2	Demanding Hard	• Laundry • Living at home • In the morning • Cleaning	• Family • COVID-19 pandemic • Easter	Nouns Verbs Adjectives	$N = 40$	$N = 40$	$N = 40$
P3	Hard	• Holidays • Weather	—	Compound nouns	$N = 22$ (low frequency)	$N = 44$ (low and medium frequency)	—

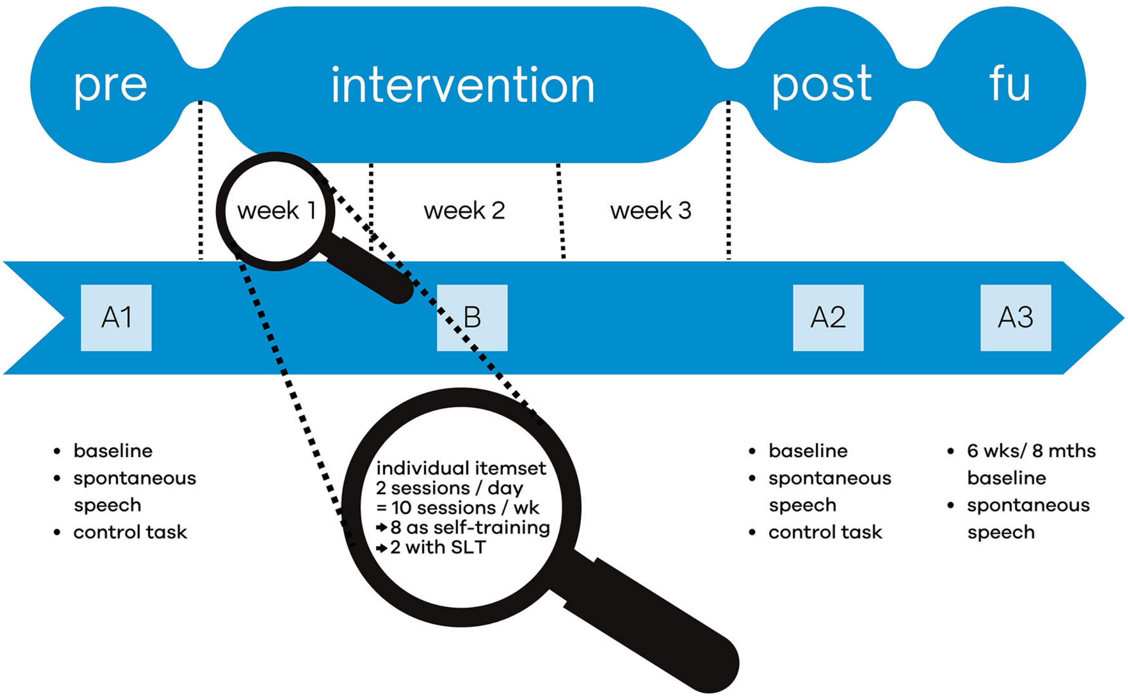


FIGURE 4
Timeline of baseline measures and intervention.

baseline design (A1-B-A2-A3). The timeline is illustrated in Figure 4.

In the intervention phase (B), participants were asked to complete 10 training sessions per week within a period of 3 weeks, resulting in 30 sessions in total. We expected them to practice twice a day on 5 days a week, leading to 15 (out of 21) training days. The very first session took place in a face-to-face setting to ensure that the participants knew how to use the tablet computer and the app. Familiarization with LingoTalk included instructions on how to start/end a training session, how to use ASR, and how to systematically choose hierarchical cues in case of incorrect answers. The SLT observed the training session and assisted if necessary until the participant felt comfortable using the app. Afterwards, the participants started the self-administered intervention with LingoTalk (session 2–6). The SLT was able to monitor the patients' progress in the professional version of LingoTalk, allowing the experimenter to check if the patient completed the therapy sessions as planned. Session 7, again, took place in a face-to-face setting. The SLT and patient reflected on the already completed sessions and addressed any queries or technical issues. In weeks 2 and 3, two sessions were also supervised by a therapist. Thus, the 30 therapy sessions consisted of six supervised and 24 self-administered sessions. To help the participants track their progress, they were provided with a schedule they could check off when they had completed a therapy session.

Participants were asked to practice all treated items in each therapy session. Treatment was always administered with LingoTalk, and the task was oral picture naming. Participants were shown a picture and heard the instructions "What can be seen here?" and "Please name the picture!" Afterwards, they named the picture. The pictures were presented either in one block (P3) or split up into several blocks (P1, P2) to keep the blocks shorter and more homogeneous. For example, for P2, we created six blocks according to topic and part of speech. For patients to receive direct feedback and to monitor their performance throughout the intervention, ASR should be used. A response would be considered correct if the ASR could identify the response. To make use of the ASR, the patients had to press the "record" button (symbolized by a green vibrating microphone), hold the button, give their answer, and then release the button (cf. Figure 2). P1 and P2 could use ASR immediately. P3, however, had major difficulties in keeping the button pressed while giving the answer. Despite intensive training, he would press the button, release it, and only then name the picture. Therefore, P3 was asked to use the self-assessment mode to classify his reactions as correct or incorrect. If an item was named incorrectly or could not be named at all, the participants could make use of gradually increasing phonological, semantic, and/or graphemic cues. An audiovisual mouth image could be used as a maximal cue. Although it was recommended to start with the weakest cue, participants were free to select whichever cue they found helpful. After three incorrect naming attempts, the target word was presented auditorily and in written form below the picture.

To answer research question 1 – can participants with aphasia manage their app-based treatment independently and do they follow the treatment protocol as instructed? – we used LingoTalk's data documentation to closely monitor the intervention phase. We evaluated how often and how regularly the participants named the treated items and compared these data to the treatment protocol. Naming accuracy for treated items was recorded for every single session to monitor each participant's progress throughout the intervention. To account for treatment effects, and to answer research questions 2a–c, baseline measures were conducted before treatment (A1), directly after treatment (A2) and in a follow-up at least 5 weeks after the intervention (A3). Baselines measures examined item-specific effects, i.e., whether treated items improved in a treated task (oral picture naming). Furthermore, different types of generalization were investigated: (1) generalization to untreated items a treated task (oral picture naming of untreated items), (2) generalization to treated items in an untreated task (oral naming by definition of treated items), (3) generalization to a comparable task [oral picture naming, WPP/subtest 3 (Blanken et al., 1999)]. Transfer to communication was measured with the Amsterdam Nijmegen Everyday Language Test (ANELT) (Blomert and Buslach, 1994). The analysis of spontaneous speech focused on the number of word-finding difficulties and phrases, as their ratio (one word-finding difficulty every n = x phrases) is a sensitive marker for the frequency of word-finding difficulties (Bayer, 1986). The higher the ratio, the fewer word-finding difficulties occur per phrase. Spontaneous speech was collected in semi-structured interviews that covered both treated and untreated topics (cf. Table 2). In addition, the Communicative Activity Log (CAL) (Pulvermüller and Berthier, 2008) informed about each participant's everyday communicative practice as perceived by the participants (CAL self-assessment) and/or a conversation partner (CAL external assessment). To control for unspecific, general improvement, a task unrelated to oral naming and not practiced during intervention was administered before and after treatment. The unrelated control task was writing non-words to dictation for P1, written picture naming for P2, and oral non-word repetition for P3. Statistical analyses with either the McNemar test or the Fisher's exact test were carried out for all baseline measures except spontaneous speech.

TABLE 3 Execution of the treatment protocol.

	Training days (within 3 weeks)	Training sessions	Sessions per day	Average number of sessions per training day
Planned	15	30	2	2
P1	17	30	1–2	1.82
P2	12	29	2–4	2.42
P3	16	46	1–5	2.88

5 Results

5.1 Execution of the treatment protocol

Participants had been instructed to complete 30 training sessions, evenly distributed over 15 days (i.e. twice a day), within a total period of 21 days. However, it was observed that none of the participants fully adhered to this protocol (cf. Table 3). While P1 deviated only marginally by completing 30 sessions within 17 days, P2 and P3 showed greater variation. P2 found it challenging to practice on a regular basis but still aimed to complete the 30 training sessions. As a result, she increased the number of sessions per day, resulting in 29 sessions within 12 days. In contrast, P3 enjoyed working with the tablet computer and completed 46 training sessions within 16 days.

All participants became considerably faster throughout the therapy process. Initially, sessions lasted ∼40–45 minutes, but by the end of the treatment period, they were completed in just 5–10 min. Visual inspection of naming accuracy (Figure 5) showed unexpected data for P3 in sessions 28–37. During this period, his naming accuracy suddenly dropped from 70% to zero. Upon investigation, P3 explained that he had attempted to use the ASR once more. It seems that he failed to do so without noticing. Consequently, none of his responses were identified as correct during this period. When P3 reverted to self-assessment in session 38, his naming accuracy returned to 100%.

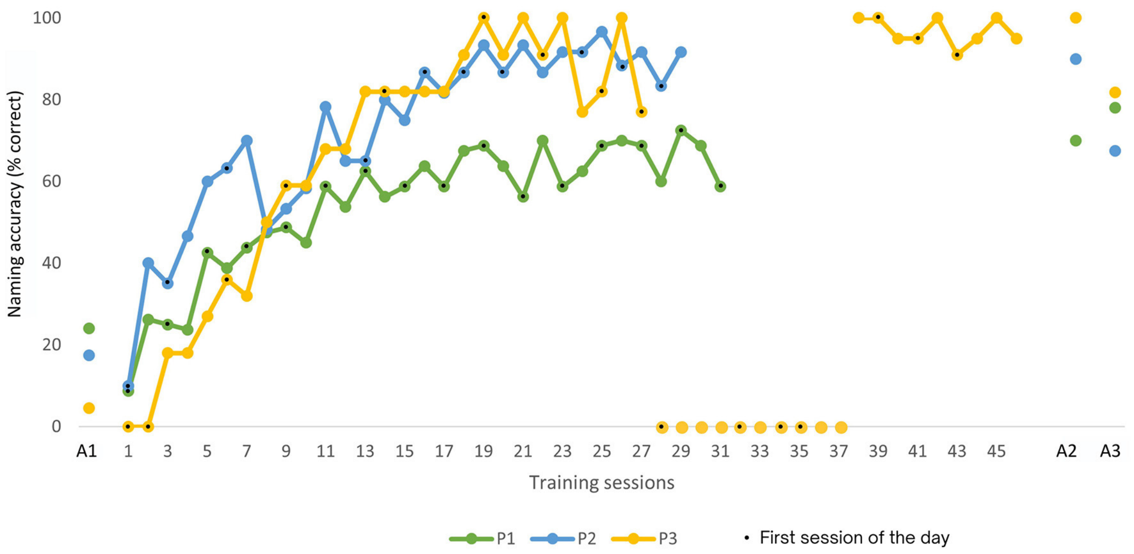


FIGURE 5
Improvement of naming accuracy during intervention, with A1/A2/A3 being baseline measures before/after/follow-up. Number of training sessions differed for P1 (*n* = 30), P2 (*n* = 29), and P3 (*n* = 46). Missing data for P3 in sessions 28–37 due to problems using the ASR.

5.2 Outcome measures

Naming accuracy for treated items continuously increased for all participants as depicted in Figure 5.

The percentage of non-overlapping data (PND) (Scruggs et al., 1987), indicating the number of training sessions where performance was better than in the initial baseline, exceeded 90% for all participants. Therefore, the improvement in treated items is considered highly reliable. Table 4 shows the results of the baseline measures before (A1), after (A2) and in a follow up (A3). The main result is that all participants showed significant improvement for treated items that sustained at least 5 weeks after treatment had been withdrawn. Generalization effects occurred to different extents.

P1 showed a significant improvement of naming accuracy for treated items (before: 12/50 correct vs. after: 35/50, $p < 0.001$, McNemar Test). This training effect was sustainable and naming accuracy 8 months after treatment was still significantly better than before (12/50 vs. 39/50, $p < 0.001$). Immediately after treatment, there was no generalization to untreated items that belonged to a treated category (4/30 vs. 9/30, $p = 0.074$), but the improvement became significant in the follow up-assessment (4/30 vs. 22/30, $p < 0.001$). There was no generalization to untreated items of an untreated category, but naming accuracy in the WPP (Blanken et al., 1999) improved significantly (30/60 vs. 48/60, $p < 0.001$). There are still very many word-finding difficulties in spontaneous speech although their amount decreased a little bit (from one in 1.54 phrases to one in 2.18 phrases and one in 5.3 phrases in the follow up). Assessment with the CAL (Pulvermüller and Berthier, 2008) could not detect any changes in P1's communication in daily life. As the performance in an unrelated control task [LEMO 2.0 T9, writing non-words by dictation (Stadie et al., 2013)] remained stable, the item-specific training effect and the generalization to untreated items and the WPP (Blanken et al., 1999) can be attributed to the intervention with LingoTalk and are not caused by some general or unspecific improvement.

P2 showed a significant improvement of naming accuracy for treated items (before: 7/40 correct vs. after: 36/40, $p < 0.001$). That improvement remained stable in a follow up test 5 weeks after treatment (7/40 vs. 27/40, $p < 0.001$). There was no generalization to any of the untreated items, including WPP (Blanken et al., 1999). Spontaneous speech analysis was not very informative as P2‘s reactions in baseline A2 were rather taciturn and brusque as she knew that she had answered the very same questions already before. While both the performance in the ANELT (Blomert and Buslach, 1994) and the external assessment of P2‘s communicative abilities (CAL) (Pulvermüller and Berthier, 2008) did not change, P2 herself reported that "she speaks much better" resulting in a significantly better self-assessment with the CAL (before: 35/65 points vs. after 51/65, $p = 0.001$, Fisher's exact test). Performance in an unrelated control task [WPP written naming (Blanken et al., 1999)] did not change, tracing back the item-specific training effect to our intervention.

P3 showed a significant improvement of naming accuracy for treated items (before: 1/22 correct vs. after: 22/22, $p < 0.001$). That improvement remained stable in a follow up test 6 weeks after treatment (1/22 vs. 18/22, $p < 0.001$). Improved oral picture naming generalized to naming by definition (1/18 vs. 12/18, $p = 0.003$), i.e. treated items improved sustainably in an untreated task. There was no significant generalization to any of the untreated items, including WPP (Blanken et al., 1999). The amount of word findings difficulties dropped from one in 5.05 phrases ("very many") to one in 6.85 phrases ("many"). The CAL self-assessment (Pulvermüller and Berthier, 2008) and the ANELT (Blomert and Buslach, 1994) could not detect any changes in P3's communicative behavior. Again, the performance in an unrelated control task [Lemo 2.0 T5, repeating non-words (Stadie et al., 2013)] remained

TABLE 4 **Results of baseline measures.**

		A1 (before)	A2 (after)	A3 (follow up)
P1	Treated items ($N = 50$)	12	35^{***}	39^{***}
	Untreated items/treated topic ($N = 30$)	4	9	22^{***}
	Untreated items/untreated topic ($N = 40$)	5	11	11
	WPP oral naming ($N = 60$)	30	48^{***}	50^{***}
	CAL self assessment (65 points)	49	51	Not tested
	CAL external assessment (45 points)	26	27	Not tested
	Control task: LEMO 2.0 T9 writing non-words to dictation ($N = 40$)	0	0	Not tested
	Spontaneous speech			
	No. of phrases	77	72	90
	No. of word-finding difficulties	50	33	17
	Ratio phrases/WFD (i.e. 1 WFD every $N = x$ phrases)	1.54	2.18	5.3
	Frequency of WFD according to Bayer (1986)	Very many	Very many	Very many
P2	Treated items ($N = 40$)	7	36^{***}	27^{***}
	Untreated items/treated topic ($N = 40$)	11	11	12
	Untreated items/untreated topic ($N = 40$)	5	3	4
	WPP oral naming ($N = 60$)	39	40	Not tested
	CAL self assessment (65 points)	35	51^{*}	Not tested
	CAL external assessment (45 points)	25	24	Not tested
	ANELT comprehensibility (40 points)	27	25	27
	ANELT intelligibility (40 points)	35	34	29
	Control task: WPP written naming ($N = 60$)	31	31	34
	Spontaneous speech			
	No. of phrases	55	40	69
	No. of word-finding difficulties	4	0	3
	Ratio phrases/WFD (i.e. 1 WFD every $N = x$ phrases)	13.75	Incalculable	23
	Frequency of WFD according to Bayer (1986)	Some	None	Hardly any
P3	Treated items (low frequency) ($N = 22$)	1	22^{***}	18^{***}
	Untreated items (low and medium frequency) ($N = 44$)	2	3	Not tested
	Treated items/untreated task (naming by definition) ($N = 18$)	1	12^{**}	10^{*}
	WPP oral naming ($N = 60$)	42	50	Not tested
	CAL self assessment (65 points)	41	43.5	Not tested
	ANELT comprehensibility (40 points)	33	30	31
	ANELT intelligibility (40 points)	38	40	29
	Control task: LEMO 2.0 T5 repeating non-words ($N = 40$)	33	31	29
	Spontaneous speech			
	No. of phrases	86	89	Not tested
	No. of word-finding difficulties	17	13	Not tested
	Ratio phrases/wfd (i.e. 1 WFD every $N = x$ phrases)	5.05	6.85	Not tested
	Frequency of WFD according to Bayer (1986)	Very many	Many	Not tested

$^{***}p < 0.001$, $^{**}p < 0.01$, $^{*}p < 0.05$ (McNemar); $^{\#}p < 0.01$ (Fisher's exact). WPP, Wortproduktionsprüfung (Blanken et al., 1999); CAL, Communication Activity Log (Pulvermüller and Berthier, 2008); LEMO 2.0, Lexikon modellorientiert (Stadie et al., 2013); ANELT, Amsterdam Nijmegen Everyday Language Test (Blomert and Buslach, 1994); WFD, word-finding difficulties.

stable and all improvement can be ascribed to the intervention with LingoTalk.

6 Discussion

Three participants with aphasia took part in an intervention using the speech-language app LingoTalk to improve lexical retrieval. Using PlanBe (Pfeiffer and Leisner, 2016), all participants were able to identify topics that were either of general interest or important in their daily life. Although PlanBe (Pfeiffer and Leisner, 2016) was originally developed for individuals who use AAC, it proved to be suitable and beneficial for clients with aphasia as well. LingoTalk's extensive database allowed for item selection tailored to the patients' individual needs. Floor or ceiling effects were avoided by adjusting the level of difficulty based on LingoTalk's item difficulty rating. Importantly, the training covered various part of speech as recommended by Renvall et al. (2013a).

The intervention with LingoTalk was supervised, but mostly self-administered by the participants. Therefore, we aimed to determine whether participants with aphasia could manage their app-based treatment independently. LingoTalk recorded how often and how regularly the participants named the treated items and tracked the naming accuracy for treated items in each session. The data demonstrated that all participants were able to use LingoTalk on their own, as each of them completed at least 29 training sessions within 3 weeks. If they could not name an item, they were able to make use of gradually increasing cues and decided themselves if they wanted to use phonological, semantic, and/or graphemic cueing. Digital technology enabled individuals with aphasia to actively and autonomously pursue their therapy goals. However, none of the participants followed the intervention protocol completely, resulting in a different number of training sessions in total and per day. This divergence might be attributed to motivational factors as indicated by participants' comments. P1 liked working with LingoTalk but found practicing on her own somewhat monotonous. She favored using the app in a face-to-face setting alongside her SLT. In the case of P2, practicing independently on a daily basis was demanding, leading to a decrease in motivation and occasional complaints. Nevertheless, she did not withdraw from the study. P3, on the other hand, enjoyed training on his own as he was "less nervous when there is no therapist present." After the treatment study concluded, he acquired a tablet computer of his own. He not only continued using LingoTalk but also started to use the internet, for example, for searching about his hobbies. The intervention with a digital application eventually sparked interest and instilled self-confidence for participating in digital services such as the use of search engines and websites.

The self-administered treatment using digital technology significantly increased the therapy frequency. Instead of six face-to-face sessions within 3 weeks, the participants completed 12 to 17 training days, which aligns much closer with the recommended minimum daily speech therapy dosage (Deutsche Gesellschaft für Neurologie, 2011). After a comprehensive introduction, digital technologies facilitate self-administered treatments that are mostly independent of therapists. This is especially beneficial in cases of a shortage of SLT services, for instance, in rural areas or when there is a lack of therapists. In such circumstances, digital technologies can ensure ongoing care.

Our second objective was to assess the effectiveness of the self-administered intervention using LingoTalk. Following a three-week intervention, all three participants showed improved lexical retrieval of practiced words. Stable performance in unrelated control tasks confirmed that the improvement could be attributed to the intervention. Consequently, we conclude that LingoTalk is a suitable app for improving word retrieval in aphasia for practiced material. The results are less clear when it comes to generalizations effects. There was no generalization to untreated items, except for P1 in the follow-up assessment. However, the lack of generalization to untreated materials, is in line with the literature [see Sze et al. (2021) for a review]. Training with LingoTalk re-established the connection between a semantic concept and its corresponding word form in the POL, as the participants repeatedly named the same set of pictures. While the LingoTalk intervention employed both semantic and phonological cues to facilitate word retrieval, there were no tasks that explicitly targeted semantic or phonological features and which could have triggered spreading activation within the semantic system or the POL. In this case, item-specific improvement without generalization to untrained materials is expected (Miceli et al., 1996; Howard, 2000). For one participant (P3), there is evidence of within-level generalization (Webster et al., 2015) for treated items in an untreated task: naming by definition improved after oral picture naming had been trained. Unfortunately, we did not collect such data for P1 and P2. Two participants (P1 and P3) showed fewer word-finding difficulties in spontaneous speech, as indicated by the ratio of word-finding difficulties to phrases, suggesting the possibility of across-level generalization (Webster et al., 2015).

All of the results should be interpreted with caution, as our study has several limitations. Firstly, the study is quite small in scale, involving only three participants. A larger sample size would provide more robust insights into whether individuals with aphasia can independently manage the LingoTalk intervention and its effectiveness. Future studies on LingoTalk should aim for greater methodological consistency. Our research originated from three separate Bachelor's theses, each investigating a single case, and as such, there were slight variations in methodology during both neurolinguistic assessment and intervention. For the purposes of this paper, we combined these three single cases *post-hoc* into one case series, resulting in some lack of coherence. For instance, different tests [AAT (Huber et al., 1983) and ACL (Kalbe et al., 2010)] were used to diagnose aphasia, making the patient profiles not entirely comparable. Treatment frequency and intensity differed among participants as none of them fully followed the treatment protocol. The participants also used different feedback modes (ASR vs. self-assessment) as one of them was not able to handle ASR. When this participant nevertheless attempted to use the ASR, he failed to do so without noticing. This led to missing data on naming accuracy in some of the training sessions. The efficacy of the intervention was demonstrated for treated items, but evidence for generalization is very limited. Generalization to treated items in an untreated task was only addressed for one participant, and generalization to spontaneous speech was based on a rather general, though established, indicator, i.e. the ratio of word-finding difficulties to phrases (Bayer, 1986). While our study investigated the effectiveness of an intervention with LingoTalk, it did not compare LingoTalk to other app-based interventions [e.g., neolexon (Jakob and Späth, 2023)] or to traditional face-to-face approaches.

Despite the study's limitations, it has yielded some interesting findings. LingoTalk is the first German speech-language app that incorporates ASR, enabling app-based evaluation and feedback in an oral picture naming task. ASR was successfully utilized by two out of three participants and offered the advantage of an immediate and objective feedback. The third patient relied on self-assessment and demonstrated a high level of reliability in evaluating his own responses. Both feedback modes provide an opportunity for patients to gain independence from their SLT. While there appeared to be an initial effect of having a supervisor present – the performance of all participants dropped in the first self-training session compared to their baseline performance – this effect did not persist over the long term.

Interestingly, the mode of feedback did not seem to influence treatment efficacy. However, the decision regarding the feedback mode should be made thoughtfully. Self-assessment requires a sufficient level of self-monitoring and honesty in evaluating incorrect responses. On the other hand, utilizing ASR demands coordination between button press and speech output which proved to be challenging for one patient. Therefore, both feedback modes should be individually tested with each patient to ensure reliable feedback.

The study revealed improved naming accuracy for treated items across all three participants. The most significant increase in accuracy occurred during the first week, followed by continued improvement in the second week, and finally, a consolidation in the third week. This pattern suggests that a two-week intervention might be sufficient to achieve ∼85–90% of the overall improvement. In the cases of two participants, P2 and P3, their accuracy rates exceeded 75% and remained stable after already 15 sessions, which could indicate a ceiling effect. This might have contributed to a sense of monotony in their training and potentially affected P2's motivation negatively. Implementing a dynamic item set (Conroy et al., 2009), where additional training items are introduced once others can be named correctly, might help maintain interest and engagement over a longer training period.

LingoTalk's evaluation screen provided patients with transparency regarding their progress, motivating them to persist with the treatment. Even when P1 and, to a greater extent, P2 faced challenges, they maintained their commitment to the scheduled training sessions. They realized that they became much faster in naming items over time, resulting in shorter training sessions. Although the number of practiced items varied significantly among participants, the initial training sessions took ∼45 min for all of them. This corresponds to the typical duration of a therapy session in standard outpatient care and should not be exceeded to ensure patient engagement.

The treatment with LingoTalk demonstrated robust and long-lasting practice effects but there was limited generalization to spontaneous speech. This outcome is probably not surprising since the treatment did not encompass any functional communication tasks. In future studies, it may be beneficial to combine the self-administered LingoTalk treatment with functional-pragmatic tasks conducted in a face-to-face setting with a SLT. One might think of this as an SLT variant of the flipped classroom model (Bergmann and Sams, 2012) where monotonous and learning-intensive content is made the responsibility of the learners. We are not aware of any scientific studies on "flipped therapies" in the context of SLT but Wu (2023) has introduced the idea from an SLT perspective. In a "flipped speech room," clients would practice specific sets of items intensively at home, while in-person sessions could focus on transferring these items into meaningful communication contexts. For instance, an SLT might create an item set for a simulated visit to the market in spring, which the client practices independently with LingoTalk. During face-to-face sessions, the SLT can then integrate these learned items into sentence structures or interactive communication tasks. Eventually, in an *in vivo* intervention, the SLT could accompany the client on an actual trip to the market to make planned purchases. Improving lexical retrieval through a self-administered, app-based treatment then aligns with a participation-oriented speech-language therapy approach, enhancing everyday communication as advocated by the International Classification of Functioning, Disability, and Health (ICF, World Health Organization, 2001).

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The study was conducted in accordance with the relevant institutional guidelines, including the EU General Data Protection Regulation (GDPR) and the Brandenburg Data Protection Act (BbgDSG), as well as the guidelines of the German Research Foundation to ensure good research practice. The participants have given their written informed consent to participate in this study and to the publication of the collected data in anonymized form.

Author contributions

JN developed the app LingoTalk. DS-A, JB, JH, and JN designed the treatment study. SA, TS, and DS-A compiled the treatment materials, guided and monitored the treatment of P1, P2 and P3 respectively, and collected the data. SA, TS, DS-A, JH, and JN performed statistical analyses of the outcome measures. JH and JN wrote the manuscript. All authors read and approved the submitted version.

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Conflict of interest

JN is the developer of the speech therapy app LingoTalk and managing director of the e-health start-up Lingo Lab UG (haftungsbeschränkt).

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fcomm.2023.1210193/full#supplementary-material

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Digital participation in traumatic brain injury: scoping review about assessment tools for computer-mediated communication

Julia Büttner-Kunert[1,2]*, Julia Royko[3], Katharina Resch[4], Nathalie Heider[2] and Zofia Falkowska[2]

[1]Department of Linguistics, Speech-Language-Therapy, Scientific Network Cognitive Communication Disorders in Traumatic Brain Injury, Ludwig Maximilians University, Munich, Germany, [2]Department of Linguistics, Speech-Language-Therapy, Ludwig Maximilians University, Munich, Germany, [3]Dr. Meilinger Speechtherapy Private Practice, Starnberg, Germany, [4]Neurological Clinic Bad Aibling, Department for Speech-Language-Therapy and Swallowing Disorders, Bad Aibling, Germany

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Lyn Turkstra,
McMaster University, Canada

*CORRESPONDENCE
Julia Büttner-Kunert
✉ julia.buettner@lmu.de

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Background: Individuals with chronic traumatic brain injury (TBI) are often affected by communication disorders which might have an impact on their social participation. Due to possible cognitive and communicative disabilities, as well as impairments of social cognitive skills, individuals with TBI have been observed to exhibit difficulties in maintaining and establishing social relationships, resulting in a greater risk of social isolation. This applies to both in-person as well as computer-mediated communication (CMC), which is considered an integral part of everyday life. Research on digital participation in the TBI population has focused on the possible challenges and barriers, but also on the benefits of CMC for social interactions. Guidelines from professional societies recommend questionnaires and checklists for assessing restrictions of communicative participation (e.g., ASHA, INCOG). However, there is no overview of whether the available instruments can capture digital aspects of participation or social media use in TBI.

Aim: In this scoping review, following the PRISMA criteria, we aimed to provide an overview over currently available instruments that help assess CMC use as a measure of digital participation in the TBI population.

Method: The databases Web of Science Core Collection, Ovid, PsycInfo and Psyndex were screened for publications between the years 2013 and 2023 with relevant search terms referring to social participation, assessment tools, CMC and the target group, in order to find suitable tools to assess digital participation in individuals with TBI. In a multistage selection process following the PRISMA criteria, the instruments found were examined in terms of items that assess digital participation. The outcome of the review is an overview of the status quo of potentially available instruments that capture aspects of CMC.

Results: Following a screening on title/abstract and full-text level, a total of 10 studies could be identified that present assessment tools that evaluate CMC use as a measure of digital participation in the TBI population. Said studies were analyzed and compared in terms of content according to the selected parameters.

Conclusion: Digital participation is an important aspect of everyday lives for individuals with TBI. Therefore, CMC should be an integral part of rehabilitation. The existing appropriate questionnaires uncovered in the current study should therefore be applied routinely to detect impairments in CMC and digital participation. Overall, however, there is still a great need for research in the field of CMC, both regarding methods for measuring digital participation disorders as well as resources.

Systematic Review Registration: https://www.germanistik.uni-muenchen.de/forschung/proj_gl/review_participation_tbi.pdf.

KEYWORDS

digital participation, computer-mediated communication, traumatic brain injury, cognitive communication disorders, assessment tools

1 Introduction

Traumatic brain injuries (TBI) are one of the most common neurological causes of disability and limitations in participation and quality of life (QoL) across all ages (McDonald et al., 2014; Anderson et al., 2019). TBIs can be caused by a bump, blow, or jolt to the head or a penetrating injury to the head, disrupting normal brain function (Marr and Coronado, 2004). Based on the affected person's clinically presented neurological symptoms, the severity of a TBI can be classified as mild, moderate, or severe (Centers for Disease Control and Prevention, 2015). Injuries resulting from trauma to the head can include focal lesions as well as diffuse damage such as axonal damage. In particular, areas of the frontal brain and temporal lobe (fronto-temporal regions) are often affected, with damage to various areas and functional circuits relevant to communication (Rosenthal and Hillis, 2012).

Due to the wide-ranging brain areas that can be affected, TBI can have an impact on several cognitive domains which in turn influence communication outcome (MacDonald, 2017). Among the most common consequences are impairments in processing speed, concentration, orientation, memory and working memory, attention, organization, reasoning, problem solving and social cognition (Salmond et al., 2005; Stocchetti and Zanier, 2016; MacDonald, 2017). Changes in cognition and communication have an impact on social participation, with studies reporting correlations between cognitive disturbances and decreased life satisfaction and social and communicative complications (Kilov et al., 2009). Individuals with TBI are reported to have fewer social contacts and difficulties in building or maintaining social relations, and to be at higher risk of experiencing social isolation (Brunner et al., 2015; Stocchetti and Zanier, 2016; Morrow et al., 2021b).

The combination of linguistic and cognitive deficits in TBI was described using the term "cognitive communication disorders (CCD)" (Togher et al., 2014). CCD refers to communication disorders in patients with neurological disorders who show impairments in both cognitive abilities (such as attention, memory, planning ability) and in processing language under various contextual conditions (American Speech-Language-Hearing Association, 2003; Christman Buckingham and Sneed, 2018; Büttner-Kunert et al., 2022). The main impairments in CCD are in the structuring and organization of communication processes, with cognitive, linguistic, and behavioral dysfunctions coinciding (Togher et al., 2014; MacDonald, 2017). Basal linguistic functions, such as phonological, semantic, or grammatical skills at word and sentence level usually appear preserved (McDonald et al., 2014; Togher et al., 2014).

Individuals with CCD have difficulties in understanding and producing conversations as well as written texts (Büttner, 2016; MacDonald, 2017). They find it difficult to understand information that goes beyond the content of individual sentences. They display problems in structuring content according to its relevance (Bootsma et al., 2021), to stay on topic, and to include the perspective of their dialog partners. CCD can be seen in a lack of a common thread, as well as in difficulties in "getting to the point" and "striking the right tone" (Togher et al., 2004; Gindri et al., 2014; Dromer et al., 2021; Büttner-Kunert et al., 2022; Elbourn et al., 2022). This is aggravated by the fact that individuals with CCD do not always fully perceive their communicative limitations and incoherence because they often lack the awareness for it (Büttner and Glindemann, 2019; Büttner-Kunert et al., 2021). Because of the described disturbances in the cognitive-linguistic interaction, CCDs therefore have a clear negative influence on the ability to act appropriately in different communication contexts. Therefore, CCD also constitutes a prototype of acquired "neuropragmatic disorders" (Bambini and Bara, 2012; Cummings, 2014; Bischetti et al., 2022).

After a TBI, heterogeneous changes in discourse behavior can occur, which have in common that people with TBI cannot attend to the communicative needs of their conversational partner. This can manifest itself in a tangential monolog-like discourse behavior or in the tendency to interrupt the interlocutor (e.g., in the presence of an impulse control disorder) or also in a very impoverished conversational behavior with few relevant utterances (Sim et al., 2013; Norman et al., 2022).

The limitations of a TBI affect not only in-person communicative situations, but also digital forms of communication and information processing (Flynn et al., 2019). Therefore, individuals with TBI belong to the population groups that are vulnerable to the "digital divide" (Duplaga, 2017). The term "digital divide" describes the differences in access to and use of information and communication technologies, especially the Internet, between different population groups that result from technical, socioeconomic and individual factors (Rogers, 2001). The digital divide was described on different levels: general access to the necessary technologies (first level), inequalities in actual use (e.g., scope, variety, and type of use) (second level), and inequalities in the utility gained (third level), i.e., how individuals benefit from participating in the digital world (Chuah et al., 2022).

Given the ongoing trend of increased digitalization in society, it may be expected that challenges in the context of digital participation in TBI will gain relevance. Therefore, the need for information regarding methods to measure digital participation will become even more important for speech and language therapy and for neurorehabilitation in general. In this context, it is important to consider that methods for surveying digital participation should also take into account different levels of the digital divide and also take into account the levels of participation as well as the level of activities within the framework of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2021). In this article, we focus primarily on the type of digital divide that manifests itself through differences in the "use" of computers and the internet (van Deursen and van Dijk, 2014). This so-called second-level digital divide (van Deursen and van Dijk, 2014; Cornejo Müller et al., 2020) is operationalized in this review as the use of CMC.

2 Digital participation in TBI

2.1 The TBI population

Under the ICF framework, communication disorders in individuals with TBI can be classified as impairment of body functions (b164: higher cognitive performance, b1670-b1679: cognitive linguistic functions), and impairment of participation (e.g., d350-d369: conversation and use of communication devices and techniques) (Rehadat, 2023). In particular, impairments in participation are considered to be pragmatic-communicative impairments at the level of interpersonal relationships and interactions (d730-d799) and significant life domains such as work, employment, or economic life (d810-d899) (Achhammer et al., 2016; Büttner-Kunert et al., 2022). Impairments in communicative abilities affect activity and participation depending on person- and environment-related contextual factors. Based on the rationale of the ICF, diagnostic approaches for the assessment of the level of participation have to be an integral part of the rehabilitation of people with TBI. Knowledge about such procedures is therefore essential to make the barriers and resources for successful communication more visible.

2.2 The concepts of digital participation and CMC

For the population of individuals with TBI, participation through digital means has been explored under the term of computer-mediated communication (CMC). This term refers to all types of communicative interactions conveyed by electronic devices such as smartphones, laptops or tablets (Flynn et al., 2019). The mediated information can be based on text, audios or videos, which are often used in order to establish or maintain social relationships or exchange information in personal or professional contexts (Flynn et al., 2019; Morrow et al., 2021b). One of the most predominant forms of CMC is social media, especially social networking sites (e.g., Facebook, Twitter), blogs (e.g., Tumblr) or online content communities (e.g., Youtube) (Baker-Sparr et al., 2018). Social media are characterized by user-generated content, that is to say, content is created by an interactive exchange of users for the purpose of sharing personal or non-personal information and providing feedback on other users' content (Kaplan and Haenlein, 2010; Brunner et al., 2015; Meshi et al., 2015; Baker-Sparr et al., 2018).

Social media use has strongly increased in recent years and can now be considered an "integral part of society" (Brunner et al., 2015). For example, more than 3 billion people world-wide use the most popular social media platforms Facebook, Twitter, and Instagram (Greenwood et al., 2016). The majority of users of social networking sites are adolescents and young adults between 14 and 25 years of age (Gupta and Bashir, 2018), but social networking is common among all age groups (Australian Communications and Media Authority, 2013). According to the most recent statistics of Eurostat (2023), the use of social media is very high among younger people: "Among younger people in the EU aged 16–24 years, almost 9 in every 10 participated in social networks (87%). This share ranged from 79% in Italy to 97% in Denmark" (Eurostat, 2021).

Social media and other forms of CMC have radically influenced the quality and nature of social relationships and communication (Baker-Sparr et al., 2018; Morrow et al., 2021b). As opposed to face-to-face communication, CMC connects communication partners independent of their geographical location, which is especially beneficial for individuals living in areas with low infrastructure or with restricted mobility (e.g., physical disabilities). The computer-mediated exchange can be partly asynchronous, which eliminates time constraints while planning and composing messages (e.g., e-mailing). CMC often provides fewer or no non- and paraverbal information (e.g., text messages), which leads to an emphasis of verbal content (Flynn et al., 2019).

In contrast to CMC and e-services, which mean a broad range of self-served technologies used by the general public, the term assistive technology refers to means that are specifically targeted toward individuals with cognitive or other impairments (Evald, 2015; Eghdam et al., 2016; Chuah et al., 2022). Building on the possibilities and challenges of technology use in patient populations such as the TBI population, there have been considerations about which tools can be utilized for therapy interventions or rehabilitation (Wong et al., 2017). The most common devices explored in this context are smartphones, mobile phones, tablets, computers, and, less commonly, pagers, voice recorders or personal digital assistants (Evald, 2015; Wong et al., 2017). Smartphones in particular, being in the possession of almost two thirds of the inhabitants in developed countries like the UK, have potential as an important kind of assistive technology, including benefits of mobility, portability and widespread use (Wong et al., 2017). The functions of smartphones, such as the use of active visual and auditory reminders, have been used in the context of memory impairment in TBI (Evald, 2015). Assistive technologies have been actively applied in internet-mediated rehabilitation, whose relevance has drastically increased during the pandemic years. According to a definition by Ownsworth et al. (2018), telerehabilitation refers to any kind of rehabilitation method which makes use of communication technologies over distance, such as phone-calls, messaging, or multimodal systems like video-calls and interactive web-platforms. Telerehabilitation comprises online measures (e.g., therapy sessions on a video call) or offline measures (e.g., self-reliant exercises on a web-based platform).

2.3 CMC in TBI

As opposed to in-person communication, CMC has been suggested to alleviate the communicative and social consequences of TBI (Baker-Sparr et al., 2018). A relevant observation here is that regular internet use is almost as common in individuals with TBI than in non-injured peers (Eghdam et al., 2016), and smartphones are used in comparable percentages as in non-injured peers (Baker-Sparr et al., 2018).

An advantageous aspect of CMC for individuals with TBI is that there is a variety of communication forms in synchronous and asynchronous formats available, relying to a different degree on written language, visual or auditory modalities (e.g., posting content on a blog, video-call via Skype). As a possible adaptive skill, users may choose the channel that meets their communicative needs best (Brunner et al., 2015). Consequently, individuals with TBI can "engage in social interactions on their own terms" (Tsaousides et al., 2011).

Certain communicative aspects of CMC may be especially advantageous for individuals with TBI as opposed to face-to-face interactions. For instance, some CMC formats like messaging rely on short written messages with little demand concerning correct spelling and grammar. This might lower the threshold to participate via technology for individuals for whom literacy is challenging. Also, written messages in asynchronous communication formats cause the interaction to be less constrained by time pressure and potentially less dependent on visual social cues (Brunner et al., 2015). The latter aspect might be especially relevant to individuals with TBI who have difficulties in interpreting social signals (Morrow et al., 2021b).

Summarizing the results from 16 studies, Brunner et al. (2015) reported that the social media use of individuals with TBI did not differ qualitatively from non-injured peers concerning the main purpose, which was maintaining social contact with friends and relatives. There is strong evidence that technology-based social media support can reduce both the physical and psychological burdens of loneliness (Morrow et al., 2021b).

However, cognitive communication disorders in TBI might impact CMC use and digital participation beyond already present challenges in real-life social interactions. In particular, participants with moderate and severe forms of TBI have been reported to use the internet or social media less frequently than peers (Brunner et al., 2015; Morrow et al., 2021b). Next to the severity of injury, some demographic factors were held responsible for less frequent use of social media, such as older age, lower income and rural residence (Baker-Sparr et al., 2018).

Additionally, person-related factors such as "low levels of skill, confidence, knowledge, and interest" (Chuah et al., 2022) were discussed to account for lower rates of internet or social media use in TBI. Both cognitive and communicative abilities can have an impact on CMC and digital participation. The successful use of CMC requires the general access and ability to utilize devices, for instance fine-motor skills and high-level cognitive functions like working memory, selective attention and self-regulation (Flynn et al., 2019). On the user level, CMC poses additional requirements as opposed to face-to-face interactions. The accessibility of internet services and websites requires the processing of complex visual stimuli, which might represent a challenge for individuals with visual or text processing impairments (Robertson and Schmitter-Edgecombe, 2017; Ketchum et al., 2020; Brunner et al., 2022). Constantly changing content (especially on social media sites) can be especially demanding in the presence of memory or learning impairments. Attention deficits make it difficult to filter out relevant information (Morrow et al., 2021b). Synchronous formats like live-chatting might pose higher time-constraints on the individuals than asynchronous formats like posting content on a social media site.

CMC in TBI also poses specific demands on social cognitive skills. Many forms of social communication require the abstraction from literal meaning and social inferencing (Morrow et al., 2021b). As opposed to face-to-face interactions, some forms of CMC (f. e. messaging) focus verbal content only, without providing additional paraverbal or non-verbal information. This increases the need of text processing and inferencing skills and might potentially contribute to miscommunications, as reported by participants in the study of Morrow et al. (2021a). Other forms of CMC (f. e. video calls), by contrast, require the ability of processing social signals like gestures or facial expressions, similarly to in-person interactions. As social cognition deficits are a common sequelae of TBI, this makes those formats potentially demanding for individuals concerned (Morrow et al., 2021b).

Overall, CMC has been discussed to have both facilitating and hindering aspects as compared to in-person interactions. It is not yet clear how these factors apply to the heterogeneous population of TBI, with individuals varying in injury-related characteristics and person-related features. Next to more general information about the frequency of use of different devices and internet-based applications, there is a need to evaluate the quality and effectiveness of CMC in the TBI population, and how user profiles change in the presence of cognitive and communicative impairments (Flynn et al., 2019). A deeper understanding on the actual benefits and challenges of CMC, as well as the development and use of adaptive strategies, are beneficial resources to improve digital participation within TBI (Morrow et al., 2021b). Based on this information, adaptive strategies like "how to use social media and how to stay safe" or "using techniques that support recall and retention" (Brunner et al., 2022) could be implemented in rehabilitation in the long-term.

2.4 Aim of the review

The aim of this scoping review is to provide an overview of currently available instruments that help to assess CMC use in adults with TBI of all degrees of severity. We assume that an increased quantity or quality of CMC use indicates a higher degree of digital participation, that is, individuals make use of CMC to interact and be involved in social interactions via digital means. This could also be associated with a higher real-world participation, but could also compensate for a lack of real-world social interactions (Ketchum et al., 2020). The instruments found in the review process will then be presented in their construction and objectives and evaluated in terms of their potential and limitations. Finally, recommendations for the assessment of CMC will be given and research gaps in this field will be identified.

3 Methods

Since the aim of this study was first to obtain an overview of the instruments available that capture CMC, the method chosen was a scoping review. Scoping reviews provide an impression of the state of the research literature on a particular topic. In contrast to systematic reviews, scoping reviews give an overview of existing evidence without assessing the methodological quality of the included studies (Elm et al., 2019). We used the PRISMA extension for scoping reviews (PRISMA-ScR) to report our results (Tricco et al., 2018). The PRISMA-ScR data sheet is provided in the Appendix.

3.1 Search strategy

Prior to conducting the scoping review, a search of relevant databases was executed to examine the availability of existing and comparable reviews on the topic. In the Cochrane database and the ClinicalTrials.gov database, no reviews were found that dealt with available instruments and questionnaires for the survey of digital participation in the target TBI population. Reviews that are related in content, e.g., the review by Brunner et al. (2015), emphasize the relevance of CMC for the participation of people with TBI, but do not provide an overview of concrete instruments.

The literature search was conducted in four different databases during the period of 2023-01-16 and 2023-02-03. The databases used were Web of Science Core Collection, Ovid, PsycInfo and Psyndex. The arrangement of the keywords was discussed by the authors and finally combined with the Boolean operators in the following manner: "traumatic brain injury" OR "head injury" OR "brain injury" OR "tbi" AND "chat" OR "social media" OR "digital participation" OR "computer mediated communication" OR "computer-mediated communication" OR "internet use" OR "messenger" AND "assessment" OR "screening" OR "survey" OR "questionnaire". The search strategy was performed on the title, the publication date of the literature was restricted from 2010-01-31 to 2023-01-31. We chose a time period comparable to a previous scoping review by this group of authors (Falkowska et al., 2021), covering the period from 2010 to 2023. Depending on the database, the results were either filtered by adulthood or filtered manually according to the age group. While we mainly targeted adult participants, we also decided to consider older adolescents. That means we also considered studies that enrolled individuals from 18 to 21 years of age.

3.2 Study selection

The first study selection process was conducted with the Rayyan program (Ouzzani et al., 2016). After deleting the duplicates, the titles and abstracts of 1,558 articles were evaluated for relevance. Each article was screened for eligibility independently by at least two reviewers. 1,545 articles were excluded on the basis of title and abstract, most frequently because of wrong population [no TBI or acquired brain injury (ABI)], wrong outcome (e.g., therapy/intervention study) or wrong study design (e.g., communicative assessment in TBI without relation to internet-based communication or interaction). 13 articles were selected for full text assessment as their content met the inclusion criteria for this review based on the respective title and abstract. Each of them was again screened for eligibility independently by at least two reviewers. From the 13 full texts, two had to be excluded since they did not relate to the target population (TBI). Furthermore, one study was excluded based on the full-text analysis because it was an intervention study. Thus, 10 full texts in total could be included.

3.3 Data extraction

In order to fulfill the goal of this review and provide an overview of the currently available instruments to assess CMC use as a measure of digital participation in the TBI population, the 10 included studies were examined as to the assessment tools used in each case. For this, the studies were briefly described in terms of the individual objectives and the individual study design at the outset. Subsequently, they were analyzed and compared in terms of content according to selected parameters: main applied measures, target group, sample size and research question(s)/aim(s) of the study (see Table 1). The main procedures were extracted from the studies and analyzed according to the following parameters: number of items, question types, duration of implementation and availability (see Table 2). In a next step, the procedures uncovered in the studies were examined as to their suitability for the investigation of digital participation in the TBI population. Finally, an overall overview of the potential and the limitations of the methods used in the studies was provided.

3.4 Data analysis and presentation

The included procedures were analyzed as to whether they examined Internet-based communication tools in the TBI population and were then summarized in tabularized form including some brief information about the respective target group, structure, and content of the items and questions.

3.5 Identification and selection

The study selection process is depicted in the following PRISMA flow diagram (see Figure 1).

4 Results

Following a screening on title/abstract and full-text level, we were able to identify ten studies which included nine assessment tools that met our inclusion criteria and examined the quantity and the respective objective of Internet-based communication tools in participants with TBI.

4.1 Aims of the studies

The specific objectives of the studies varied in detail (see section 4.3 Study Summaries for further information). Most of the studies had the goal to examine CMC-related aspects in individuals with

TABLE 1 Tabular overview of the finally selected studies and their main applied measures.

Nr.	References	Main applied measures	Target group	Sample size	Research question(s)/ aim(s) of the study
1	Baker-Sparr et al. (2018)	Internet usage survey, facebook intensity scale (Ellison et al., 2007)	Individuals with moderate-to-severe TBI	337 individuals with TBI	Investigating internet and social media use among individuals with moderate-to-severe TBI
2	Bedell et al. (2017)	Survey	Teenagers and college students with mild-to-severe TBI	6 teenagers with TBI, 7 parents of teenagers with TBI and 6 healthy teenagers, 7 college students with TBI and 13 healthy college students	Identifying barriers and strategies in social communication of teenagers and college students with TBI
3	Eghdam et al. (2016)	E-services questionnaire (ICT-CFQ)	Individuals with ABI	282 individuals with ABI (of which 113 with TBI)	Investigating frequency and quality of use of regular e-services and social media by individuals with ABI
4	Flynn et al. (2018)	Participation assessment with recombined tools-objective (PART-O) (Whiteneck et al., 2011)	Individuals with moderate-to-severe TBI	18 individuals with TBI and 16 informant friends,18 healthy individuals and 11 informant friends	Examining social participation, friendship quantity, and friendship quality of individuals with TBI
5	Flynn et al. (2019)	Participation assessment with recombined tools-objective (PART-O) (Whiteneck et al., 2011)	Individuals with moderate-to-severe TBI	25 individuals with TBI and 26 healthy individuals	Characterizing friendship networks, social participation and methods of communication (including CMC) used by individuals with TBI
6	Goverover and DeLuca (2015)	Internet use questionnaire, actual reality task	Individuals with chronic moderate-to-severe TBI	10 individuals with TBI and 10 healthy individuals	Assessing the prior experience with using a computer of individuals with TBI
7	Ketchum et al. (2020)	Internet usage survey (Baker-Sparr et al., 2018), participation assessment with recombined tools-objective (PART-O) (Whiteneck et al., 2011)	Individuals with moderate-to-severe TBI	331 individuals with TBI	Examining the association between social Internet use and real-word societal participation in individuals with TBI
8	Kilov et al. (2015)	Adapted computer user profile (Adapted CUP), based on the computer user profile (CUP) (Todis et al., 2005)	Individuals with moderate-to-severe TBI	16 individuals with TBI and 40 healthy individuals	Adapting the CUP for the use with healthy individuals and establishing test–re-test reliability measures of items on the original and adapted versions of the CUP when used by individuals with and without TBI
9	Morrow et al. (2021b)	Web-based survey	Individuals with chronic moderate-to-severe TBI	53 individuals with TBI and 51 healthy individuals	Characterizing how and why individuals with TBI use social media and CMC platforms, evaluating changes in CMC after TBI, and eliciting suggestions from individuals with TBI for improving access to social media after injury
10	Wong et al. (2017)	Smartphone survey	Individuals with chronic mild-to-very severe TBI	29 individuals with TBI and 33 healthy individuals	Investigating patterns of smartphone use amongst individuals with TBI, identifying potential barriers to use, and examining the relationships between smartphone use and daily functioning

TBI, Traumatic Brain Injury; ABI, Acquired Brain Injury; CMC, Computer-Mediated Communication.

TABLE 2 **Tabular overview of the tool characteristics.**

Nr.	Measure	Original authors of the tool	Reference(s)	Number of Items	Question types	Duration of implementation	Availability/publication
1	Internet usage survey	Baker-Sparr et al., 2018	Baker-Sparr et al., 2018, Ketchum et al., 2020	Not indicated	Not indicated	Not indicated	Not made available after request
2	Facebook intensity scale	Ellison et al., 2007	Baker-Sparr et al., 2018	8 items	5-point Likert scales, alternatively open-ended questions	Not indicated	Freely available (see http://www-personal.umich.edu/~enicole/scale.html)
3	Survey	Bedell et al., 2017	Bedell et al., 2017	20 items	Single-choice, multiple-choice, yes-no and open-ended questions	30–90 min	Freely available (see study appendix)
4	E-services questionnaire (ICT-CFQ)	Eghdam et al., 2016	Eghdam et al., 2016	17 items	Single-choice, multiple-choice and open-ended questions	Not indicated	Freely available (see study supplements)
5	Participation assessment with recombined tools objective (PART-O)	Whiteneck et al., 2011	Flynn et al., 2018, Flynn et al., 2019, Ketchum et al., 2020	24 items	5-point Likert scales	30 min	Freely available (see study appendix)
6	Internet use questionnaire	Goverover et al., 2010	Goverover and DeLuca, 2015	7 items	Single-choice and yes-no questions	Not indicated	Freely available (see study appendix)
7	Adapted computer user profile (adapted CUP)	Todis et al., 2005	Kilov et al., 2015	54 items	7-point Likert scales, nominal yes-no and categorical questions	Not indicated	Freely available (see study appendix)
8	Web-based survey	Morrow et al., 2021b	Morrow et al., 2021b	15 items	Multiple-choice, yes-no and open-ended questions	TBI group: 2x 30 min; NC group: 30–45 min	Freely available (see study supplements)
9	Smartphone survey	Wong et al., 2017	Wong et al., 2017	309 items	Multiple-choice and open-ended questions	Not indicated	Not published

TBI, Traumatic Brain Injury; NC, Noninjured Comparison participants.

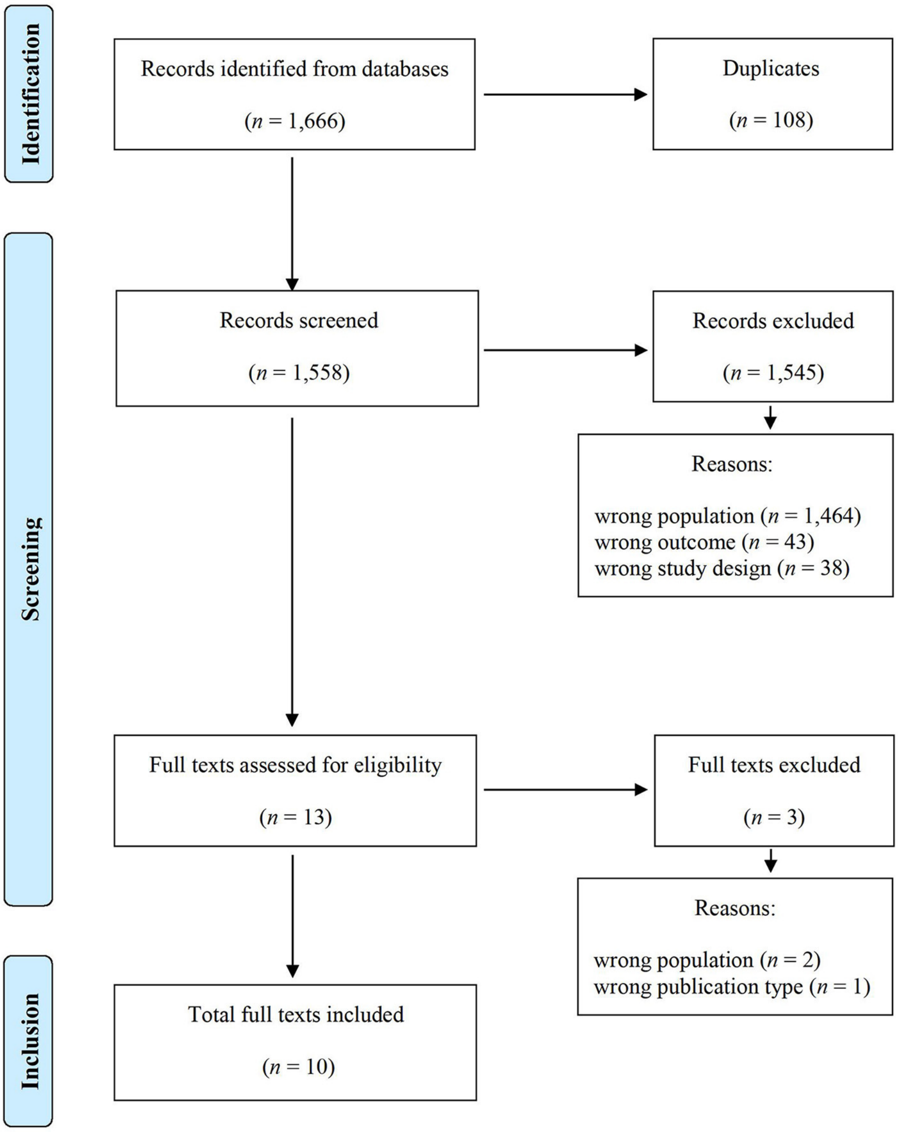

FIGURE 1
PRISMA flow diagram. From: Page et al. (2021). For more information, visit: http://www.prisma-statement.org/.

TBI and compare performance with healthy controls. In (2)[1], the questionnaire also served the goal to support the development of an app and coaching program. In (6), the questionnaire supplemented the more central measure of an Actual Reality Task. According to the different goals of the studies, the applied questionnaires and surveys differed in scope and in domains that were addressed.

4.2 Sample characteristics of the target group

According to our inclusion criteria, the target populations of all studies were individuals with TBI, most commonly in the chronic phase. Study (3) included individuals with ABI, of which TBI was the largest subgroup (40.07%). The severity of TBI of participants was moderate-to-severe (1, 4, 5, 6, 7, 8, 9), with all grades of severity from mild-to-severe (2, 10) or not specified (3). The grade of severity was determined most commonly by duration of loss of consciousness following the trauma, duration of posttraumatic anterograde amnesia, or the Glasgow Coma Scale (GCS) score (Teasdale and Jennett, 1974) (see e.g., 4). The trauma happened at least 6 months (4, 5, 9), or more than one year (1, 2, 6, 7), before the investigation. The period of brain damage was not restricted in (3) and (10), with varying periods from several weeks to more than 10 years post injury. In (8), time since injury was assessed but not reported. The number of participants with TBI ranged from 10 individuals (6) to 337 individuals (1). In more than half of the studies, performance was compared with neurologically healthy controls (2, 4, 5, 6, 8, 9, 10). Six cases (2, 4, 5, 6, 8, 9) involved

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[1] Numbers refer to 10 selected studies in alphabetical order, see Table 1.

age- and education-matched control groups and one case (10) involved only an age-matched control group. In two studies (2, 4), caregivers, relatives (e.g., parents), friends or professionals were also interviewed to provide a multiperspective approach to the respective research questions.

4.3 Study overview and summaries

In the following section, we provide a short summary of the finally selected studies and their main applied measures. Table 1 provides an overview of the procedures, structured according to the respective authors of the studies and the year of publication, the name of the procedure, the target group, sample size and research question(s)/aim(s) of the study. We included studies from countries worldwide that were published in either English or German.

Baker-Sparr et al. (2018) aimed to characterize the internet and social media use among adults with moderate-to-severe TBI. The participants were 337 individuals who had to meet the inclusion criteria of the Traumatic Brain Injury Model Systems (TBIMS) National Database. The authors developed a tool called Internet Usage Survey in order to assess the participants' internet and social media use. Key domains that were covered by the survey were types of online activity, use of social media as well as size of online community and intensity of use, modes of access, frequency and patterns of usage, barriers to online accessibility, and factors that prevent non-users from engaging in online activity. For the purpose of assessing the extent of social media use, the survey also included the Facebook Intensity Scale (FBI) (Ellison et al., 2007), which is an eight-item questionnaire that depicts an individual's extent of engagement with Facebook including the total number of Facebook Friends, minutes per day spent on Facebook as well as six Likert scale questions assessing emotional connectedness with Facebook. The authors also reported several limitations of the present study that might affect the generalizability of the results, such as a focus on quantity of internet usage and pre-injury level of familiarity with online technology (Baker-Sparr et al., 2018). The survey is supposed to be available via the TBIMS National Database but could unfortunately not be accessed due to technical problems with the Website.

Bedell et al. (2017) conducted a multi-site study with a total of 39 participants from five different participant pools. Information from different target groups (persons who had TBI, relatives, peer groups, professionals) was considered. The study included teenagers and college students with TBI over the age of 18, their parents and also age-matched teenagers and college students without TBI. The objective was to use feedback from questionnaires and interviews as part of an iterative design process to enable the development of a coaching app which was intended to improve social communication. The surveys focused on preferred activities and frequency of participation, barriers and facilitators to social participation, as well as cell phone and app use. Their results showed that individuals with TBI mentioned more barriers to social participation and fewer strategies to overcome those barriers than youth without TBI. A summary of the total 20 questions, which range from single-choice, multiple-choice and yes-no questions to open-ended questions, can be found in the appendix of the article by Bedell et al. (2017).

Eghdam et al. (2016) investigated the use of e-services in a group of brain-injured individuals ($n = 282$), where TBI was the most common cause ($n = 113$) of ABI. Given the lack of adequate survey instruments to assess the use and experience with e-services, the authors presented the ICT-CFQ, a self-developed questionnaire, comprising 17 items in the form of single-choice, multiple-choice and opened-ended questions asking about the quality and quantity of the use of e-services in individuals with ABI. The questionnaire was based on and cross-validated with information provided by the ICF, as well as medical experts' and rehabilitative professionals' opinions. Overall, about 89% of the 282 participants with ABI reported regularly using some kind of e-services on their personal computers, mobiles or tablets, of which the most popular types were applications for communication and e-banking, while reading (e-books) and health promotion service apps were the least popular e-services. Additionally, all participants filled out the Cognitive Failure Questionnaire (CFQ) (Broadbent et al., 1982), which the authors conducted to test how participants tackle everyday challenges in the presence of cognitive impairment. The authors found out that ABI participants who complained about strong challenges due to cognitive impairment nevertheless used e-services regularly. In the open answer section, participants reported advantages and personal challenges with e-service use, for example the risk of behavioral influence (e.g., risk of addiction), difficult design (e.g., information overload, unwanted pop-ups and advertisements) or technical issues (e.g., hardware problems, battery life). Eghdam et al. (2016) emphasize the high proportion of individuals with ABI rely on e-services while facing different types of challenges caused by cognitive impairment. They also point to a potential bias in the study, since individuals with strong challenges in the use of e-services may not have even participated in this online study. The ICT-CFQ questionnaire is available in the supplementary material of Eghdam et al. (2016).

Flynn et al. (2018) investigated social participation, friendship quantity and friendship quality of adults with TBI by including a group of uninjured adults. The authors examined 18 adults with moderate-to-severe TBI as well as consulted 16 of their friends. In order to be able to compare the results with those of healthy peers, 18 uninjured adults and 11 of their friends were consulted as well. Measures that were used consisted of the Participation Assessment with Recombined Tools-Objective (PART-O) (Whiteneck et al., 2011), the Social Network Questionnaire (SNQ) (Roberts and Dunbar, 2011), and the McGill Friendship Questionnaire (MFQ) (Mendelson and Aboud, 1999). The PART-O includes 17 items about the number of hours a week spent working or at school, the type and frequency of social activities, and if the individual has any intimate relationships or meaningful friendships. Each item must be scored on a 0–5 point Likert scale. The questionnaire takes approximately 30 min to complete, but the individual questions are however not freely available yet. The PART-O contains an item for Internet use and was therefore included in the search (see Table 3). The latter two assessment tools—SNQ and MFQ—aim to measure friendship quantity and obtain information about friendship quality (Flynn et al., 2018). Since none of the two methods mentioned explicitly measures the digital participation of the participants, they will not be discussed further here.

Flynn et al. (2019) published the results of an investigation with 25 individuals with TBI and 26 healthy individuals. The aim

TABLE 3 **Tabular overview of the tool characteristics and validity.**

Nr.	Measure	Development of the tool	Content of the tool	Application of the tool	Construct validity: does the tool reveal the opportunities and barriers for people with TBI in relation to digital participation?
1	Internet usage survey	Topic areas were generated based on previously published studies concerning internet use in TBI and general population. Tool contains items that were adapted from general population surveys as well as new items generated by experts in TBI	Key domains: types of online activity, use of social media, modes of access, frequency and patterns of usage, barriers to online accessibility, assistive devices and compensatory strategies, factors that prevent or deter non-users from engaging online	Suitability was first tested in cognitive interviews with 10 persons with TBI, later survey items were adapted based on the feedback. The final survey was applied by phone (93%), in-person (5%) and by mail (2%)	Items revealed potential barriers and opportunities, and confidence of internet use in participants with TBI
2	Facebook intensity scale	Original version created as part of an online survey applied to undergraduate students ($n = 286$)	Goal: assessment of extent of engagement with Facebook. Contains questions on total number of Facebook Friends, minutes per day spent on Facebook, and emotional connectedness with Facebook	Authors adapted the scale to fit for any social media platform, in case that Facebook was not the most visited one	The scale shows the quantity of social contacts and emotional dependence and time spent on Facebook (original version) or the most-visited social media platform (see adapted version by Baker-Sparr et al., 2018)
3	Survey	Survey served to systematically examine the perspectives of multiple stakeholders on social participation, with the goal to inform the initial design of the Social Participation and Navigation (SPAN) app and coaching program	Survey focused on preferred activities and participation frequency, barriers and facilitators to social participation, mobile phone/app use	Survey data was collected on paper or electronic	Survey informes about social participation barriers, supports and strategies, use of smart phones and apps or chat rooms, from the perspective of teenagers with TBI and their parents
4	E-services questionnaire (ICT-CFQ)	Design of the questionnaire was based on information from the ICF, ABI rehabilitation professionals' and medical experts' perspectives and existing questionnaires. Items were based on the most common and important problems for persons with ABI based on relevant chapters of the ICF	Experience with e-services, use of computers, mobile phones or tablets, preferences, positive and negative aspects of e-service use in daily life, social group memberships or e-services	First pilot testing with 2 individuals with ABI, revised	The tool reveals positive and negative aspects of the use of e-services and mobile devices, as well as social networks and social media use in the ABI population. In combination with the Cognitive Failures Questionnaire, individual challenges due to cognitive impairment can be estimated
5	Participation assessment with recombined tools objective (PART-O)	Created from a pool of items by combining the Craig Handicap Assessment and Reporting Technique (CHART), Community Integration Questionnaire version 2 (CIQ-2) and Participation Objective, Participation Subjective (POPS). After pilot testing, item were reduced considering infit and outfit values.	Three domains: productivity, social relations, and "out and about". Questions about the numbers of hours spent in work or school, type and frequency of social activities, intimate relationships or meaningful friendships	Pilot testing with 13 persons with TBI (interviewed in person or by phone)	The tool assesses general quantities of professional activity and social relations, with one specific question concerning quantity of internet use

(Continued)

TABLE 3 (Continued)

Nr.	Measure	Development of the tool	Content of the tool	Application of the tool	Construct validity: does the tool reveal the opportunities and barriers for people with TBI in relation to digital participation?
6	Internet use questionnaire	Not indicated	General and specific questions about previous experiences using computers and the Internet, and specifically querying about experience with purchasing airline tickets online, scores from 0 (no internet experience) to 21 (much internet experience)	Applied in combination with a Actual Reality task	The questionnaire only assesses the quantity of internet use and experience, however does not refer to quality, barriers or opportunities specific for individuals with TBI
7	Adapted computer user profile (Adapted CUP)	Kilov et al. (2015) adapted the tool from Todis et al. (2005) for the use in a control group, with the exclusion of items that referred to injury-related information (54 instead of 62 items)	Assesses the nature and frequency of social communication and computer and Internet use in persons with Acquired Cognitive Impairments. Four domains: demographics, social communication and activity engagement, injury-related information, computer use	In this study, an adjusted version of the CUP was administered on individuals with TBI and controls on two time points (second assessment 2 weeks later).	The CUP assesses the quantity and purposes of internet use, quality of use (typing habits), frequency of social contacts, barriers of computer and internet use. Section 3 of the CUP refers specifically to injury-related information, fit for individuals with TBI
8	Web-based survey	Included items from the Social Networking Usage Questionnaire (Gupta and Bashir, 2018) and an analysis of Facebook friend networks (Manago et al., 2012), with modification to some items to fit for TBI	Questions about social media platform use, activities on social media, types and quality of relationships with social media friends, perceived benefits and drawbacks when using social media, changes of social media use since injury. Active and passive use of social media is considered	As part of a larger project, participants answered up to 280 questions online (30 to 45 min, or two times 30 min for TBI participants)	The tool provides an assessment of quantity, purpose and barriers of social media use for individuals in TBI
9	Smartphone survey	Based on a survey conducted by Hart et al. (2004), examining the experience and attitudes of individuals with TBI with mobile devices	Duration and frequency of smartphone use and applications (application types: memory and organization, communication, entertainment, therapy), usefulness and purpose of apps and functions, smartphone use within rehabilitation settings, barriers of smartphone use, factors contributing to difficulty using the technology	Pilot testing with two TBI participants, refining based on feedback. Test-retest evaluation on six participants with TBI (1–2 weeks after first trial)	The tool assesses the general use of smartphones and applications types also concerning therapy and rehabilitation, barriers or facilitating technology in TBI

TBI, Traumatic Brain Injury; ICF, International Classification of Functioning, Disability and Health; ABI, Acquired Brain Injury.

of this study was to characterize the friendship networks and the social participation of people with TBI. Moreover, they analyzed which communication methods, including CMC, are used by adults with TBI. Social participation was measured also with the PART-O (Whiteneck et al., 2011) and the SNQ (Roberts and Dunbar, 2011) was used to measure the friendship quality. The participants additionally had to list the communication method they used when communicating with the listed friends. The authors found out that adults with TBI have smaller social networks and name face-to-face meetings as the preferred communication method (Flynn et al., 2019).

In their study, Goverover and DeLuca (2015) applied an Internet Use Questionnaire to assess prior experience with using a computer of individuals TBI and healthy individuals. To this end, they applied their questionnaire to ten individuals who had sustained a moderate-to-severe TBI at least one year prior to the study and ten healthy individuals. Both groups were demographically matched on age and education. Using seven items, the Internet Use Questionnaire captures one's previous experience with using computers and the Internet as well as one's experience with purchasing gifts and cookies via the Internet. For each item—single-choice or yes-no question—several answer options are available, each of which has a different score. The total score could range from 0 (no Internet experience) to 21 (much Internet experience). The questionnaire is freely available in a previous study by Goverover et al. (2010). Another component of the study by Goverover and DeLuca (2015) was the completion of a so-called Actual Reality task with the following objectives: First, to use the internet to perform an actual everyday life task, and second, to examine possible differences in the performance of individuals with TBI and healthy individuals. Although this task delivers some hints of the everyday use of the internet in the TBI population, it is not addressed in detail in this scoping review, which provides an overview over the currently available measuring instruments for assessing CMC use of individuals with TBI. A detailed description of the AR Task and their results can be found in Goverover and DeLuca (2015).

The objective of the study by Ketchum et al. (2020) was to shed light on the association between social Internet use and real-world societal participation in individuals with TBI. For the study, 331 participants with moderate-to-severe TBI were recruited. The authors assessed the social Internet use based on the items from Baker-Sparr et al. (2018). According to the amount of social Internet use, participants were divided into a group of social Internet users (n = 232) and non-users (n = 99). In a follow-up interview 1 year after the questionnaire assessment, Ketchum et al. (2020) administered the PART-O (Whiteneck et al., 2011), which provides subscales for productivity (e.g., employment), social relations and leisure and community activities. Also, the PART-O includes an item about Internet use in the Social Relations subscale. The authors observed that participants with higher participation scores according to the PART-O also reported higher levels of Internet use. Social media use was therefore interpreted as a supplement instead of a replacement of real-life-participation (Ketchum et al., 2020). The authors interpreted this association in the sense that "similar barriers and facilitators affect both online and real-world social participation" (Ketchum et al., 2020) in TBI cases. For example, impairment in memory, language or executive functions could affect both social media use and the ability to "initiate and maintain social relationships in the real world" (Ketchum et al., 2020).

The study by Kilov et al. (2015) examined the reliability of a computer and Internet survey (Computer User Profile, CUP) which was originally developed by Todis et al. (2005). With the CUP it is possible to assess the nature and frequency of social communication and computer and Internet activities. The CUP includes 62 items in four domains: (1) demographic data, (2) social communication and activity engagement, (3) injury-related information, and (4) computer use. Answer types varied from checking boxes on 7-point Likert scales to checking boxes on nominal yes-no or categorical questions. Likert scaled items asked how often participants engaged in social communication and leisure activities and how often they participated in computer/Internet activities (e.g., writing emails, using chat rooms, downloading music). Kilov et al. (2015) analyzed the responses to the CUP in individuals with moderate-to-severe TBI (n =16) and in an age- and education-level-matched control group (n = 40). For the control group, an adapted version of the CUP without injury-related items was applied. Kilov et al. (2015) showed that the CUP and the adapted version for non-injured participants have satisfactory test-retest reliability measures. Intra-class correlation coefficients and kappa coefficients were conducted to measure reliability of individual CUP items. The CUP questionnaire is freely available in the appendix of the study by Kilov et al. (2015).

As part of their study about CMC in adults with and without TBI, Morrow et al. (2021b) conducted a web-based Survey of 53 individuals with a chronic history of moderate-to-severe TBI (TBI group) and of 51 non injured peers (NC group). Both groups were demographically matched according to age and education. With the aforementioned survey the authors pursued three objectives: characterizing how and why adults with TBI use social media and CMC platforms, evaluating changes in CMC after TBI, and eliciting suggestions from individuals with TBI for improving access to social media after injury. In general, the survey consisted of up to 280 items, but in the context of the present study, the authors considered only 15 items that were relevant to social media usage and changes in usage related to TBI. These 15 items differ in their question types. Thus, in addition to multiple-choice questions, yes-no and open-ended questions also occur. The implementation took 60 min for the TBI group, divided into two times 30 min, and 30–45 min for the NC group. The short version of the Web-based Survey with its 15 items is freely available in the appendix of the study by Morrow et al. (2021b).

With their Smartphone Survey, Wong et al. (2017) aimed to analyze patterns of smartphone use amongst people with TBI, explore potential barriers to use, and examine relationships between smartphone use and daily functioning. The participants were 29 people with TBI in the chronic phase and 33 non-injured participants. The severity of the initial injury in the TBI group ranged from very severe to mild. The items were based on an earlier work by Hart et al. (2004), which included questions relating to self-reported needs for improvement and interest in portable technology. Additional items were derived from a pilot study with two participants with TBI, using their feedback to optimize the content of the Smartphone Survey. The resulting survey consisted of 309 items, using both multiple-choice and open-ended formats. Question topics covered duration and frequency of smartphone use and different app types ($n = 24$), perceived utility of different apps and features, and smartphone use in rehabilitation services. Barriers to smartphone use and factors contributing to difficulties in using the technology were also evaluated. The questionnaire was used in different ways, as an online survey, on the phone and in person. The individual questions of the survey have not yet been published.

4.4 Availability of the tools

Seven questionnaires applied in the studies were freely available, one questionnaire was not yet published (Smartphone Survey, Wong et al., 2017), and one was not made available by the authors after request (Internet Usage Survey, Baker-Sparr et al., 2018, with similar items used by Ketchum et al., 2020). All information concerning the questionnaires that were not available were second-hand, based on the information provided in the studies.

4.5 Characteristics of the tools

Within the studies analyzed, we found nine tools that met our inclusion criteria of assessing aspects of digital participation in TBI (see inclusion criteria in sections 3.1 and Supplementary material). All of the tools were self-administration questionnaires that can be filled out by individuals with TBI either online or in a printed version. All tools served to assess the frequency, quality and purpose of internet and/or social media use in TBI. Most tools aimed at the general internet use (f. e., Internet Use Questionnaire, Internet Usage Survey, Adapted Computer User Profile) or e-service use (see: E-Services Questionnaire). Other tools focused on social media (survey by Morrow et al., 2021b), or a specific social media platform [see: Facebook Intensity Scale (1)]. The Smartphone Survey by Wong et al. (2017) and also parts of the survey by Bedell et al. (2017) placed an emphasis on the general purpose, frequency and barriers of smartphone use. The PART-O aims primarily to assess general productivity and social relations and includes only one item related to digital participation. Typical questions within the questionnaires concern:

- frequency of internet or social media use (f. e., "In a typical week, how many times do you use the Internet for communication, such as for e-mail, visiting chat rooms, or instant messaging?", PART-O, Whiteneck et al., 2011);
- quality of internet or social media use [f. e., "Are you able to participate in Internet chatrooms?", Adapted Computer User Profile, (8)];
- purpose of internet or social media use [f. e., "I use social media for … (example: keeping in touch with friends and family)", survey by (9)];
- quality of social relations via internet or social media [f. e., "Do you use the Internet to connect with other people with similar cognitive problems?", E-Services Questionnaire, (3)];
- barriers or challenges of internet or social media use [f. e., "If you are not using a computer, why not? (example: visual problems)", Adapted Computer User Profile, (8)];
- benefits or potential of internet or social media use [f. e., "Do you use any Internet service that helps you with your forgetfulness, difficulty concentrating, or other cognitive problems?", E-Services Questionnaire, (3)].

The instruments applied had a number of items ranging from rather few items [seven items in the Internet Use Questionnaire (6)] to extensive questionnaires like the Smartphone Survey with 309 items (10). The questionnaires included different question formats such as Likert scales (4, 5, 8) or a mixture of single- and multiple-choice, yes-no and open-ended questions (2, 3, 6, 8, 9, 10). Frequently, Likert scales were used to elicit frequency of use or satisfaction with use [e.g., Adapted Computer Use Profile (8)].

While some questionnaires used items from existing questionnaires on social or digital participation (PART-O, survey by Morrow et al., 2021b, Smartphone Survey), other questionnaires were designed for the purpose of the specific study based on previous knowledge from existing research (f. e., Internet Usage Survey) or on the experience of rehabilitation professionals and medical experts (f. e., E-Services Questionnaire). Kilov et al. (2015) adapted the Computer User Profile for both the TBI and general population, as it was originally designed for a broader target group of individuals with cognitive impairments. The survey by Bedell et al. (2017) served the specific cause of assessing the perspective of both individuals with TBI and their relatives concerning social participation and smartphone use in the context of the development of a smartphone app and coaching program. As for the Internet Use Questionnaire (6), the development of the items was not further described. The internal consistency of the questionnaires (f. e., split half-analysis) was not reported in any of the studies. For the Adapted Computer User Profile (Kilov et al., 2015) and the Smartphone Study (Wong et al., 2017), the assessment was repeated 1–2 weeks after the first trial. Both author groups reported sufficient test-retest reliability. Interestingly, Kilov et al. (2015) found higher reliability coefficients for adults without TBI than for adults with TBI.

For external validation, additional measures like demographic variables and injury characteristics have been taken into consideration to varying degrees by all studies reported. In seven of ten studies, performance was compared with a healthy control group in order to reveal characteristics of CMC in individuals with TBI. In four studies, additional cognitive, emotional and social measures were applied. Next to the Smartphone Study, Wong et al. (2017) performed the Cognitive Failures Questionnaire (CFQ) in order to test verbal learning, emotional functioning, everyday functioning and self-reported cognitive performance. The authors reported more frequent use of memory and organization apps in TBI individuals who indicated poorer cognitive performance in the CFQ. Also, they found that TBI individuals who used communication apps more often reported themselves to be better socially integrated according to the Community Integration

Questionnaire (CIQ). Goverover and DeLuca (2015) conducted an actual reality task and examined information processing speed, episodic learning and memory, visual spatial memory, executive functions, emotional functioning, daily functioning and quality of life; however, no correlations between internet use experience and these measures were reported. Eghdam et al. (2016) assessed subjective cognitive performance with the CFQ and found TBI individuals who reported fewer cognitive complaints to use more e-services as indicated by their questionnaire. In order to evaluate the PART-O, Flynn et al. (2018) assessed quality and quantity of friendship relations with two additional questionnaires, but did not report interactions between PART-O and these measures.

5 Discussion

The aim of the present scoping review was to identify measurement tools that contribute to the assessment of CMC in individuals with TBI. In our study, CMC was considered as a means to assess digital participation in people with TBI. How little the field of CMC has been studied so far was evident from our review revealing only very few standardized assessments which can actually be used as questionnaires with precise instructions and which are characterized by test quality criteria. Many of the studies had a rather exploratory character with very high sample sizes and/or many items (e.g., Wong et al., 2017; Ketchum et al., 2020). These surveys served rather to identify suitable questions and items and can be seen as precursors for the development of questionnaires. These surveys are not suitable for routine use, as they are not standardized, use a lot of open-ended questions and are very time-consuming (sometimes between 60 and 90 min).

In relation to our research questions mentioned at the beginning, we can summarize that we found a total of 9 tools for the measurement of CMC in the specified search period. Of these, 7 are available for practical use (see Table 2). The majority of the methods can map the opportunities and barriers of CMC to varying degrees (see Table 3).

Concerning the target group, all questionnaires were applied to individuals with TBI. As for the examined populations, it should be noted with criticism that some of the studies conducted web-based surveys. This implies that only individuals with internet access and the ability to use technology were able to participate. Overall, this leads to a selection bias in the studies presented here by excluding severe cases of TBI or individuals with specific CMC complaints, which also means that the examined tools might be not suitable for the whole population of TBI (Baker-Sparr et al., 2018; Morrow et al., 2021b).

As for the validity of the tools, some of the studies have carried out further measurements in regards to criterion validity. Only Kilov et al. (2015) and Wong et al. (2017) provided test-retest-reliability measures for their questionnaires. Our examination revealed a need for studies that examine the validity, reliability, and objectivity of the surveys and questionnaires and that also take into account secondary criteria such as acceptance, fairness, economy, and robustness to social desirability. In general, a lack of standardized instruments, especially ones accompanied by normative data, can be identified. In the following, a brief overview of the opportunities and barriers of CMC which could be obtained from the selected studies will be given.

5.1 Challenges and risks of CMC for individuals with TBI

The use of CMC devices can present a challenge for individuals with TBI who suffer from cognitive impairments like memory changes, social cognitive impairments or communicative impairments. Adults with TBI report using social media less frequently than non-injured controls and being faced with challenges in social media access and use (Morrow et al., 2021b). At the same time, some studies report a high level of individuals with ABI regularly using Internet technologies, and depending on these every day (Eghdam et al., 2016).

Brunner et al. (2015) also addressed certain risks in the social media use for individuals with TBI. One important point is Internet safety: individuals with TBI are possibly at a higher risk of encountering online miscommunications, cyber-bullying, online scams, web-based manipulation or fraud. Another aspect is the risk of over-use and addictive behavior concerning internet or social media use, as possibly enhanced by changes in inhibition and self-regulation (Eghdam et al., 2016; Morrow et al., 2021b). In the social media context, TBI individuals have been reported to publish inaccurate or inappropriate content or violate confidentiality of information more often (Brunner et al., 2015).

5.2 Benefits and potential of CMC for individuals with TBI

Individuals with TBI may have a greater risk of encountering difficulties in CMC use due to linguistic or cognitive impairment, and of therefore becoming affected by the digital divide. At the same time, technology provides the potential to overcome barriers and constraints (Chuah et al., 2022). The benefits of availability, mobility, flexibility, and rapidity not only apply to users overall, but also to the use of CMC in TBI (Eghdam et al., 2016). Individuals can use communication technologies at a comparably low financial expense and can interact independently of their geographic location. Content-wise, communication technologies allow individuals with TBI to interact with online communities and groups of interest according to their needs, which allows them to get information or (peer) support in stigma-free environments (Brunner et al., 2015; Morrow et al., 2021b; Chuah et al., 2022). Especially younger individuals who engage in social networks rely on the use of CMC technologies (Bedell et al., 2017).

CMC can be actively used to provide an environment to generalize therapy skills. Technology-based interactions can be used as an additional, cost-effective means of training or monitoring communicative or cognitive skills addressed in therapy (Chuah et al., 2022). Therapy goals could both address the domain of activity (e.g., handling applications on a smartphone), as well as the level of participation (e.g., formulating messages in an online forum). For instance, smartphone functions like calendars and reminders can be used to improve organizational or memory skills

(Wong et al., 2017). Telerehabilitation allows for remote therapy opportunities from home (Chuah et al., 2022). Integrating the safe and effective use of CMC into rehabilitation as a therapy goal could possibly even serve as a means of increasing social participation for individuals with TBI (Morrow et al., 2021b).

Generally, the use of communication technologies is an integral part of life for individuals with TBI, allowing them to connect with family and friends. Eghdam et al. (2016) reported that the use of internet-based tools is not diminished, but equally important for people with TBI. Research points to higher satisfaction and lower grades of social isolation for individuals with TBI who use social media (Brunner et al., 2015).

5.3 Limitations of the study

One limitation of our study concerns our search strategy. Our specific criteria led to the generation of fewer but more relevant results. However, it must be mentioned that some measurement tools were not picked up by the applied search terms (see Appendix). While we did not explicitly assess the study quality of the articles we found, we do provide some information on the study design and content of the tools. The assessment of study quality could be the aim of a future systematic review. In contrast to systematic reviews, scoping reviews do not necessarily have to be registered (or cannot be registered at all, e.g., in PROSPERO). However, in order to improve transparency, future reviews should be registered in advance, e.g., in BMJ Open, which also publishes study protocols.

6 Conclusion

Our systematic data research revealed that there is a great need for research in the field of CMC in general, including methods for measuring digital participation disorders and resources. Based on our findings we recommend that the existing questionnaires should be applied routinely to detect impairments in CMC and digital participation. CMC should be an integral part of rehabilitation in TBI, as digital methods of communication are of great importance in society in general and also for teenagers and adults with TBI. In this context it is important to consider the benefits and risks of CMC use in TBI. Although this issue was partially addressed in the present study, a more in-depth investigation of the risks and benefits needs to be conducted in further studies. Individuals with TBI encounter similar risks in using CMC as the general population, as well additional challenges caused by linguistic or cognitive impairment. Generally, the same challenges apply for both computer-mediated, as well as face-to-face communication interactions. For example, impairments in memory, language or executive functions could affect both CMC and real-live relationships (Ketchum et al., 2020).

Next to possible challenges in CMC use in TBI, the use of communication technologies is equally relevant and also satisfactory for this population. Professionals should be aware of the relevance of communication technologies and also the possible need for assistance to ensure a safe and effective use for individuals with TBI. CMC goals "should be included in formal rehabilitation plans for people with TBI, both to improve peer interaction and to show patients how to minimize the risks of online activity" (Ketchum et al., 2020). The possible challenges and individual needs of individuals with TBI should be addressed and targeted in rehabilitation for both natural as well as technology-mediated communicative interactions.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

JB-K contributed to funding, conception, and design of the study. JB-K, JR, KR, NH, and ZF conducted the study retrieval and selection and wrote sections of the manuscript. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fcomm.2023.1221149/full#supplementary-material

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EDITED BY
Petra Jaecks,
Bielefeld University, Germany

REVIEWED BY
Elena Theodorou,
Cyprus University of Technology, Cyprus
Melissa McCarthy,
The University of Newcastle, Australia

*CORRESPONDENCE
Maria Barthel
✉ maria.barthel2@hawk.de

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Evidence-based decision-making in speech-language pathology via video-based telepractice—A qualitative video interaction analysis

Maria Barthel[1]*, Silke Wittmar[2], Bernhard Borgetto[2] and Juliane Leinweber[1]

[1]Health Campus Göttingen, Faculty of Engineering and Health, HAWK Hildesheim/Holzminden/Göttingen, Göttingen, Germany, [2]Faculty Social Work and Health, HAWK Hildesheim/Holzminden/Göttingen, Hildesheim, Germany

Introduction: In speech-language pathology, there is a constant need to make evidence-based decisions based on the patient's needs and goals, speech-language pathologist's clinical expertise, and external evidence. During the COVID-19 pandemic, it was possible for the first time in Germany to implement video-based telepractice in the outpatient care of speech-language pathology. This study aimed to find out how evidence-based decisions are made in video-based telepractice and what forms of evidence are used.

Methods: Speech-language pathologists who were working in outpatient services recorded their video-based telepractices for the research project. Five recorded video-based telepractices were transcribed using a simple transcription system and video interaction analysis was used to analyze the video recordings based on grounded theory methodology.

Results: Interactions between patients and speech-language pathologists are characterized by evidence-based decisions that can be observed. Speech-language pathologists make decisions based on their clinical expertise, patient-related experiences, and patient self-assessments. There is little evidence of negotiation between patients and speech-language pathologists to make joint decisions. Results showed that speech-language pathologists do not explicitly name external evidence to justify their decisions to patients. Shared decision-making is encouraged by a participative interaction between patients and speech-language pathologists. However, there was a predominant paternalistic interaction in which the speech-language pathologists made decisions on their own. To represent the decision-based interactions between patients and speech-language pathologists in a video-based therapy session, a process model was developed.

Discussion: Evidence-based and shared decision-making are important in speech-language pathology to provide patient-centered treatments. The exchange of information between the patient and the speech-language pathologist is important in order to make joint decisions based on these different levels of knowledge. In this way, the patient becomes an active participant in the digital treatment, in the video-based telepractice. As a result, the quality of care can be improved. Further research should reconstruct the implicit (possible) use of external evidence.

KEYWORDS

video-based telepractice, decision-making, evidence-based, speech-language pathology, digital participation, qualitative research, video interaction analysis

Introduction

During the COVID-19 pandemic, video-based telepractice was allowed to be provided as a telemedical service in an outpatient speech-language pathology (SLP) service for the first time in Germany. The implementation of video-based telepractice was an opportunity to maintain access to SLP service and thus reduce gaps in therapy due to reduce in-person contact. SLPs and patients needed to decide whether continuing therapy via video-based telepractice was feasible with the available technical resources and privacy considerations.

Video-based telepractice as a telehealth service (Gemeinsamer Bundesausschuss, 2020) is a synchronous form of therapy. It is delivered in real time via an audio and video connection, creating an immediate personal contact similar to in-person therapy (ASHA, n.d.). Video-based telepractice can be delivered to individuals with different types of disorders (e.g., aphasia, dysphagia, dysphonia, stuttering) and clinical conditions (e.g., Parkinson's disease, autism spectrum disorder) of different ages. Research findings have shown that there is high satisfaction and broad patient acceptance of patients of different ages in the use of video-based telepractice (e.g., Coleman et al., 2015; Rangarathnam et al., 2015; Wales et al., 2017; Sutherland et al., 2018; McGill et al., 2019; Theodoros et al., 2019; Weidner and Lowman, 2020).

Video-based telepractice is a digital form of therapy in which patients can digitally participate in health care (Neuhaus, 2022). Digital participation is defined in terms of having access to technical equipment (e.g., notebook, mobile phone) and a stable internet connection as well as the ability to use digital applications. Digital participation enables individuals to perform individually relevant activities in various areas of life and to become involved in their own life situation (Neuhaus, 2022; Steiner, 2023). To use video-based telepractice in outpatient speech-language pathology, patients and speech-language pathologists need the necessary hardware (e.g., laptop, PC, mobile phone, camera) and software (e.g., videoconferencing system, online therapy platform) and must be able to use them (Bilda et al., 2020; Lauer, 2020; Barthel et al., 2021b). However, financial, structural and personal difficulties (e.g., unreliable internet connection, limited financial resources, low digital literacy) can limit access and skills and make digital participation in healthcare difficult (Neuhaus, 2022; Steiner, 2023).

This article examines how decision-making occurs in patient-clinician interactions with patients of different ages and clinical indications in video-based telepractice to examine the possibilities of a successful digital participation for people with special needs. It focuses on how patients and clinicians are involved in decision-making and what components characterize a decision-making process.

Decision-making in speech-language pathology

Decision-making processes in SLP should involve multiple forms of evidence to make informed decisions in patient care.

Evidence-based practice in SLP

Evidence-based practice (EBP) "is the conscientious use of current best evidence in making decisions about the care of individual patients or the delivery of health services" (Cochrane, 2011). EBP in SLP has been described as being guided by three core components (ASHA, 2004, 2023; Dodd, 2007; Dollaghan, 2007):

1. The best available evidence from systematic research is called external evidence, current best evidence or external scientific evidence.
2. The knowledge and experience of SLPs and their professional and communication skills needed in the therapy process to make shared decisions is referred to as clinical expertise.
3. Patient interests, needs, circumstances, priorities, expectations are called client value, evidence concerning the preferences of a fully informed patient, client preferences or client perspectives.

Higginbotham and Satchidanand (2019) criticized this understanding of EBP for not distinguishing between clinical expertise and patient-specific evidence. They argued that internal evidence— systematically generated data from patients in the therapy process—should be considered separately, to emphasize its importance in decision-making during the therapy process. They also propose combining clinical expertise and clinical opinion as one expression (Higginbotham and Satchidanand, 2019). Fissel Brannick et al. (2022) noted in their scoping review that there is still no consistent distinction or conflation of internal evidence, clinical expertise, clinical opinion, or evidence internal to clinical practice in the literature, which can lead to uncertainty for therapists in evidence-based decision-making.

Therefore, the advanced EBP model (ASHA, 2023) defines three components. Firstly, the "patient's and caregiver's perspective", which includes the patient's values, individual circumstances, perspective of the caregivers. Secondly, it includes "evidence (external and internal)", where external evidence refers to best current scientific literature and internal evidence refers to information from subjective observations or objective measurements about patients gathered during the treatment process. Thirdly, the "clinical expertise" refers to e.g., knowledge from education or critical thinking from professional experience.

Concepts of decision-making

Decision-making processes should be based on EBP. Decisions must be made throughout the therapy process (e.g., diagnosis, intervention, counseling). There are two well-known concepts of decision-making: evidence-based decision-making and shared decision-making.

Evidence-based decision-making (EBDM)

Evidence-based decisions should be based on external and internal evidence, clinical expertise, and the perspectives of patients and their caregivers (ASHA, 2023). As a result, they can provide quality services that reflect people's values and needs. Evidence-informed decision-making in clinical care and health systems has evolved from EBDM. This development focuses on the fact that other factors (e.g., institutional context, equity, feasibility, affordability, sustainability) should be included in the decision-making process; this is in addition to the forms of evidence mentioned so far [World Health Organization (WHO), 2021]. Emphasis is on a reflective approach to the sources of information (e.g., clinical care, health systems) on which decisions are made.

Shared decision-making (SDM)

SDM involves clinicians and patients making decisions together based on the best available evidence. Patients are encouraged to think about treatment options, the benefits and limitations of each option, and to communicate their preferences. Patients' autonomy is respected and their involvement is enhanced (Elwyn et al., 2010; Elwyn, 2020). Key components of SDM are (1) understanding what constitutes a decision and acknowledging decisions, (2) communication and collaboration among all involved persons, and (3) existing power and dependencies (e.g., professional role, status, knowledge) between patients and clinicians (Elwyn, 2020). Thus, SDM focuses on the social interaction among all parties involved in the decision and all the associated knowledge bases and forms of interaction.

Both concepts, EBDM and SDM, serve to ensure that patients receive high quality care that is based on the best available evidence. While EBDM focuses on the incorporation of diverse evidence into decisions (ASHA, 2023), SDM aims to ensure that patients are fully informed so that they can share decisions with professionals (Elwyn et al., 2010, 2012). In a systematic review, Stacey et al. (2017) show that SDM results in, e.g., patients becoming more knowledgeable, more confident in their decisions, and more actively involved in the decision-making and care process.

Decision-making and ICF

In person-centered health services for children and adults, the International Classification of Functioning, Disability and Health (ICF) can be used as a classification of health and health-related conditions. The ICF is an international framework for organizing and documenting information on functioning and disability. This model provides a multi-perspective, biopsychosocial approach that describes (1) functioning and disability in terms of the body (=body functions and structures) and activities and participation, and (2) contextual factors (=environmental, personal) (World Health Organization (WHO), 2013).

Using the ICF model, SLPs can systematically gather and link information from the different levels of the ICF model with information from external evidence, clinical expertise, and patient preferences in decision-making processes, e.g., when determining therapy goals, to measure patient-reported outcomes (Threats, 2008, 2012). This practice in decision-making can support striving for independent living and social participation for patients and thus pursue the fundamental goal of speech-language pathology (Threats, 2008, 2012).

Influences in decision-making processes

In addition to the two concepts of decision-making and the ICF model, it is also interesting to consider whether and how EBP and other factors influence the clinical decision making of SLPs. In SLP, clinical decisions should be made with the patient and, when appropriate, the family member. This is intended to increase patient participation in SLP and ensure therapeutic success (Günther, 2013; Furlong et al., 2018). This goes far beyond the mere provision of information by patients and the naming of their ideas as forms of participation. In ICF-oriented and evidence-based therapy orientation and goal setting, as well as in complex disease manifestations, the continuous inclusion of patients' needs and their involvement in decision-making is required in order to do justice to the individuality of the patient (Günther, 2013). Furlong et al. (2018) also emphasize that clinical decision-making processes in in-person services with children with speech and language disorders must be deeply individualized. As EBP is a patient-centered approach, evidence from research and clinical evidence must be continuously related to the needs of individual patients (e.g., values, preferences, living environment). This dynamic process enables individualized and evidence-based healthcare (ASHA, 2004).

Selin et al. (2019) present that various clinical factors of children (e.g., using verb tenses, forming complex sentences) influenced SLPs' decision-making process when diagnosing and treating children with specific language disorders. Thus, the characteristics of the children influenced the decision-making process more than the characteristics of the SLPs. Nevertheless, practice-based evidence as a characteristic of SLPs (e.g., clinical experience, qualifications, colleague opinion) strongly influences the clinical decision-making process (McCurtin and Clifford, 2015; Selin et al., 2019). Similarly, the interpretation of diagnostic results and the interpretation of clinical symptoms influence the decision-making process (Selin et al., 2019). McCurtin and Clifford (2015) illustrate that SLPs with additional qualifications and long-standing professional experience made treatment decisions based on scientific knowledge and paid less attention to patient preferences.

In addition to external evidence and patient and clinician characteristics, workplace conditions influence the decision-making processes of SLPs. Time pressure, task density, guidelines, prescribed treatment pathways, ethical and financial considerations, etc. influence clinical decision making in the diagnostic and therapeutic process (McCurtin and Clifford, 2015; Furlong et al., 2018; Selin et al., 2019). McCurtin and Clifford (2015, p. 1179) assume that "pragmatic and contextual reasoning" emerges from workplace conditions and influences decision-making processes.

Aim of the study

The aforementioned literature focus on the various components of EBP and factors that influence clinical decision making in in-person service. In March 2020, it became possible for the first time in Germany to offer and perform video-based therapy in outpatient SLP. Due to the COVID-19 pandemic, a temporary special permit was granted to offer video-based telepractice to people with certain disorders (e.g., voice disorders, orofacial myofunctional disorders, stuttering, aphasia). Because (evidence-based) decision making in SLP is a relevant topic in literature and research, it is relevant to investigate how different forms of EBP and other factors influence SLPs' decision-making processes in video-based telepractice. The research question of the study was: how do decision-making processes occur between patients and SLPs in video-based telepractice in outpatient service, and what components of evidence do they take? The aim of the study was to conduct the first analysis of video-based telepractice in outpatient SLP services during the COVID-19 pandemic in Germany. Of particular interest was how evidence-based decision-making was realized.

Therefore, a qualitative research design was chosen to answer the research question in a methodological appropriate manner.

Materials and methods

This paper reports on data collected within the research project "Videotherapie in der ambulanten logopädischen Versorgung" (ViTaL). The research ethics committee of the University of Applied Sciences and Arts Hildesheim/Holzminden/Göttingen (HAWK) approved this study. The data represented in this study are based on a video interaction analysis (Tuma et al., 2013). Here, five recorded video-based telepractices were analyzed to describe how evidence-based practice, specifically decision making, occurs in video-based SLP.

Methodological framework

Qualitative research is used to explore issues or phenomena and to describe their characteristics, complex relationships, contextual conditions, and subjective experiences and meanings in order to understand the issue or phenomenon (Creswell, 2007; Maxwell, 2013). In qualitative social research, there are various methodological approaches (e.g., ethnography, phenomenology, grounded theory, narrative research), which are well known in the social, behavior, and health science literature. Each approach offers a systematic procedure based on methods described in the literature, so that data collection and data analysis are not carried out arbitrarily, but comprehensibly and according to criteria for qualitative social research (e.g., inherent openness, flexibility, *adequacy)* (Creswell, 2007; Maxwell, 2013). The research process is framed by a theoretical paradigm (e.g., constructivism, hermeneutics). The selection of the theoretical paradigm is based on the research topic and forms the methodological framework of the research process. From this, research strategies (e.g., ethnography, phenomenology, participation observation) and methods of data collection and analysis (e.g., interviewing, observation, focus group, textual analysis, visual analysis) are determined (Creswell, 2007).

Ethnographic research as an approach of qualitative-interpretive research observes social interactions and describes the commonly developed and shared patterns of behavior, values, language, beliefs, etc. of people or groups. The meaning of these patterns in the respective context is examined (Creswell, 2007; Knoblauch and Schnettler, 2012). There are different types of ethnography, e.g., realistic ethnography, autoethnography, confessional ethnography, visual ethnography (photography, video) (Creswell, 2007). The methodology of interpretive video analysis is influenced by the ethnomethodological tradition of conversation analysis. It reconstructs the practices that people use in their everyday lives to make themselves understood by other people. Through these familiar practices, through interaction and reflection on actions, people generate a construction of social reality. The social structures of this reality have to be considered in their situational context (Knoblauch and Schnettler, 2012; Tuma, 2018).

Ethnographic research methods are described in the literature on speech-language pathology care, such as the ethnographic interview (Westby et al., 2003) or the qualitative and/or quantitative analysis of video recordings of in-person therapy with people with aphasia (Merlino, 2021) or home-based video recordings of typical everyday situations of children with language development disorders (Overby et al., 2019) or of children with or without autism (Watson et al., 2013). However, video recordings are also used in seminars for SLPs to strengthen their observation and reflection skills through retrospective analysis (Stokes, 2013).

Participants

Outpatient SLPs were recruited by newsletter, social media, homepage, etc. of the Deutscher Bundesverband für Logopädie e.V. (dbl) (the official national professional association of logopedics in Germany) and other research networks (e.g., working groups, students, alumni) (Figure 1). SLPs were asked to record their video-based telepractices.

In May 2020, nine interested SLPs were introduced to the entire project and its requirements, during an online video conference. They were given a written description of the project, the informed consent form, and the privacy policy to participate in the project. For all documents, there was a version for the SLPs and a version for the patients. As the purpose of the study was to explore the decision-making process in video-based telepractice in outpatient service, the only criterion for recruiting patients was that their synchronous therapy had to be video-based. No other inclusion criteria were communicated to SLPs to recruit patients. The reason for this is that it was not possible to assess whether SLPs and patients would be willing to record the video-based telepractice because it was a new medium and some of the use of it was still uncertain.

Since no recordings of video-based telepractices had been made up to that point, recordings of all disturbance patterns, symptoms, therapy phases, etc. were considered relevant for the initial collection and analysis of this data material. Furthermore, the infrastructure (e.g., low internet capacity, software without recording mode), the additional organizational effort for the SLPs and the insight into the privacy of the patients could have argued against recording. Eight SLPs agreed to record video-based telepractice for one to seven patients each. From May 28, 2020, to July 30, 2020, the participating SLPs recorded 23 video-based

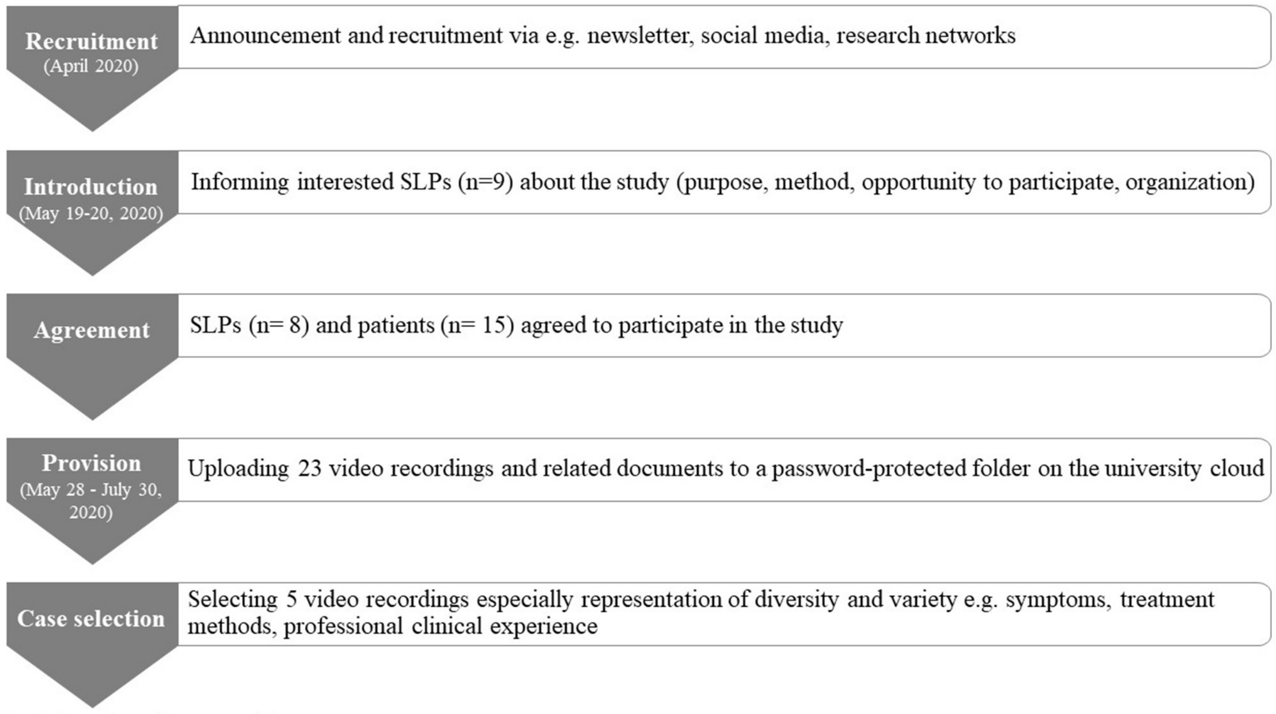


FIGURE 1
Process from recruitment to case selection.

telepractice sessions, which were provided to the researchers: one video recording of one patient at a time (SLP1, SLP3, SLP6, and SLP7), two video recording of one patient at a time (SLP5, SLP8), three video recordings from two patients (one from one patient and two from another) (SLP2) and 12 video recordings of seven patients (one to four recordings per patient) (SLP4). In addition, the SLPs completed a short questionnaire with sociodemographic questions about themselves as therapists and about their patients (Table 1).

SLP1 and SLP3 are students in their 6th semester of seven semesters of studying at a university. From the beginning of their studies, they observe SLP services and increasingly assume the role of therapist or co-therapist under the supervision of their teachers. The combination of professional knowledge, practical experience and critical reflection takes place from the beginning of the study in order to obtain their state license to work as a SLP at the end of the 6th semester. Thus, it can be assumed that the selected students are novices in the learning process of developing an understanding of EBP and skills for implementation of evidence-based decision making.

Data collection

The SLPs recorded the video-based telepractices either with the videoconferencing software they used (ZOOM: SLP1, SLP3, SLP4, SLP6, SLP7, and SLP8) or with the free software OBS (www.obsproject.com/de) if the telepractice could not be recorded with the videoconferencing software (e.g., RED connect: SLP2, Sprechstunde online: SLP5).

Each SLP received a link and password e.g., to upload the video files to the HAWK's password-protected cloud. One SLP (SLP4) was unable to upload the video files to the cloud because of a very weak Internet connection. These video files were encrypted on a USB flash drive and were sent by postal service. MB received the USB flash drive and uploaded the video files to the cloud. All video files were stored in the HAWK cloud by MB under anonymized labels.

Data selection

As more video recordings were provided than could be analyzed, 5 video recordings from different SLPs and patients were selected. Consideration was given to the principle of qualitative research to select cases for data analysis that represent the diversity of individuals, settings, or behaviors (Maxwell, 2013). Purposeful case selection was also guided by identifying variations in the typical population and then systematically selecting cases that represented the most important variations. Minimum and maximum variations were also considered.

Breidenstein et al. (2013) recommend and justify five case selection criteria in ethnographic research to select appropriate cases for analysis when faced with large amounts of fieldwork data. In the study, these criteria were followed to select SLPs and their patients for data analysis. Cases were selected at the level of individuals, specifically SLPs, because it was assumed that decisions in the therapy process are primarily made by SLPs and that decision-making processes are initiated by SLPs. The key criteria for this study were that the spectrum of the research field be

TABLE 1 Short questionnaire.

Information/SLP	Information/patient
Age (years):	Age (years):
Sex:	Sex:
What is your professional status? ○ Trainee ○ Student ○ Employee ○ Owner of an outpatient clinical practice ○ Freelancer ○ Others:	How long has the patient been in your outpatient clinic practice?:
What professional degree(s) do you have?:	What is the indication code on the current prescription for speech-language pathology?:
How long have you been working in your profession?:	What kind of symptoms does the patient have that are relevant to the speech-language pathologist's treatment?:
What is the main focus of your work as a SLP?:	What speech therapy content are you currently treating with the patient?:
How long have you been doing video therapy?:	How many total therapy sessions (in-person therapy and video-based therapy) have you conducted with the patient so far?:
How many sessions of video therapy have you conducted so far?: ○ 1–10 ○ 11–20 ○ 21–30 ○ 31–40 ○ 41–50 ○ 51–60 ○ 61–70 ○ 71–80 ○ 81–90 ○ 91–100 ○ >100	How many sessions of video-based therapy have you conducted with the patient so far?: In which phase of the treatment is the patient at the moment (taking the history, diagnosis, therapy/intervention, consultation, agreement on goals, completion, etc.)?:

represented by SLPs and patients, and that the data show decisions and decision-making processes in great detail. This approach followed an iterative process, using the five selection criteria in a circular rather than linear way (Breidenstein et al., 2013). This was in accordance with the basic principle of minimum and maximum contrast in qualitative research (Glaser and Strauss, 1998).

Case selection criterion 1: data quality

The selected cases (e.g., interview passages, video recordings) must be particularly rich in detail (Breidenstein et al., 2013).

In this study, the video recordings provide a detailed account of the therapy that took place and the interactions between patient and therapist. For data analysis, video recordings were selected in which decision-making processes (e.g., agreeing on the exercise modification, demonstrating different exercise options) or decisions made (e.g., determining the next exercise, determining the exercise modification) were evident. In the selected video recordings, the results of making decisions with or without giving reasons (SLP1 to SLP8) and of negotiating and deciding together (SLP1, SLP3, SLP5) were identifiable. Due to existing shared decision-making processes, the records of SLP1, SLP3 and SLP5 were selected for analysis. The video recording of SLP6/P6 was selected for maximum contrast. It did not show any negotiation and decision making processes between the patient and the SLP.

SLP7 (female, 22 years old, student/6th semester) was excluded from the data analysis because the video-based telepractice was recorded with an external camera, which severely limited the sound quality and thus the intelligibility of the patient's verbal communication. In addition, the external camera focused the patient's image on the screen, so that the therapist's nonverbal communication was barely visible and thus could only be analyzed to a limited extent.

The transcripts were as detailed as necessary to address the research question and objectives of the study. Pauses, symptoms, repetitions, volume, gestures, and interruptions etc. were used in the transcription to represent social interaction, especially in the decision-making process. In addition, technical difficulties (e.g., delayed audio and video transmission) and the reactions of the SLP and patients were transcribed. No video recordings were excluded from data analysis due to technical difficulties (e.g., delayed audio transmission, interrupted internet connection).

Case selection criterion 2: spectrum of possible cases

The selection of cases follows the principle of contrast. The cases represent the spectrum of possibilities by showing as much variance as possible (Breidenstein et al., 2013).

In this study, the cases are intended to represent the spectrum of speech and language therapy. The principle of minimum and maximum contrast is the guiding principle. In order to represent the investigation field as broadly as possible, similar cases and very different cases were selected. Information from patients and therapists sociodemographic questionnaires was used. Based on available sociodemographic data of patients and SLPs, 5 individual cases were selected to represent the heterogeneity of patients and SLPs. Among SLPs (SLP1 to SLP8), e.g., work experience ranged from academic training (3 years) to 29 years, and working focus ranged from no focus in academic training to a focus in, e.g., pediatric or neurological work area. The 15 patients e.g., ranged in age from 6 to 82 years, and symptoms included fluency disorders (stuttering, cluttering), developmental language disorders, orofacial myofunctional disorders, aphasia, dysarthria, and voice disorders. The video recording of the youngest patient (P3) was chosen so that the age contrast with P2 (60 years old) and P4 (78 years old) would be maximum. Selection criteria included patients' symptoms to reflect the numerous symptoms and treatment methods, and the number of previous video-based telepractices to reflect the frequency of use and experience with video-based telepractice.

SLP1 and SLP3, both students with little professional experience and both treating a patient (P1, P3) with stuttering, form a minimal contrast to each other. The maximum contrast is SLP2, SLP4 and SLP5 with more professional experience, different professional status and adults with language disorder (P2), neurogenic speech disorder (P4) and voice disorder (P5). SLP6 (female, 47 years, working focus: voice disorders, stuttering, children with speech and language disorders) was excluded because, like SLP1 and SLP3, she treated a patient with stuttering and, like SLP4 and SLP5, she is a practice owner with a similar working experience (18 years). SLP8 was excluded because she worked in an outpatient practice, had a bachelor's degree, was of the same age and had the same work experience (as SLP2), and had a working focus on developmental language disorders (as SLP5). She also had a child with a total number of previous telepractice of 10 (similar to P1 and P3).

Case selection criterion 3: relevance of the case in the context of the field

Events (e.g., situations, people) that the participants themselves identified as particularly important (Breidenstein et al., 2013).

In this study, participants were informed through the study information and online study presentation that decision making and decisions made during the delivery of video therapy would be analyzed. They made their own decisions about which video-based telepractice to record with which patients, and then they decided which video recordings to make available to researchers. This was not influenced by the researchers. In this way, the SLPs were able to select the video-based telepractices of the patients that they considered to be most relevant. The reasons given by the participants for the selection of the patients and their recorded video-based telepractice were the consent of the patients or their relatives, the symptoms of the patients, or the own working focus. Based on the research question and the purpose of the study, sequences were selected and analyzed by the researchers in which explicit decision-making by SLPs and patients and the negotiation of decisions in video-based telepractice were evident.

Case selection criterion 4: typicality of the case

Criterions such as representativeness, frequency, and everydayness can also be used to select cases (Breidenstein et al., 2013).

In this study, no recorded video-based telepractices of SLPs and patients were excluded based on this criterion. The five selected cases (Table 2) illustrate typical symptoms of disorders in SLP, the age range of patients, and the known methods of treatment in SLP. In the case of the SLPs, the professional field is represented by different levels of professional experience, the existence of the working focus, and the beginning of the offering of video-based telepractice. Table 2 lists the information obtained from the sociodemographic questionnaires of the patients and the SLPs who were selected for the data analysis.

Case selection criterion 5: confusing aspects of the case

Case selection can also focus on the unusual, the unexpected, and the misunderstood. Analyzing situations that cause confusion makes it possible to focus on the differences between the culture of the participants and the cultural self-evidence of the observer (Breidenstein et al., 2013).

The researchers' assumption that SLPs give reasons for their decisions led to a search for sequences of decisions in which no reasons were given. It turned out that all the video recordings showed sequences in which the SLPs did not give reasons for their decisions. Therefore, this did not become a criterion for case selection. In one recording (SP2/P2), a decision made by the SLP to perform the exercise was corrected by her after P2 asked several times. Because of this, this video recording was selected for analysis. Other sequences, such as patients disagreeing with the SLP's decisions, or a negotiation process not being completed due to technical difficulties, did not occur in any of the 23 video recordings.

Setting

All of the recorded telepractice sessions are equivalent to a 45-min therapy session, which is most common in Germany. During the video-based telepractice, all patients were at home (e.g., in the kitchen, living room, or workroom at home). The SLPs were located in a therapy room in the outpatient clinical practice (SLP1, SLP3, and SLP5) or in their home office (SLP2, SLP4). Within this study, the start of the video-based telepractices was defined when the SLPs enter the digital space of the videoconferencing software. The end was defined when the patients and SLPs say goodbye (SLP1, SLP2, SLP3, SLP4) or when they are interrupted due to technical problems (SLP5). Based on the therapy process, all video-based telepractices demonstrated treatment sessions.

The participating SLPs used various hardware (e.g., computer, laptop, tablet, etc.) and software (e.g., ZOOM, Red Connect) for video-based telepractice. The synchronous therapies were always performed using audio and video transmission. Various features of the videoconferencing software (e.g., screen transfer, screen sharing) were used to show digitally recorded home practices

TABLE 2 Sociodemographic data of the patients and the SLPs.

Speech-language pathologists							Patients						
	Age (years), Sex	Professional clinical experience (years)	Professional status	Working focus	Beginning to conduct telepractice	Total number of telepractices		Age (years), Sex	Symptoms	Phase of treatment: current treatment content	Treatment since	Total number of therapies	Number of previous telepractice
SLP1	23, female	3	Student	None	May 04, 2020	11–20	**P1**	17, male	Stuttering (blocks, whole-word repetitions, prolongation, reduced verbal output, word and situational avoidances)	Treatment, consulting: desensitization techniques, speech motor training	January, 2014	13 (after a treatment break)	13
SLP2	30, female	7	Employee in an outpatient clinical practice	Dysphagia, aphasia, articulation disorders, phonological disorders	April 01, 2020	31–40	**P2**	60, male	Aphasia (difficulty retrieving words, agraphia, difficulty reading of texts)	Treatment, consulting: restorative and compensatory treatment (writing, reading, retrieving words)	April, 2020	21	21
SLP3	22, female	3	Student	none	May 21, 2020	1–10	**P3**	6, male	Stuttering (syllable and whole-word repetitions, prolongation, blocks)	Treatment: desensitization techniques, speech modifications technique	March, 2020	11	10
SLP4	44, female	20	Owner of an outpatient clinical practice	LSVT LOUD®, dysphagia, aphasia, apraxia of speech, dysarthria	March 16, 2020	more than 100	**P4**	78, female	Dysarthria; patient with Parkinson's disease	Treatment: intensive voice treatment (LSVT LOUD®)	April, 2019	52	19
SLP5	53, female	29	Owner of an outpatient clinical practice	Voice disorders, fluency disorders, developmental language disorders	April 15, 2020	21–30	**P5**	49, female	Voice disorder (decreased vocal endurance, abnormal resonance/hypernasal, breathy vocal quality)	Completing treatment: symptomatic voice therapy (e.g., airflow management, resonance)	September, 2019	17	6

or videos. The video feature was often used to display therapy materials in front of the camera for the other person to see. Due to the limited capacity of the internet, technical problems, such as audio and video transmission interruption occurred. To handle this, therapists and patients agreed to use the chat function of the videoconferencing system if the audio transmission was severely delayed and they could no longer understand each other, or to ignore the poor video transmission and concentrate on the audio transmission. Another way of handling technical malfunctions was for therapists and/or patients to log back into the videoconferencing system.

It is important to note that the patients and SLPs were largely familiar with the technical use of videoconferencing software at the time the video-based therapies were recorded. However, social interaction via a videoconferencing system was unfamiliar to the SLPs as well as to the patients and their families compared with social interaction in in-person therapies. It should also be noted that all patients were in the "intervention" phase of therapy and were receiving individual therapies.

Data analysis

The data were analyzed based on the interpretive video interaction analysis (Tuma et al., 2013). A distinctive feature of video interaction analysis is that it analyzes video recordings that document social actions and practices in natural, everyday situations (Knoblauch and Vollmer, 2018; Tuma, 2018). Thus, these situations were not produced specifically for the research project. They would have occurred even if the researchers had not commissioned the recording. The task and goal of video interaction analysis is to analyze the audiovisually perceptible practices and actions of the actors as a process. Consequently, it is not still images from video recordings that are analyzed, but always sequences of nonverbal and verbal interactions in order to reconstruct social action as a process (Tuma et al., 2013; Tuma, 2018). The video recordings are used as a research medium, to study nonverbal and verbal communicative interactions between all persons in social situations. The purpose is to sequentially analyze and interpret interactive practices in situationally produced social reality (Knoblauch and Schnettler, 2012; Tuma, 2018). The ethnomethodologically based video interaction analysis reconstructs the order of social interactions in the situation and focuses on both spoken language and nonverbal modalities. Depending on the research question and the topic of the research project, e.g., mimic, gestures, symbols, sounds, language, body posture are analyzed as elements of nonverbal and verbal interaction (Moritz, 2018)

Within this study, the social interaction between patients, relatives and SLPs were studied to analyze the clinical decision-making processes that are routinely used in video-based telepractice in outpatient services. The various phases of data analysis were initially carried out by MB (first author). The results were then discussed in ongoing meetings of the research team (MB, SW, BB, and JL) in an analytical and critical-constructive exchange of expertise. Discussions included e. g. the marked sequences per analysis protocol, code naming, assignment of overarching themes, criteria for minimum and maximum contrasts for comparing cases (SLP/P) and sequences. This was done by constantly alternating between analyzing and discussing in order to secure the analysis process and the results. Thus, there was a constant comparison of sequences with similar and varying sequences (e.g., transition to a new exercise, repetition of an action) within and between cases. In this way, the principles of credibility and dependability (Yadav, 2022) for qualitative research were observed.

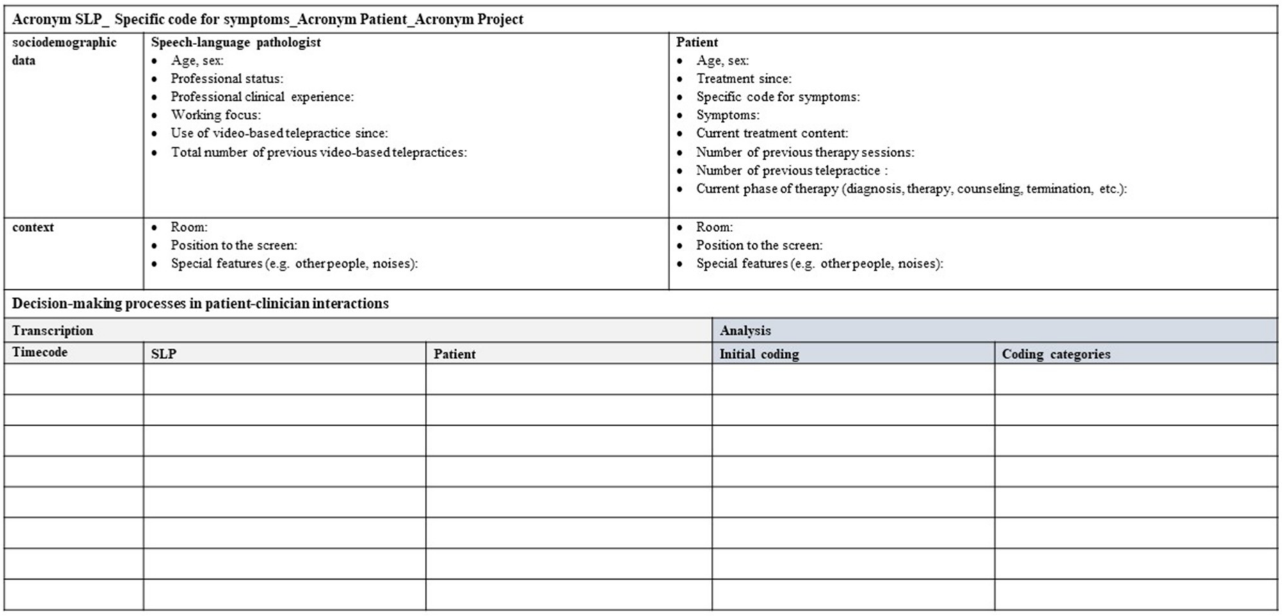
The interpretive video interaction analysis was realized in two steps: within-case analysis and cross-case analysis.

Step 1: within-case analysis

The first step was to analyze the social interactions of each case individually in the video recording. In this way, the social decision-making processes in different sequences of video-based telepractices will be described. The video recordings were analyzed in terms of how decisions are made during and within the interaction between the patient and the SLP and which elements indicate decision-making processes. An analysis protocol was used for transcription and analysis (Figure 2).

In the first column of the table, the timecode is entered to mark the time of the sequence. In the "SLP" and "Patient" columns, all verbal utterances, nonverbal elements (e.g., facial expressions, gestures, direction of view, posture, showing pictures), and technical features (e.g., beginning and end of screen transmission) were transcribed. Furthermore, paralinguistic elements were included in the transcription (e.g., duration of a break: (3)–break of 3 seconds; intonation: emphasized word–"That was much louder! very good."). For this purpose, the simple transcription system of Dresing and Pehl (2015) was used. Transcribing was done by MB. Within this study,

First, MB marked the sequences in the transcripts in which she identified decisions made and decision-making processes. In constant comparison with the video recording, the transcript of each individual case was divided into sequences, and sequence markers were set in relation to the research questions (internal sampling) according to the interpretative video interaction analysis (Tuma et al., 2013). Verbal elements of explanation (e.g., because, in order to, due to) and nonverbal elements (e.g., head shake, shoulder shrug) that could indicate agreement, disagreement, or indecision were used to determine the sequences. New verbal and nonverbal elements were continuously compared with the previously analyzed elements from the other analysis protocols to identify similarities and differences and to further develop the results (Glaser and Strauss, 1998). For instance, reflection of self-perception and perception of others, completion of an exercise or instruction of a new exercise were categorized as nonverbal and verbal communication. In this way, minimum and maximum contrast sequence comparisons could be determined during the course of the video-based telepractice for subsequent fine analysis. Maximum contrast sequences include e.g., sequences with decisions with and without explanation, or sequences in which a decision is negotiated between the patient and the SLP vs. sequences in which a decision is predetermined by the SLP. Minimal contrast sequences are, e.g., sequences in which decisions are negotiated between the patient and the SLP, but the patients are of different ages, or sequences



Acronym SLP_ Specific code for symptoms_Acronym Patient_Acronym Project				
sociodemographic data	**Speech-language pathologist** • Age, sex: • Professional status: • Professional clinical experience: • Working focus: • Use of video-based telepractice since: • Total number of previous video-based telepractices:		**Patient** • Age, sex: • Treatment since: • Specific code for symptoms: • Symptoms: • Current treatment content: • Number of previous therapy sessions: • Number of previous telepractice : • Current phase of therapy (diagnosis, therapy, counseling, termination, etc.):	
context	• Room: • Position to the screen: • Special features (e.g. other people, noises):		• Room: • Position to the screen: • Special features (e.g. other people, noises):	
Decision-making processes in patient-clinician interactions				
Transcription			**Analysis**	
Timecode	**SLP**	**Patient**	**Initial coding**	**Coding categories**

FIGURE 2
Analysis protocol.

in which the SLP explains a decision and the explanations are based on the therapist's experience or on the approach of the therapy method. These marked sequences were then reviewed and discussed with the other members of the team (SW, BB, and JL). As a result of all five within-case analyses, four sequences with decision processes (negotiation, weighing arguments) and 26 sequences with explanations and 61 with decisions without explanations were identified as relevant for further analysis. The sequences ranged in length from 1:24 min to 9:37 min. A blank line was inserted after each sequence in the analysis protocol. This separates the sequences from each other.

The purpose of the detailed analysis was to analyze and compare different sequences of a single case. In addition to analyzing the multiple occurrences of similar actions by one person in a sequence (e.g., asking a question, shaking one's head, interrupting the practicing verbally or nonverbally), special attention was paid to identifying the specifics of the interaction between the patient and the SLP in that sequence were identified (e.g., verbal and nonverbal responses (SLP) to shaking one's head (P) or, after asking a question (SLP) waiting for the response or providing response options). The qualitative analysis was documented in the fourth and fifth columns. Following the grounded theory, the coding process and category formation were conducted (Strauss and Corbin, 1996; Glaser and Strauss, 1998; Dietrich and Mey, 2018). For the nonverbal and verbal elements that were present in these sequences, short labels were noted as initial codes in the fourth column in order to reconstruct the meaning of the segment. In this phase of coding the first case (SLP1/P1), four overarching coding themes emerged to which initial codes could be assigned: (1) default vs. negotiation (SLP), (2) nonverbal/verbal element of interaction, (3) action-related phenomenon, and (4) form of evidence/influencing factors. Consequently, the fourth column of the analysis protocol was divided into these four themes. Table 3 illustrates two examples.

The coding themes were used in the initial coding of the other four cases. During this inductive procedure, the coding themes were confirmed. In doing so, the qualitative principle of the inductive procedure was followed. Therefore, there was no list of expected, known from literature interactions that were deductively searched for in the transcript. At this stage, any notion that arose while analyzing the material was allowed to flow. Categories were then formed from the overarching themes that emerged from the initial coding and were noted in the fifth column (Table 3).

Step 2: cross-case analysis

This also took place in the comparative approach of the grounded theory methodology (Strauss and Corbin, 1996; Glaser and Strauss, 1998; Dietrich and Mey, 2018).

On the one side, actions and interactions in which decisions or decision-making were analyzed in individual cases and which were similar in content were now compared across cases. The similarity of content referred, e.g., to the request for self-assessment (SLP), the verbal and nonverbal response (P), and the subsequent reaction (SLP), or specifying the target action with or without reasoning (SLP), performing the exercise (P), and receiving feedback the SLP. The contrast was in the different contexts (e.g., symptoms, presence/absence of relatives, number of previous therapies). Typical courses of interaction were reconstructed in a differentiated way.

On the other side, sequences of interactions with a similar context were compared (e.g., involvement of relatives, teaching self-awareness to patients who had never received in-person therapy, consolidation of speech modification techniques).

TABLE 3 Initial Coding and coding categories—exemplary extract of the analysis.

Transcription			Analysis				
Timecode	SLP1	P1	Initial coding				Coding categories
			default vs. negotiation	nonverbal/verbal element of interaction	action-related phenomenon	form of evidence/influencing factors	
02:45		*(Screen sharing documented home practice: list of words beginning with [m])*					
	"You might tell me about the situation. maybe you remember what you said and how it was. tell me a little bit about it."						
		(blocks: inability to initiate sounds)					
	"Start again. start again and remember to prolong the [m]."		Default with explanation	Interrupting			Repeat determined target action (SLP)
		"After the m::: (.) m:::: (.) [m:::ittage::::ssen] (.)" *(several blocks and breaks).*					
	"Stop (.) stop. stop. [Mittagessen] is hard, isn't it? There is especially the [m] and the [e] again. Now do it again and prolong it for a very long time. take your time. and then very easily into the vowel."	"Yes." "Mhm" *(confirming)* "Yes."	Default with explanation	Interrupting			Repeat determined target action (SLP)
		"Mhm" *(confirming) (sits up straight)* "[M::::ittagessen]" *(applies prolonged speech)*					
	"Mhm *(confirming)* the beginning was very good now. Super. Now you stopped briefly in between, right?" "Was that because was that a problem from a breathing or"	"Mhm" *(confirming)*		Confirm	Feedback		
				Inquire self-perception			Self-assessment
		"No."		Giving self-assessment			Self-assessment
	"Okay. Can you do that again right now, please?"		Default without reasoning	Request repetition of the exercise	Increasing exercise intensity		Default
		"Mhm *(confirming)* [M:::::ittag] (2) [M::::ittagessen]" *(two attempts to pronounce the word, applies prolonged speech)*					
05:26	"Good! the [m] was now prolonged really well. so that was really good. what's unfair is that it's two words that are put together. and [Essen] starts with a vowel. that's difficult, of course. but we'll leave that for now, because we haven't practiced vowels yet.	"Mhm" *(confirming)* "Yes." *(nodding)*	Default with reasoning: treatment plan and treatment methods (sounds and words)	Feedback: Explain the practice of specific word-level speaking requirements	Applying standardized therapy method, Presenting internal evidence or clinical expertise	Specific expertise about the therapy method	Default with reasoning Evidence (external and internal)

(Continued)

TABLE 3 (Continued)

Transcription			Analysis				
Timecode	SLP1	P1	Initial coding				Coding categories
			default vs. negotiation	nonverbal/ verbal element of interaction	action-related phenomenon	form of evidence/ influencing factors	
12:38	"Then we're going to do some stretching. (.) You can see me, right?"	"Yes."	default		inquire the technical foundation to interact		Determine target action
	First an exercise that pulls sideways *(right arm stretched over the head to the left)* and there we pull here so the whole side (.), right? and you can observe what is better for you when you pull sideways. exhale at [sch:(5)] (.) and when you come back take the other arm *(standing frontally to the camera, both arms down)* and again [sch:(4)] and imagine that you are getting longer and longer at the [sch]. (.) again. [sch:(4)]"	*(standing frontally to the camera)* "[sch:(4)]" *(left arm stretched over the head to the right)* "[sch:(4)]" *(right arm stretched over the head to the left)*	Default with explanation	Visible and audible demonstration of the correct execution of a new target action	Concrete order of the practice exercises	Specific expertise about the target action	Evidence (external and internal) Determine target action
	"And the other option is the other way around. There's no bad, there's no good. See which one is more comfortable for you. (.) You have to be in this position (left arm stretched over the head to the right) and then slowly bring the arm back over the head. [sch:(6)]" [sch:(6)]"	*(right arm stretched over the head to the left)* "[sch:(6)]" "[sch:(6)]"	Default: modified target action	Visible and audible demonstration of the correct execution of a new target action	Concrete order of the practice exercises	Specific expertise about the target action	Evidence (external and internal)
	"The motion over the head is a fast one *(left arm stretched over the head to the right)* [sch:(3)] and this is a slow one. (.) one more time."	*(left arm stretched over the head to the right)* "[sch:(3)]" "[sch:(5)]"					
	"Which one would you say you would prefer?"			Inquire self-perception	Request		Request a self-assessment (SLP)
	"Yes."	"When the motion goes back so slowly *(both hands are in the area of the lower ribs)*, then I feel that when the arm goes back slowly, then the width is more. I feel that I can breathe here (hands in the lumbar area) when the arm goes back slowly."		Giving self-assessment	Answer/reaction		Patient perspective
15:24	"So the variation where you start with the arm at the top and then bring it down is the better one. Very good! then we'll take the same movement and make it a voice exercise."	"That's right!"	default with reasoning: patient's self-assessment	Ensure understanding	Inquire (SLP) Confirm (SLP)	Patient's self-assessment	Determine new target action (SLP) Patient perspective

The cross-case analysis of similar interactions aimed to describe the temporal sequence and structure of the interaction between the patients and the SLPs. This was to reconstruct across cases how decisions are made or how decision-making occurs in video-based telepractice.

Results

Basis for interactions

The results indicated that SLPs maintain strategies for a common basis of interaction during video-based telepractice. Nonverbal and verbal communication as part of social practices was limited by the resulting delays in audio or video transmission. To overcome these difficulties, SLPs and patients used various technical interaction strategies. For instance, at the beginning of the treatment, they agreed to use the chat function, to focus on the sound transmission, or to ignore the limited image transmission. In this way, they re-established a common basis for interaction.

In addition, pragmatic practices (e.g., gesture, including head shaking, nodding, hand gestures; pauses in fluent speech) that SLPs and patients used to maintain their interactions were demonstrated. It was noticeable that patients and SLPs sometimes could not see each other. It was not maintained when practice materials were held in front of the video camera, or when patients looked down while writing or reading and talking to the SLP, or when the SLP explained something to them.

Characteristics of decision-making

By analyzing the data, it could be reconstructed that the decision-making process is strongly influenced by the social interaction between the patient and the SLP. A paternalistic interaction or participative interaction between patients and SLPs characterizes decision making in video-based telepractice (Figure 3). The descriptive characterization of the two styles of interaction applies to the social interactions in video-based telepractice in outpatient SLP services analyzed in this qualitative study.

A paternalistic interaction by the SLP was most evident when structured treatment (e.g., LSVT LOUD®) were used. A more participative interacting was observed in the video-based telepractice, where different individual exercises were combined (e.g., symptomatic voice therapy). The analysis showed that the patient's age, symptoms, total treatment time, etc. had less influence on the decision-making than the style of interaction. In the cross-case analysis, it became clear that negotiation to decide how to perform the next exercise (Case 3: 2 sequences; Case 5: 1 sequence) occurred in both Case 3 (SLP: 22 years/P3: 6 years) and Case 5 (SLP5: 53 years, P5: 49 years). Similarly, both SLPs give a similar number of decisions without giving reasons (SLP3: 11; SLP5: 12) and decisions with giving reasons (SLP3: 2; SLP5: 5). Although both cases are maximum contrasts in terms of age, no difference in decision making could be found. The cross-case analysis also revealed that in all cases there were more decisions without reasoning given (SLP1: 14, SLP2: 13, SLP3: 11, SLP4: 11, SLP5: 12) than decisions with reasoning given (SLP1: 8, SLP2: 3, SLP3: 2, SLP4: 8, SLP5: 5). This is done in patients with different symptoms (e.g. stuttering, aphasia, voice disorder) and with different total treatment time: from 1 month (P2) to 6.5 years (P1).

The SLP's paternalistic interaction characterized social interactions, e.g., by "determine target action" within a therapy sequence or by "determine home practice."

> *SLP2: (holds an image card in front of the camera) "What is important to me today is that you also tell me the generic term. it's still a bit difficult (removes image card, looks at screen) to find a generic term for everything in this category. the generic term is especially important to me today. that you find that for the, uh, the pictures that we have now. (holds an image card in front of the camera, SLP2 is not visible (3) SLP2 removes image card, looks at screen)*
>
> *P2: "This is (2) uh one (3) u::ch"*
>
> *SLP2: (holds an image card in front of the camera, is not visible)*
>
> *P2: (looks left, looks at screen) "That is always so difficult to find the (1) the generic term."*
>
> *SLP2: "That's what I explained to you before, that everything got a bit mixed up because of the stroke (2) and we're trying to sort it out now. (1) and this categorizing, which you also have to do as home practice from time to time, or now you find these generic terms, that just helps you. (3) and that's why we do/*

In quote 1, it can be seen how the SLP2 determines the target action without asking the patient how relevant the goal of the exercise is for him, and whether, and if so, how, the exercise could be performed. She does not respond to his nonverbal and verbal signals (e.g. looking away from the screen, expressing displeasure), but justifies why this target action is necessary based on the cause and symptoms of the disease. The target action and goal are predetermined by the SLP and there is no negotiation or modification of the exercise.

SLP also mentioned their clinical expertise and experience. The focus was on the correct execution of the actions, and the clinical expertise of the SLPs determined the therapeutic approach, i.e., SLP1 asks for the patient's self-assessment of his use of speaking technique using specific criteria and also self-assesses his use of speaking technique using the same specific criteria (quote 2).

> *P1: "Yes. (1) subtract" [applies speaking technique] (laughs)*
>
> *SLP1: (laughs) "Oh, you have chosen some difficult words! wow! (laughs)*
>
> *P1: "Yes." (laughs)*
>
> *SLP1: "I'm going to ask you again for the criteria and you can just give a thumbs up (shows it) or thumbs down (shows it). okay?"*
>
> *P1: "Yes."*
>
> *SLP1: "Was it long enough?"*
>
> *P1: "Yes." (he stretches up his right thumb)*
>
> *SLP1: "Yes! it was long enough. (1) was it loud enough?"*
>
> *P1: "Yes." (he stretches up his right thumb)*
>
> *SLP1: (nods) "Yeah, I think so too. so, with the "s" I think you can be much louder than with the "m". it's really less of an issue. (1) and how was the transition to the vowel?*

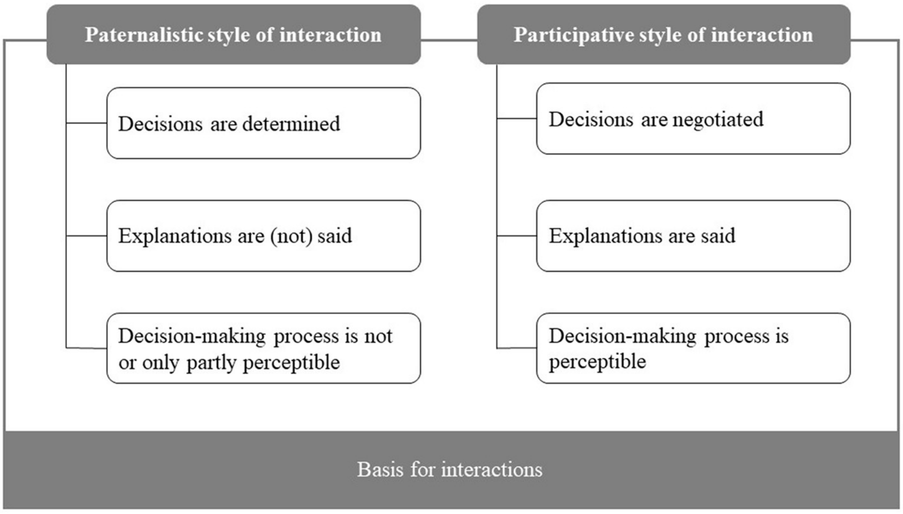


FIGURE 3
Characteristics of decision-making in video-based telepractice.

> *P1: (looks down, yawns with mouth closed, looks at screen, smiles) "That was very good. yes." (he stretches up his right thumb)*
>
> *SLP1: (nods) "Yes, I thought so too. (nods) was fine. great! (1) then try again. again, stretch long enough, but just long enough so that you still have enough air for the rest of the word. okay? so you can memorize it well. (1) here we go."*

She does not link the evaluation of his speaking to his wishes for therapy. SLP partly justified their decisions by referring to the patient's therapy goal or to previous successes or difficulties in practicing. The SLPs often did not explain to the patients and the continuously present (P3: mother) or partially present (P2: wife) relatives why a target action had to be repeated, or they decided to start a "new target action."

A participative style of interaction was evident in the video-based telepractice when the SLPs asked the patients to rate their perception of the vocal quality or their effort during "perform target action" (quote 3).

> *P5: (1) "Ni(.)ha ni(.)ho. (.) ni(.)ha ni(.)ho. (.) ni(.)ha ni(.)ho. (.) ni(.)ha ni(.)ho. (.) ni(.)ha ni(.)ho." (.)*
>
> *SLP5: "OK. let it go. feel, sense. is the feeling still here now? (hand on chest) has it increased? has it decreased? (2) is the breathing more stimulated than before?"*
>
> *P5: "It is mainly that it sticks so much here (the left hand to the lower right costal arches) (.) yes, such a sticky feeling is (.) it's almost like that, yes, like when so layers stick together. and if I do that a few times, it will unstick. (.) and now it's good. so it's less here (.) in the abdomen (.) the further feeling is than so more back here, which I feel is very pleasant." (both hands are in the lumbar region)*
>
> *SLP5: "Yes, okay. then let's do a little stretching exercise one more time. (.) you can see me, can't you?"*

During voice training, SLP5 asks the patient how she assesses her breathing (quote 3). This requires the patient to be able to perceive, describe and assess herself and her breathing. SLP5 confirms the patient's self-assessment and, based on this, provides a new target action that relates to the patient's self-awareness. She uses the patient's self-awareness to continue voice therapy.

Based on the self-assessment, but also on the patient's needs, negotiations took place between the patients and the SLPs about, e.g. "repeat action" or "extended practice." In these more participative interactions, patients' self-assessments were used as starting points for modified action or new target actions. When interacting with patients in this way, SLPs brought their clinical expertise and experience, as well as specific knowledge from previous therapy sessions with each patient. The shared dialogues and patient self-assessments allowed the SLPs to flexibly adapt interventions to the current needs, everyday communication situations and the individual living environments of the patients on a situation-specific basis.

Shared decision-making processes took place, e.g. after the self-assessment of the previous implementation and documentation of homework by the patient (P1) or by the mother (P3). Afterwards, the patient respectively the mother and the SLP discussed and decided how to implement home practice more often in the future (P1) and how to use popular and existing games at home (P3). With P3 and P5, further exercise actions were discussed together, taking into account preferences (P3) and physical self-awareness (P5) in the decision-making process. Negotiations in the decision-making process took place in participative interactions.

The data analysis revealed that SLPs rarely explicate their internal decision-making process and thus rarely explain or justify their decisions to patients and relatives. As a result, it is not clear to others on what professional basis the decisions were made, e.g. to "correct" the patient's target actions or to "finish action" and "determine new target action." When SLPs justified their decisions, they referred to their expertise (e.g., on the symptoms of the disease, on the implementation of the therapy method) and to previous experience with the patient (e.g., progress in the course of therapy, self-assessment skills). The SLPs justified their decisions in participative and paternalistic interactions with the patients and relatives. The internal evidence and the client perspectives were expressed in different degrees of explicitness. No explicit inclusion of current external evidence (e.g., guidelines, scientific evidence) could be reconstructed when analyzing video-based telepractice.

Process model of decision-based interaction

Based on the results of the within-case and of the cross-case analyses, a process model was developed which illustrated how patients and SLPs interact during a video-based telepractice session (Barthel et al., 2021a). Three phases characterize video-based telepractice sessions: (1) situational, content-based arriving, (2) interactive, process-based treatment, and (3) situational, content-based closure (Figure 4).

The visible and audible interactions in each phase and the resulting interaction process throughout the therapy session are based on decisions made by the SLP and the patient. On the one hand, decisions relate to content related structural aspects of speech and language therapy, such as the therapy method or the transfer of practice as the next therapy step. On the other hand, decisions refer to the concrete interactionist situation, such as "determine target action," "confirm target action," "request self-assessment," and "determine home practice. The various decisions all lead to continuous practicing in the "interactive, process-based treatment" phase. They maintain the process-based interaction between patient and SLP.

Discussion

With the introduction of video-based telepractice during the COVID-19 pandemic, SLPs needed to rapidly transition their outpatient service from in-person to video-based therapy. The study examined the decision-making that occurs in the interactions between patients and SLPs in a video-based telepractice. It focused on the components that characterize a decision-making process.

A common basis for social interactions in video-based telepractice is of fundamental importance for decision-making processes. Social interactions between patients and SLPs are characterized by verbal and nonverbal elements. This enables patients and SLPs to relate to each other and processual interaction can take place. The results of the study show that processual interaction is possible in video-based telepractice for people with communication disorders of different ages. Of course, powerful technical equipment (e.g., hardware, software and internet connection) is required for patients and SLPs to interact in video-based therapy (Bilda et al., 2020; Lauer, 2020; Barthel et al., 2021b). The availability of technical equipment (e.g., laptops, computers, cameras) among patients and SLPs, the availability of videoconferencing systems (e.g., Red Connect, Zoom) among SLPs, and the existing skills to use the technical equipment and functions of the digital applications enabled patient's digital participation in health care. In this way, the health care in outpatient SLP services could continue without interruption due to restrictions during the COVID-19 pandemic.

When SLPs explicitly name their decisions, they use their clinical expertise and specific knowledge to reason their decisions. Conspicuously, this knowledge is used in paternalistic interactions to ensure that e.g., the structured performance of LSVT LOUD® is done correctly. The structured performance refers, e.g., to the frequency and duration of practicing, as well as the order and repetition of practice sessions (LSVT Global, 2023). This did not take into account the individual living environment of the patients, their self-assessment and their needs. In more participative interactions, although specific patient-related knowledge and clinical expertise are also used to justify further action in therapy, the focus is on the patient's self-assessment (=client perspectives), available resources, and individual lifeworld. Higginbotham and Satchidanand (2019) suggest differentiating internal evidence into clinical expertise and internal evidence based on data-based knowledge of patient performance. Alternatively, the diamond model (Higginbotham and Satchidanand, 2019) can explain the different reasons for the decisions made by the SLPs very well. In a review, Fissel Brannick et al. (2022) pointed out the difference in terms and definitions for clinical evidence. They argue that clinical opinion, clinical expertise, and practice-based evidence should be clearly defined and used unambiguously in professional and interprofessional communication and in discussions with patients and their families (Fissel Brannick et al., 2022). The clinical evidence provided by the SLPs in the present study can be described as clinical expertise. In the cross-case analysis, it was found that the SLPs used different types of knowledge (e.g., previous experience with the patient, the patient's self-perception, knowledge of the therapy method) to make decisions such as "determine to repeat action," "determine modified target action," or "determine new target action." Two essential attributes of good clinical decision-making are the use of multiple sources of knowledge and the needs of the patients (Fissel Brannick et al., 2022). However, it was not possible to reconstruct whether consensus recommendations, research findings or clinical expertise from other SLPs were used in the decision-making process. These are three more important aspects of clinical expertise in decision-making (Fissel Brannick et al., 2022).

In the paternalistic interactions and the participative interactions, decisions in the therapy process are made predominantly on the basis of the results of previous decisions. Thus, therapists and/or patients assume effects with respect to the previous course of action. All of the studies included in the scoping review by Fissel Brannick et al. (2022) were of interventions delivered in in-person settings. Although this review did not include a study that examined the use of clinical evidence in video-based telepractice, it is reasonable to assume that the use of multiple sources of knowledge is also relevant to video-based telepractice. It is important to examine what sources of knowledge SLPs use in addition to patient needs and their clinical expertise and interne evidence. As the use of video-based telepractice had only been available to all SLPs in Germany for a few weeks at the time of the study and social interaction via videoconferencing software was new to them, there was little expert advice from colleagues or professional associations. How SLPs acquired the

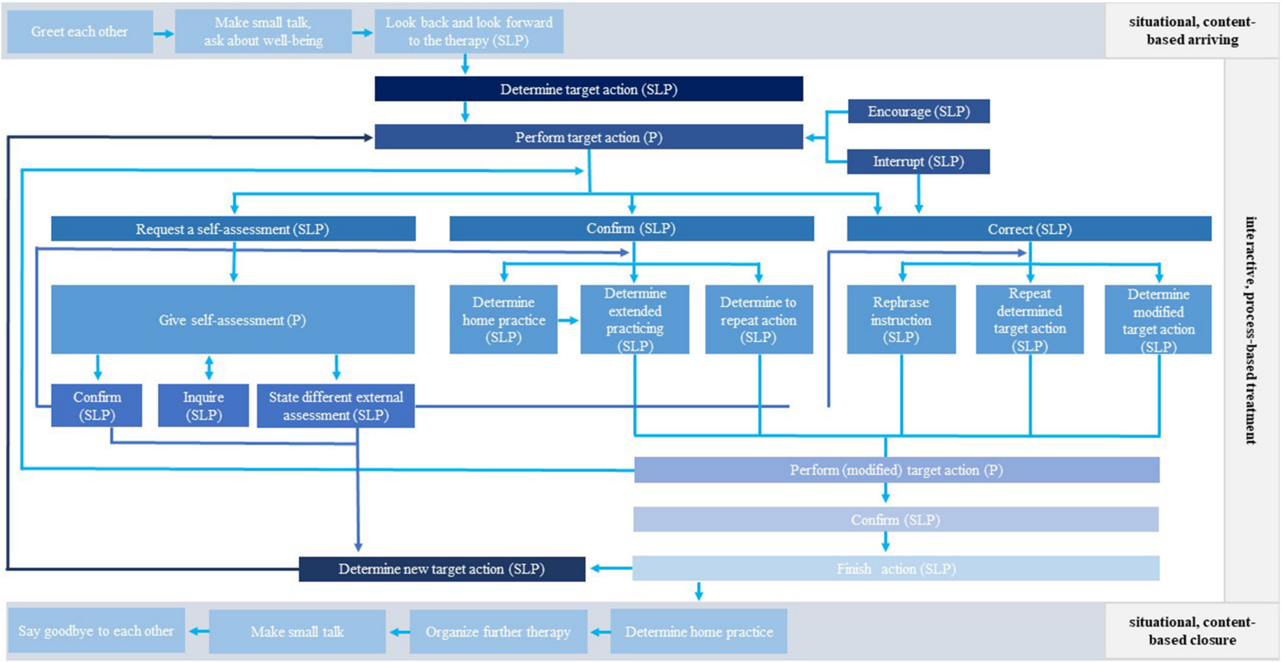


FIGURE 4
Process model of patient-therapist interactions (P: patient, SLP: speech-language pathologist) (Barthel et al., 2021a).

knowledge to carry out video-based telepractice and what decisions that led to, e.g., implementing therapy methods in a modified manner or using familiar implementation from in-person therapy is currently not described in the literature. Differential knowledge of influences on clinical evidence may be relevant not only to in-person therapy (Higginbotham and Satchidanand, 2019; Fissel Brannick et al., 2022) but also to video-based telepractice, e.g., to distinguish between clinical opinion and clinical expertise and to understand their influence on the clinical decision-making process.

For paternalistic interactions and for participative interactions the external evidence (ASHA, 2004; Dollaghan, 2007) or external scientific evidence (Higginbotham and Satchidanand, 2019) could not be explicitly reconstructed in the analysis. The results of research or guidelines (=external evidence) were not an explicitly mentioned point of reference for decision-making. Greenwell and Walsh (2021) reported that SLPs use different sources of evidence. Client perspectives and external evidence were the most commonly named (Greenwell and Walsh, 2021). It would be interesting to know how the external evidence and client perspectives from patients and relatives, and the internal evidence from SLPs influence the decision-making and how they interact with each other. How patient-related clinical experience, clinical expertise, and current external evidence combine to lead to the best possible decision and treatment cannot be shown by video interaction analysis. However, different forms of evidence do influence decision-making in in-person therapy (Dollaghan, 2007; Higginbotham and Satchidanand, 2019; Greenwell and Walsh, 2021; Fissel Brannick et al., 2022).

However, the results of the video interaction analysis of this study emphasized that EBDM and interacting must be understood as a process. SDM as a social interaction is present, even if it is not always explicit in nonverbal and verbal communication. The participative approach of decision-making is evident both in asking for patients' self-assessment and needs for treatment and home practice, and in the communicative negotiation of therapy content and procedures. This promotes the digital participation of patients in the video-based telepractice. The results thus demonstrate two core elements of SDM: at least two people are involved and they share information (Elwyn, 2020). The other two core elements of SDM—focusing together on the further course of treatment and reaching consensus (Elwyn, 2020)—could only be reconstructed in short negotiation processes. There was no evidence of patient refusal or questioning of the clinical process during the participative interactions in video-based telepractice. However, this could lead to more content and goal-related justifications by SLPs and more communicative negotiation processes between patients and SLPs. Why patients did not inquire about the content of the practice, did not question it, or even reject it, could be due to the fact that only practices they were already familiar with were performed, that the explanations and the nonverbal and verbal specification of the target action were understandable, or that this pattern of interaction had consciously or unconsciously developed due to the previous number of therapy sessions.

Numerous reviews have shown that video-based telepractice is effective in a great many areas: adults with various communication disorders (e.g., chronic aphasia, dysphagia, primary progressive aphasia) (Weidner and Lowman, 2020), adults with Parkinson's disease (Theodoros et al., 2019), children and adults who stutter (McGill et al., 2019), parents of children and children with autism spectrum disorders (Neely et al., 2017; Sutherland et al., 2018), primary school children (4–12 years) with speech or language impairments (Wales et al., 2017), individuals with a recommendation for voice therapy (Rangarathnam et al., 2015), and individuals with acquired brain injury (traumatic brain injury or stroke) (Coleman et al., 2015) have all shown effective application of video-based telepractice. Due to the complexity of the diseases and various symptoms, it is important to consider the extent to which patients can digital participate in video-based telepractice, the role they are assigned, or the role they take on. Consequently, it is necessary to reflect on how digital participation and SDM can be realized in video-based telepractice. Special attention must be paid to the personal competencies of patients and their physical, linguistic, and cognitive abilities (Steiner, 2023) in order to enable digital participation in SLP services via video-based telepractice for patients of all ages and with different communication disorders. If necessary, technical and structural adaptations and changes in treatment performance must be made in order to provide digital health care (Steiner, 2023).

The role of the SLP also changes in video-based telepractice. Because video-based telepractice occurs at a physical distance (ASHA, 2020), the patient's physical self-awareness and self-evaluation (=client perspectives) seems to be more necessary than in in-person sessions. The SLP becomes a "verbal guide" for the patient. The patient must be able to tactilely and aurally perceive and verbally express himself or herself. Based on self-assessment and the reported needs, the SLP must be situationally flexible in deciding how to proceed with the video-based practicing. Incorporating client perspectives as a feature of participative interactions challenges the SLP to be able to quickly combine client perspectives and clinical expertise. In addition to client perspectives, participative interactions also take into account the individual's lifeworld. SLPs ask about the patients' material and social resources. Patients use materials that they have at home and also use for home practice. As a result, SLPs are better able to support the transfer of practice content to the patient's everyday life because the SLP can see where the patient lives, how he or she practices at home, and what he or she uses to do so. Video-based telepractice allows SLPs to incorporate individual resources and the patient's home and living environment into decisions. This can be an opportunity to increase patient adherence to treatment and goals, and to promote transfer (Barthel et al., 2021b).

The results of the present study are consistent with international findings (e.g., Coleman et al., 2015; Rangarathnam et al., 2015; Wales et al., 2017; Sutherland et al., 2018; McGill et al., 2019; Theodoros et al., 2019; Weidner and Lowman, 2020) that show video-based telepractice can be delivered to individuals with different communication disorders (e.g., aphasia, stuttering, voice disorders) and clinical conditions (e.g., Parkinson's disease) of different ages. One way that people with communication disorders across the lifespan can digitally participate in healthcare is via video-based telepractice as a digital form of outpatient SLP service. Speech and language telepractice is considered necessary in the German health care system, among other things, to counteract physical distances and limited mobility, to integrate the evidence-based transfer of therapy content more strongly into the patients' lives. Video-based telepractice is necessary to meet the advancing digital healthcare.

Limitations

Method

The small sample size imposes restrictions on the generalizability of the findings. Further studies with higher sample sizes are warranted. Furthermore, it must be critically noted that students with little professional experience and SLPs with many years of professional experience have very different knowledge and experiences of EBP. Therefore, it can be assumed that their understanding of EBP and its implementation in speech-language pathology and audiology practice are different. Nevertheless, the cross-case analysis identified typical interaction patterns and typical communicative actions that shape decision-making processes in video-based telepractice (Barthel et al., 2021a). In addition, the theoretical sampling in the selection of individual cases, the sequencing of the video recordings based on the research questions, and the coding process, among other things, provided the methodological and analytical potential to conceptually reconstruct the multifaceted subject area through the individual case analysis and the following cross-case analysis (Dietrich and Mey, 2018; Strübing, 2021).

Process model

The process model focuses on the social interactions between patient and SLP and their decisions in video-based telepractice. A limitation is that continuously or partially present relatives are not explicitly listed in the phases of the process model (Figure 4) and in the styles of interaction (Figure 3), and their role is not differentiated. Since relatives are an important resource in SLP, the involvement of relatives should be focused on in order to describe their role in decision-making processes in a more differentiated way, e.g., in all phases of therapy and depending on the age of the patients. Their interactions could be mapped in an extended model to concretize decisions related to how relatives are guided for "home practice" or how they are integrated into "perform target action." This could reveal similar or different decision-making processes as well as styles of interaction of the SLPs.

In considering the process model, it is important to note that the patients, the SLPs, and the family members were using the video-based telepractice for at least six therapy sessions. It is reasonable to assume that during this time, interactions were implicitly and/or explicitly developed that influenced decision-making in video-based telepractice. How social practices of decision-making occur in other phases of the therapy process (e.g., clinical history, diagnosis, counseling, or final session), what patterns of decision-making occur in group therapy, and how little experience with social interactions in video-based telepractice affects decision-making are not answered by the study. Therefore, the process model can only map individual therapy in the treatment phase. In this video-based observational study with a cross-sectional design, it was not possible to reconstruct how nonverbal and verbal pragmatic communication factors (e.g., speech contribution, gestures) depend on the relationship between patients and SLPs, or on symptoms of the communication disorder, and in turn influence decision-making processes.

Conclusion

SLPs can design decision-making processes in participative interactions in video-based telepractice. For this reason, it would be possible that all participants can make shared, evidence-based decisions in the intervention process. In cross-sectional observational studies, decisions in different interaction styles are recognizably shaped by client perspectives and clinical expertise. As it was possible to offer video-based telepractice for the first time in Germany in spring 2020, the study served as a first survey. The results of the present study can be used as a starting point for further research projects on video-based telepractice in Germany. Further research is urgently needed to analyze the differentiation, e.g., between communication disorders, the age of the patients, the professional experience of the therapists, and their influence on the decision-making process in video-based telepractice. This should focus on a differentiated analysis of digital participation in speech and language pathology for people with communication disorders at different ages. On the one hand, the focus should be on the access to digital health care and the competence to use hardware and software, taking into account individual needs and living conditions. On the other hand, active involvement through a participative style of interaction is also important to enable patients to actively participate in the decision making process of digital care. This should also focus on the necessary social and digital skills of SLPs that are needed to ensure the digital participation of people with communication disorders in video-based telepractice in outpatient SLP services (Steiner, 2023). This refers both to the access and use of digital applications and to the participative style of social interactions in digital care.

The use of different qualitative and quantitative methods of data collection and analysis in different research designs can address the complexity of video-based in outpatient SLP service (e.g., heterogeneous patient populations, ICF orientation) and decision-making processes. This can be used to gain further essential insights into the conditions and patterns of interaction in evidence-based decision-making processes in video-based telepractice and also in SLP in general.

The implicit role of client perspectives, internal and external evidence and clinical expertise in interactive decision-making needs to be elicited from the perspectives of SLPs and patients and made explicit for use in treatment.

To concretize the sources of knowledge of SLPs, it would be relevant to know which sources of knowledge influence the interne evidence and clinical expertise. It would be interesting to determine whether and how, e.g., research findings, theory-based knowledge, or the expertise of colleagues are incorporated into clinical decision-making processes.

In future research it would be interesting to find out when decisions in the video-based therapy process are explained and justified, whether and how often they are explained repeatedly, and what this depends on for SLPs. It would also be interesting to know how aware SLPs are of decision-making processes in video-based telepractice and how they might make them explicit. Qualitative research approaches (e.g., stimulated recall interviews) could be used to make decision-making processes—especially cognitive ones—explicit and to reconstruct their relevance (Dempsey, 2010; Vall et al., 2018).

A decision-making process in which the patient ultimately made the decision about how to proceed with practicing was not analyzed in the video interaction analysis. It was not founded that SLPs were asking patients to make a choice between different practice options or intensities. It would be interesting to find out in which situations and for which content patients make the final decision and SLPs leave the final decision to the patients. It would also be interesting to find out what patients and families want to know from their perspective in order to make an informed decision. Qualitative research methods would be appropriate to explore the views, experiences, and wishes of patients and their families.

Additionally, as working conditions have a high impact on decision-making processes in in-person therapy (McCurtin and Clifford, 2015; Furlong et al., 2018; Selin et al., 2019), further research examining how working conditions influence decision-making processes in video-based telepractice are needed to uncover potential workloads that could reduce quality of care. The workplace-related advantages and disadvantages of video-based telepractice (Wittmar et al., 2023) should be compared with the working conditions of in-person therapy in order to decide when which form of care—in-person therapy, video-based synchronous and asynchronous telepractice, hybrid service (ASHA, 2020)—is necessary to improve the quality of care in outpatient SLP.

It would also be interesting to know when and how decisions are influenced when synchronous video and in-person therapies take place during the course of therapy. This could provide knowledge about the role of patients and the competencies of SLPs in order to shape the future of evidence-based and digital SLP in Germany.

Data availability statement

The datasets presented in this article are not readily available because it is not possible to anonymize the recorded video-based teletherapies. Due to privacy and ethical concerns, the data cannot be made publicly available. Further inquiries can be directed to the corresponding author. Requests to access the datasets should be directed to MB, maria.barthel2@hawk.de.

Author contributions

MB, SW, BB, and JL contributed to conception and design of the study. MB wrote the first draft of the manuscript. MB and JL contributed to manuscript revision. All authors contributed to the article and approved the submitted version.

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EDITED BY
Lisa Milman,
Utah State University, United States

REVIEWED BY
Edoardo Nicolò Aiello,
IRCCS Istituto Auxologico Italiano, Italy
Thomas Picht,
Charité University Medicine Berlin, Germany

*CORRESPONDENCE
Carolin Weiss Lucas
✉ carolin.weiss@uk-koeln.de
Kristina Jonas
✉ kristina.jonas@uni-koeln.de

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Digital participation of brain tumour patients in the assessment and treatment of communication disorders

Carolin Weiss Lucas[1]*, Sophia Kochs[1], Johanna Jost[2], Ricardo Loução[1,3], Martin Kocher[3], Roland Goldbrunner[1], Dorothee Wiewrodt[2] and Kristina Jonas[4]*

[1]Centre for Neurosurgery, Department of General Neurosurgery, Faculty of Medicine, University and University Hospital of Cologne, Cologne, Germany, [2]Department of Neurosurgery, University Hospital Münster, Münster, Germany, [3]Centre for Neurosurgery, Department of Stereotactic and Functional Neurosurgery, Faculty of Medicine, University and University Hospital of Cologne, Cologne, Germany, [4]Department of Special Education and Rehabilitation, Faculty of Human Sciences, University of Cologne, Cologne, Germany

Introduction: Communication deficits have a severe impact on our social interactions and health-related quality of life. Subtle communication deficits are frequently overlooked or neglected in brain tumour patients, due to insufficient diagnostics. Digital tools may represent a valuable adjunct to the conventional assessment or therapy setting but might not be readily suitable for every patient.

Methods: This article summarises results of three surveys on the readiness for telemedicine among (a) patients diagnosed with high-grade glioma, (b) matched controls, and (c) speech and language therapists. The respective surveys assessed the motivation for participation in telemedical assessments and supposed influencing factors, and the use potential of digital assessment and therapy technologies in daily routine, with a spotlight on brain tumour patients and the future prospects of respective telemedical interventions. Respondents included 56 high-grade glioma patients (age median: 59 years; 48% males), 73 propensity-score matched neurologically healthy controls who were instructed to imagine themselves with a severe disease, and 23 speech and language therapists (61% <35 years; all females).

Results and discussion: The vast majority of the interviewed high-grade glioma (HGG) patients was open to digitisation, felt well-equipped and sufficiently skilled. The factorial analysis showed that digital offers would be of particular interest for patients in reduced general health condition ($p = 0.03$) and those who live far from specialised treatment services ($p = 0.03$). The particular motivation of these subgroups seemed to outweigh the effects of age, equipment and internet skills, which were only significant in the control cohort. The therapists' survey demonstrated a broad consensus on the need for improving the therapy access of brain tumour patients (64%) and strengthening their respective digital participation (78%), although digitisation seems to have yet hardly entered the therapists' daily practise. In summary, the combined results of the surveys call for a joint effort to enhance the prerequisites for digital participation of patients with neurogenic communication disorders, particularly in the context of heavily burdened HGG patients with limited mobility.

KEYWORDS

telemedicine, remote, speech, language, neurocognitive, video conference, glioma, neuro-oncology

1 Introduction

Communication is an essential part of our life and, thus, communication deficits (in the sense of impaired voice, speech, and language functions, pragmatics, and general communication skills) heavily affect health-related quality of life (Hilari and Byng, 2009; Neumann et al., 2019). Social participation can be significantly restricted depending on the severity of the communicative impairment and the underlying individual deficits, i.e., limitations in oral and written language production and reception, vocal and speech motor functions, and pragmatics (Baylor et al., 2011; Jin et al., 2021). This makes it even more difficult to maintain social relationships (Palmer et al., 2016, 2019). Unfortunately, communication disorders are common in patients with cerebral lesions like brain tumours, depending on their location and a variety of patient- and tumour-specific factors (Thomas et al., 1995; Kirkman et al., 2022; Ueda et al., 2022; Heinzel et al., 2023).

Timely detection of communication deficits using adequate diagnostic tests is crucial to identify the need for therapy and support. However, this leads to a dilemma. On the one hand, participation in (extensive) speech, language and communication examinations, and therapy sessions, can be challenging in heavily burdened and/or physically impaired patients. On the other hand, lack of participation in regular examinations results in missed diagnoses, leading to delayed or missing treatment of the respective communication deficits and associated limitations in self-sufficiency, social participation, and quality of life (Neumann et al., 2019; Palmer et al., 2019).

This is particularly relevant for brain tumour patients. This patient cohort usually suffers not only from a substantial psycho-oncological burden, even in cases of rather benign tumours (Jungk et al., 2021), but is also subjected to a demanding treatment schedule, including radiation- and chemotherapy, especially in the 1st months after tumour diagnosis and initiation of the neuro-oncological treatments. These factors might be primary reasons for the overall low rate of comprehensive neurocognitive assessments in these patients (Weiss Lucas et al., 2021).

Nowadays digitisation is progressing more and more in all areas of life. However, this entails challenges of digital participation, not only in and through digital technologies, but also within the digital world (United Nations, 2021; Jaecks and Jonas, 2022). In particular, the possibility of digital participation through respective technologies opens up new opportunities and can improve access to certain services, i.e., to the above-described diagnostic deficiency in brain tumour patients. Moreover, the use of digital technologies offers a pragmatic approach to overcoming spatial distances and organisational challenges, thereby improving access to (regular) appointments related to care. Such approaches have recently been reviewed and reported as a promising complement to traditional psychological support programs (Ownsworth et al., 2021). Likewise, they could help enhance patients' access to, e.g., speech and language therapy for patients with communication disorders. For instance, digital diagnostics could address transportation issues, especially in cases of patients with limited mobility or reduced general health conditions. Moreover, it could provide a pragmatical solution to the logistic challenge of integrating time-consuming face-to-face assessments and interventions in the hospital setting, which require a quiet room and focused participation over a relatively long period of time. Lastly, it could separate the testing or therapy setting from the often psychologically distressing hospital environment (cf. Wahl and Jankowski, 2019; Lauer, 2020).

One possible concern could be that brain tumours primarily affect elderly individuals, with a median age around 65 years and a peak incidence in the 7th decade of life (Tamimi and Juweid, 2017)—an age group which is commonly perceived to have relatively limited access and experience related to modern technologies, such as telemedicine applications and internet skills in general (Berner et al., 2020; Medienpädagogischer Forschungsverbund Südwest, 2021).

Over the recent years, a still very limited number of digital speech and language therapy tools have been reported for use in this context, beyond the pure telemedicine approach of conducting patient visits via video call, e.g., the LingoTalk app (Heide et al., 2023), the neolexon apps (Thunstedt et al., 2020), the Constant Therapy (Braley et al., 2021), and the ORLA (Cherney et al., 2021) digital/computer programs, as well as more recent virtual technology approaches (e.g., Marshall et al., 2020; Repetto et al., 2021). Further promising tools are still in development or awaiting publication, e.g., the TELL (Corsten and Iserloh, n.d.) and the Dysartrain (Klose and John, n.d.) platforms for interactive digital speech and language therapy. To date, there is little consensus regarding the equivalence/validy of such instruments, and recommendations regarding the use of distinct tools are missing.

This research project therefore deals with two main objectives:

(1) We set out to investigate the openness of age-matched subjects and HGG patients to telemedical participation. We hypothesised that the overall motivation for telemedical participation might be higher in a real-life scenario (i.e., HGG patients' perspective) compared to the imaginary severe disease context (i.e., healthy subjects' perspective), especially for patients with reduced mobility, far residency-to-hospital distance, and considerable (physical or mental) disability. Moreover, we assumed that the presence of technical resources and skills, as along with factors such as young age, male gender, and high educational level, might positively influence the receptiveness towards a telemedicine setting (Medienpädagogischer Forschungsverbund Südwest, 2021).

(2) We also explored the extent to which telemedicine approaches have already been incorporated into the daily routine practise of speech and language therapy professionals, both in general and particularly related to brain tumour patients with communication deficits.

2 Materials and methods

The research project was divided into three anonymous survey phases targeting: (I) 75 healthy controls, (II) 50 HGG patients, and (III) 20 German speech and language therapists. In the first phase, subjects were asked to imagine being severely ill and provide their estimated motivation to participate in telemedical assessments. In the second phase (real-life scenario), HGG patients were asked to estimate their motivation for such participation. Throughout both phases, important influencing factors, such as access to technical equipment, knowledge, and mobility were assessed to inform the factorial analysis. In the third phase, the use of telemedicine and other digital assessments and instruments in daily diagnostic and therapeutic practise for neurogenic communication disorders was evaluated among speech and language therapists, with a particular focus on the assessment and treatment of brain tumour patients.

2.1 Participants

2.1.1 Healthy participants

Healthy adults (of 18 or more years of age) were recruited from an institutional database and by public calls using print and social media in January 2021. To enable a well-balanced 1:1 matching whilst optimising the ratio between study effort and useable data, we pursued a strategy of age- and gender-stratified recruitment of the healthy cohort. To construct a matched cohort corresponding to the median age of HGG patients (∼65 years; Tamimi and Juweid, 2017), we planned to recruit 75 neurologically healthy respondents (i.e., 3: 2 matching of controls and HGG patients). Participants were contacted via phone call at least 24 h prior to survey execution, and were asked about their willingness to participate. Important inclusion criteria were German language as mother tongue as well as the absence of relevant neurological, communicative, and/or other neurocognitive deficits.

2.1.2 Patients

HGG patients were recruited between March and August 2021 with the intention of including ∼50 respondents in this study. Participants were identified using institutional databases of the university hospitals of Cologne and Muenster, and were asked, via phone call more than 24 h prior to survey execution, for their willingness to participate in the study. Important inclusion criteria were adult age (of 18 or more years), German language as mother tongue, histologically confirmed diagnosis of cerebral glioma WHO grade 3 or 4, as well as the absence of heavily disabling communicative or other neurocognitive deficits (thus impeding the informed consent and/or an evaluable self-report). Further demographic characteristics such as gender and educational level were assessed but did not represent in-/exclusion criteria.

2.1.3 Speech language therapists

Target professionals, i.e., speech and language therapists with professional and practical expertise, were recruited in September and October 2022 via professional and social networks, as well as personnel contacts of the authors, and were asked to participate in the survey anonymously. Here, we aimed at the collection of data from at least 20 respondents.

2.2 Survey components and administration

In a paper-pencil survey, which was distributed by mail, the existence of technical equipment, the availability of a household member or other well-known person with substantial computer and internet skills, as well as the participants' own computer and internet skills were assessed, along with the motivation to participate in a telemedicine assessment or therapy. Moreover, age, gender, and educational level were included in the data base.

2.2.1 Survey of healthy participants

At the beginning of the survey, healthy participants were instructed to imagine themselves in a situation of severe illness (Imaginary patients' perspective; cf. Supplementary material for wording and details).

2.2.2 Survey of patients

In the HGG patients' survey version, the following additional parameters were assessed: mobility, histological grade, and residency-related parameters i.e., number of inhabitants, public transport facilities, as well as distance from the closest centre for integrated neuro-oncology and from the treating neuro-oncological care unit (cf. Supplementary material for wording and details). Of note, the last-mentioned parameters were assessed by the authors according to the postal code of the participants' residency and of the respective healthcare centres.

Finally, the overall clinical status of the patients was also considered, using a binary scale to describe whether the patients were physically or mentally incapacitated to the extent that they could not care for themselves [according to a Karnofsky Performance Index (KPI; Karnofsky and Burchenal, 1949) of 70–100/100 according to the latest documented medical assessment].

2.2.3 Survey of speech and language therapists

The assessed parameters of the conditionally programmed electronic survey included caseload characteristics (i.e., the relative number of patients seen by therapists with a diagnosis of HGG vs. other acquired neurogenic communication disorders), and the frequency of use of telemedicine and other digital technologies in the assessment and/or therapy of acquired neurogenic communication disorders. Both the type of the digital technology and the type of communication disorder were asked to be further specified.

Furthermore, speech and language therapists were asked to rate the extent to which they believed that telemedical vs. in-person settings were therapeutically equivalent, which patient subgroups might be more vs. less suitable for telemedical approaches, and how digital participation could be improved.

Regarding brain tumour patients, speech and language therapists were also asked if they consider the referral rate for the therapy of communication disorders sufficient and, if not, to speculate over possible reasons.

Moreover, age, gender, and educational level, as well as the professional qualification and work environment of the survey participants were included in the database.

TABLE 1 **Overview of demographic characteristics and survey results of HGG patients vs. propensity-score-matched (PSM-) controls.**

Demographic characteristics	HGG patients	PSM-controls	Fisher exact/*T-test*
Age (median [range])	59 [21;88]	60 [25;92]	$p = 0.544$
Male gender	48%	50%	$p = 1$
High educational level	45%	54%	$p = 0.450$
Technical equipment			
Computer or tablet	95%	88%	$p = 0.527$
Computer	93%	84%	$p = 0.237$
Tablet	46%	54%	$p = 0.255$
Web-camera	63%	64%	$p = 1$
Headset	45%	34%	$p = 0.333$
Computer/internet skills			
Own skills	57%	52%	$p = 0.705$
Skills of household member	36%	48%	$p = 0.251$
Unsure	11%	20%	$p = 0.292$
No skills in household	11%	11%	$p = 1$
Motivation			
Generally motivated	54%	41%	$p = 0.256$
Motivated due to pandemic	14%	16%	$p = 1$
Unsure	18%	27%	$p = 0.364$
Unmotivated	14%	16%	$p = 1$
Mobility (trip to medical appointment)			
Driving own car			
Possible	18%		
Regularly chosen option	14%		
Driven by household members	61%		
Taxi	20%		
Bike/walking	20%		
Public transport	4%		
Clinical status			
Self-caring ability (physical and cognitive)	86%		
Logistics (residency ↔ treating medical unit)			
Inhabitants (median [range])	23,145 [1,357;1,088,040]		
Distance (median [range])			
To closest neurooncological unit	20 [0;73]		
To treating neurooncological unit	32 [0;402]		
Public transport facilities of residency			
Railway	80%		
Bus terminal	75%		
Bus stop	98%		

The table provides the data of the two equally sized groups (n = 56 each). Of note, mobility data (related to the treatment-coordinating hospital) were not obtained from the PSM-control subjects.

TABLE 2 *N*-fold cross table of significant factors by motivational level.

Cohort	Factor		Motivational level				Corr. rho (uncorrected *p*-value)
			0 un-motivated	1 unsure	2 motivated in pandemic	3 generally motivated	
PSM-controls	Complete technical equipment	Yes	0	2	1	15	0.55^{***} (1.3×10^{-5})
		No	9	13	8	8	
	Adequate skills in household	Yes	2	9	9	21	$0.54^{***,\$}$($1.5 \times 10^{-5}$)
		No	7	6	0	2	
	Age (years)	≥60	7	9	4	8	$-0.31^{*,\S}$(0.018)
		<60	2	6	5	15	
HGG patients	Self-caring clinical status	Yes	8	10	7	23	−0.29 (0.028)
		No	0	0	1	7	
	Close distance to neuro-oncological unit (km)	<33	7	5	4	12	−0.28 (0.034)
		≥33	1	5	4	18	
	Complete technical equipment	Yes	2	1	3	15	0.22 (0.101)
		No	6	9	5	17	

Of note, for the binarisation of ordinal or metric factors, cut-offs were set to the group median, i.e., travel distance of 33 km, age of 60 years, and skills: adequate own digital skills or respective skills of household member.

Corr, Pearson's point-biserial correlation; PSM, Propensity score based matched.

Grey font: weak statistical trend, $0.05 < p < 0.2$.

$^{*}p < 0.05$ (FDR-corr.), $^{***}p < 0.001$ (FDR-corr.).

$^{\$}$Correlation with ordinal variable of household skills (four levels): $p = 4 \times 10^{-8}$ (i.e., $p < 0.0001$, FDR-corr.).

§Correlation with metric variable age: $p = 0.0015$ (i.e., $p < 0.05$, FDR-corr.).

2.3 Statistical analysis

The statistical analysis was performed using LibreOffice Calc (version 6.4.7.2) and R Studio (version 2023.06.1, based on R version 4.3.1). The statistical threshold was set to $p < 0.05$ by default. Notably, data distribution was considered not normal if the Shapiro-Wilk test resulted in a significance estimation of $p < 0.01$. Whenever appropriate, false discovery rate (FDR) correction was applied for multiple comparisons (Benjamini and Hochberg, 1995).

Propensity score-based, pairwise (1:1) matching of control subjects to the HGG patients' cohort was performed using the "optmatch" package in R and the {matchit} function (Hansen and Klopfer, 2006). The underlying algorithm uses the sum of the absolute pair distances between the respective control units and the corresponding treated units in the matched sample, similar to the nearest-neighbour matching method. This procedure automatically allocates the best matching partner out of the control group to each patient (not allowing for multiple allocation of controls), in this case considering the three major demographic parameters age, gender, and educational level (binary scale with "high" defined by holding a university entrance qualification) as matching criteria. The resulting matched control group is referred to as Propensity-Score-Matched-control (PSM-control) group throughout the manuscript.

For group comparisons between binary-scaled data, Fisher's exact test was used, whereas for comparisons between metric variables, Student's T-test or Wilcoxon's rank sum test was applied (for normally distributed vs. non-parametric data, respectively).

To evaluate the factorial influence on the motivation for telemedicine participation, the factors motivation and skills were converted into four-level ordinal scales, ranging from 0 (not motivated/unskilled) over 1 (unsure) and 2 (pandemic-dependent motivation/household member skilled) to 3 (generally motivated/own skills). For correlations with continuous or ordinal parameters, Spearman's rank correlation coefficient (rho) was calculated. For associations with binary-scaled parameters, point-biserial correlations (corr) were computed. The following factors were considered for multiple correlations analysis: age (continuous), gender (binary), educational level (binary), the presence of complete technical equipment (binary), the availability of skills in the household (four levels), patients' car mobility (binary), dependency on a driver (binary), size of the town/city of residency (continuous), distance between residency and treating neuro-oncological unit (continuous), and the self-caring clinical status (binary).

Moreover, a multivariate ordinal regression analysis was performed using the {vgm} function for vector generalised linear model fits from the "VGAM" package (Yee and Wild, 1996; Yee,

2015) in R. To this end, feature selection was performed based on the results of the aforementioned correlation tests, using a liberal statistical threshold of $p < 0.2$. To achieve homogeneous scale levels among included factors, the selected non-binary features were binarised according to the group median.

To explore and visualise the distributions of age and travel distance (from home to the specialised treatment unit) across motivational levels, violin plots with added scattered dots were created using the "gglot2" library (Wickham, 2016) and the {geom_sina} function of the "ggforce" library in R (Pedersen, 2022).

3 Results

3.1 Readiness of HGG patients vs. PSM-controls for telemedicine

3.1.1 Participants

Seventy-three healthy subjects (47% males, 53% females) were surveyed, most of them with high educational level (62% graduated with a university entrance qualification) and with a median age of 64 years, ranging from 24 to 95 years.

In addition, 56 HGG patients (age median: 59 years; range: 21–88 years; 48% males/52% females; 45% with a university entrance qualification) including 91% glioblastoma patients (WHO grade 4) and 9% patients with anaplastic glioma (WHO grade 3) were included in the study.

To balance the patients' age, gender, and educational level against a matched cohort of healthy subjects, two equally sized cohorts of patients and healthy subjects (56 subjects each) were composed by pairwise matching using the aforementioned propensity-score matching procedure (cf. methods, statistics). The respective demographic characteristics of the patient cohort and the resulting PSM-control group (with an age median of 60 years, 50% males/females and 54% of high educational level) are summarised in the top section of Table 1.

3.1.2 Practical prerequisites for digital participation

The survey results show that, overall, appropriate equipment for digital participation is widely available in private households. Among HGG patients, 93% of the participants have access to a computer, and the majority (63%) possess an additional web camera, whereas more than a third of the participants stated having a headset available (45%).

Beyond the technical facilities, more than half of the survey participants stated that they felt sufficiently comfortable themselves with internet-related applications (57%), and the vast majority reported sufficient internet skills in their household (79%). However, some participants (11%) were unsure about the availability of sufficient skills, and 11% reported no appropriate digital experience in their household. No statistically significant group differences were found between the patient and the PSM-control cohort for any of these criteria (Table 1).

3.1.3 Motivation for telemedical participation and related factors

Again, no significant difference was observed regarding the response behaviour of both groups (cf. Table 1 for groupwise results and comparative statistics). Approximately half of the patient survey participants (54%) reported a general willingness to participate in telemedical assessments or interventions, also beyond the context of a pandemic. Another 32% of the respondents would consider participation driven by a pandemic or were otherwise unsure. The minority (14%) claimed to be unmotivated for digital participation in the medical context.

To investigate the influence of various factors on the motivation for telemedical participation, correlation analyses were performed separately for both the HGG patient and the PSM-control cohorts.

In **HGG patients**, neither age (rho $= -0.08$; $p = 0.535$), gender ($p = 1$), or education ($p = 0.450$) nor availability of skills in the household (corr $= 0.05$; $p = 0.689$) significantly influenced motivation. For this cohort, significant correlations were found with not self-caring clinical status (ordinal variable; rho $= -0.29$, $p = 0.030$) as well as with the distance of the residency from the treating neuro-oncological unit (metric variable; rho $= 0.28$, $p = 0.035$), corresponding to a significant difference between the patients with long vs. short distance (i.e., $</\geq 33$ km; $p = 0.048$). Moreover, a statistical trend was observed for the availability of full technical equipment (corr $= 0.22$; $p = 0.101$). In contrast, for the **PSM-control cohort** (imaginary patients' perspective), significant associations were found with the factors age (metric variable; $p = 0.002$, rho $= -0.41$), equipment ($p < 0.001$) and skills ($p < 0.001$), whereas no significant effect was apparent for the factors gender ($p = 0.382$) and education ($p = 0.596$). Correlations of motivational level with binary or binarised factors reaching the level of at least statistical trends are summarised in Table 2. For an additional visual impression of the distributions of age and travel distance across motivational levels, see Figure 1.

Based on the results of the correlation analysis and applying a threshold of $p < 0.2$ for feature selection, multifactorial ordinal regression analysis was performed including the remaining binary/binarised factors (see Table 2) and highlighted that the strongest influence expressed by the odds was attributed to the availability of complete technical equipment for both cohorts (PSM-controls: odds $= 9.6$ vs. HGG patients: odds $= 2.1$; Table 3). The supposed age effect in the PSM-control cohort proved non-significant in the multivariate analysis ($p = 0.536$; Table 3). However, at least for PSM-control subjects, an additional effect of the in-house availability of internet skills was shown (odds $= 2.8$, $p = 0.005$). Although not reaching the level of statistical significance, the HGG patients' travel distance from home to the medical treatment unit and the overall clinical status contributed to the model, with a comparatively higher odds being attributed to the clinical status (odds $= 0.2$ vs. 0.4; Table 3). This may reflect that the vast majority (88%) of patients in incapacitated clinical status were generally motivated for a telemedicine participation (cf. Table 2).

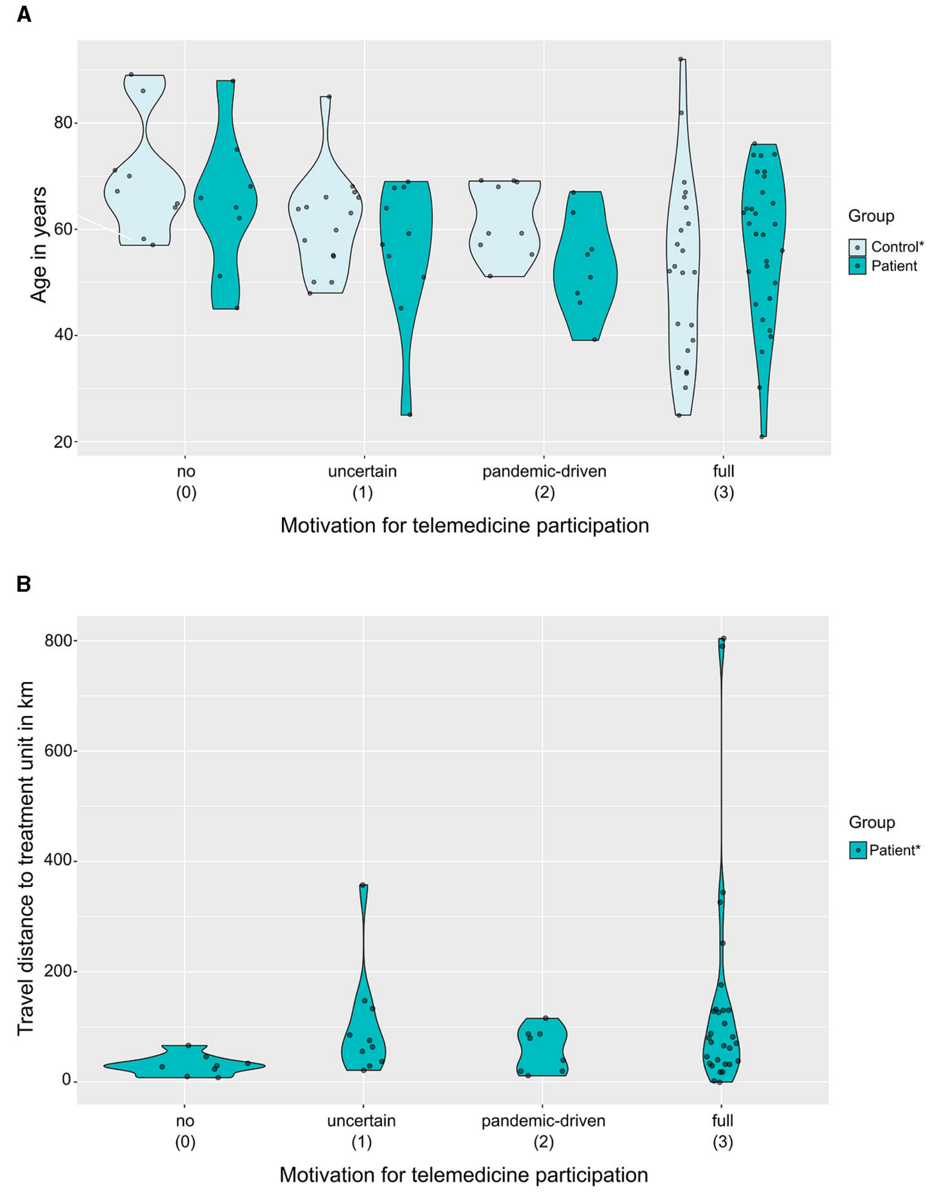

FIGURE 1
Distribution of age and the distance of the treating neurooncological unit from home, grouped by motivational levels. The violin plots with added scattered plots illustrate the relationship of the motivational levels (x-axis) with **(A)** age (y-axis), grouped by patient (blue) vs. PSM-control (light blue) cohorts; and with **(B)** the travel distance from home to the neuro-oncological treatment unit of the HGG patients. *Significant Spearman's correlation: $p < 0.05$.

3.2 Survey of speech and language therapists

3.2.1 Participants

Twenty-three female speech and language therapists, mostly of young age (61% <35 years; 9% 35–39 years; 4% 40–44 years; 13% each: 45–49 and 50–54 years) participated in the survey. the vast majority held a university diploma/master's degree (87 %), and approximately a third of the participants worked in either an outpatients' clinic (39%), a rehabilitation centre (30%), or an acute care hospital (35%), and 13% in a nursing home. Thirteen percent of the participants were additionally affiliated to an educational institution (professional school or university), and 17% were self-employed.

3.2.2 Digitisation in acquired neurogenic communication disorders

The vast majority of the participants (91%) stated that they regularly worked with individuals diagnosed with neurogenic communication disorders (i.e., at least 15% of their case load). Only 9% of the respondents reported encountering neurogenic communication disorders very rarely (i.e., in <1% of the consultations) in clinical practise.

A third of the participants (35%) responded that they used telemedicine and other digital instruments or procedures for the diagnostics or therapy of neurogenic communication disorders. Most of them (88%) apply telemedicine and other digital tools for aphasia therapy, with half of them using them regularly and the other half on an exceptional basis (i.e., in <5% of the therapy sessions). Of note, the regular use of video conferences in this context was unusual (13%).

Regarding the equivalence of the diagnostic/therapeutic value of video conferences respectively, 75% stated that the telemedicine setting would yield worse results than an in-person setting, whereas the remaining 25% assumed equality.

There was a broad consensus among survey participants that certain patient characteristics are particularly (un)suitable for a telemedicine diagnostic/therapy setting for neurogenic communication disorders. For instance, elderly and severely incapacitated patients were widely regarded as unsuitable by several participants, whereas young and cognitively fit patients, were assumed to be well-suited, especially if they live in rather remote places and/or have limited mobility (Table 4). Interestingly, distinct survey participants added that they regard video-based remote intervention particularly useful to increase the frequency of therapy sessions, also in the context of returning to work, rather than to fully replace the in-person setting. Others pointed out that patients with dysarthria and (chronic) aphasia without major additional cognitive deficits might represent a rather good target for a telemedicine therapy setting. Likewise, one participant suggested the Lee Silverman voice treatment (LSVT) for Parkinson's disease as a particularly well-suited telemedicine application.

TABLE 3 Ordinal regression analysis to evaluate factorial influence on the degree of motivation for telemedicine participation.

Factor	*z*-value	*p*-value	Odds
PSM-controls			
Age ≥ 60 years	0.6	0.536	0.7
Complete technical equipment	3.0	0.003^{**}	9.6
Adequate skills in household	2.8	0.005^{**}	7.4
HGG patients			
Self-caring clinical status	−1.6	0.108	0.2
Distance residency—treating neurooncological unit < 33 km	−1.5	0.136	0.4
Complete technical equipment	1.3	0.211	2.1

Of note, distance, age, and skills level were included as binarised measures (cf. Methods and Statistical analysis).
$^{***}p < 0.001$.

3.2.3 Experience with brain tumour patients

The majority of the participants (73%) have experience with the diagnosis/treatment of communication disorders in brain tumour patients; however mostly rather sporadically. Only four participants responded that brain tumour patients constitute at least 20% of their caseload. Of note, most of these participants responded that in their experience, the referral of brain tumour patients to speech/communication therapy happens either too late (91%) or insufficiently (64%). The survey participants suspected that lack of knowledge/awareness of the therapeutic potential, lack of time/workload, as well as different priorities (e.g., tumour control) of the medical staff could be important reasons for inappropriate referral.

Interestingly, 78% of the survey participants expressed the opinion that digital participation of brain tumour patients in the diagnostics and therapy of communication disorders should be improved. They suggested enhancing access and introduction to digital media and participation, as well as developing specific apps for individualised speech, language, and communication training (e.g., for self-instructed therapy) as possible ways to achieve advancements in this context.

TABLE 4 Presumed suitability of patients for telemedicine.

High suitability		Low suitability	
Characteristics	*N* (proportion)	Characteristics	*N* (proportion)
Good cognitive performance	6 (43%)	Advanced age	8 (42%)
Reduced mobility/necessity of medical home visits	6 (43%)	Cognitive deficits	8 (42%)
Long travel distance	5 (36%)	Poor technical skills/resources	8 (42%)
Young age	4 (29%)	Strong deficits (e.g., receptive aphasia and speech apraxia)	7 (37%)
Good technical skills/resources, affinity with media	4 (29%)	Vision/hearing deficits	3 (16%)
Poor general health condition	2 (14%)	Poor general health condition	2 (11%)
Supporting household member	2 (14%)	Others: dysphagia, non-native speakers, poor collaboration, and nursing home residents	1 (5%) each

The table summarises the essence of the free text entries made by the surveyed therapists.

4 Discussion

The results of our surveys show that telemedicine applications could have great, still largely unexplored potential for the treatment of brain tumour patients. The increased use of digital technologies could help to close the diagnostic and therapeutic gaps in this particular, heavily burdened patient group and spare them long and exhausting journeys to follow-up examinations (eventually without pathological findings). In the therapeutic setting, for example, the diagnosis and therapy of speech, language, and communication disorders in brain tumour patients could be improved and the frequency of treatment increased.

Although only a minority of German speech and language therapists currently use telemedicine or other digital diagnostic or treatment tools on a regular basis (in- or outside the context of brain tumour patients), there is a broad consensus that improving the participation of this patient cohort through telemedicine and other digital technologies is worthy of further attention and enhancement.

The vast majority of the interviewed HGG patients was open to digital technologies, was overall well-equipped, and felt sufficiently skilled to participate in video-based telemedical assessments and interventions. Only a few of all interviewed subjects (15%) refused such receptiveness. In large agreement with the assumptions expressed by the participating speech and language therapists and our initial hypotheses, the factorial analysis of the HGG patients' survey showed that digital offers would be of particular interest to patients in reduced general health condition and those living in rather remote locations, far from centralised treatment offers. Interestingly, the particular receptiveness of these patient subgroups to digitisation seemed to outweigh the effects of age, equipment, and internet skills, which were only evident in the PSM-control cohort.

4.1 Openness to telemedical participation: imaginary scenario vs. "real-life"

Our hypothesis that the "real-life" HGG patients' perspective might render subjects more receptive to digital participation compared to imaginary severe disease, i.e., healthy subjects imagery perspective, was not proven in this study. This is possibly due to the sample size, which was not designed to show (rather) weak statistical effects. Although we observed a higher proportion of "unsure" subjects in the PSM-control cohort (27% vs. 18%) against a higher percentage of generally motivated patients compared to PSM-controls (54% vs. 41%), these differences were not statistically significant. On the other hand, the lack of significant differences in response behaviour may suggest that the imaginary disease instruction of PSM-controls could be an adequate model to assess telemedicine readiness and, thus, be helpful to accelerate future surveys of this type by prioritising more readily available healthy cohorts.

4.2 Availability of technical equipment, digital skills, and support

The availability of technical equipment at home and corresponding knowledge, possibly conveyed by a relative or friend, are fundamentally conducive to participation in telemedicine offers. Across both PSM-control and patient cohorts, this survey demonstrated a good overall availability of the basic technical equipment, with >90% possessing a computer or tablet and approximately two-thirds of people being equipped with a webcam. The results are comparable to the results of the SIM study (Medienpädagogischer Forschungsverbund Südwest, 2021), a comprehensive investigation of the media use of people over 60 years of age in Germany, although our survey showed even higher rates of appropriate equipment (computer, tablet or similar). A possible explanation for this difference could be the high proportion of people with higher educational qualifications in our survey. Another encouraging aspect of this study is the largely positive assessment of one's own abilities or the abilities of a person in one's own household, enabling the use of telemedicine offers. In contrast, only 11% of the survey participants denied having adequate computer and internet skills in the household, which largely overlapped with those participants lacking technical equipment. As a result, ~90% of the target population, including a large proportion of patients in advanced age groups, is technically eligible for telemedicine offers. This highlights the great potential and expediency of expanding telemedicine applications for brain tumour patients.

4.3 Effects of demographic and disease-related factors on motivation for digital participation

In addition to technical resources and skills, willingness to accept telemedicine offers are also decisive for their successful implementation in clinical practise. In this study, approximately half of the respondents were intrinsically motivated regarding telemedical services such as video-based assessments and therapy, making them readily available. Another third were unsure or linked their motivation to the framework conditions of a pandemic. Although the principle problem of an unacceptable underrepresentation and under treatment of communication disorders (and other neuropsychological and neurocognitive disorders) in brain tumour patients remains widely unchanged after the pandemic, it seems noteworthy that the pandemic, despite its myriad of negative impacts, seems to have significantly improved access and openness to participation through digital technologies (Cacciante et al., 2022; Jaecks and Jonas, 2022) among people and professionals of all generations. This is partly reflected by the 15% of survey respondents who reported their motivation as being driven by the pandemic.

Especially among this undecided patient group, better information about the possibilities and requirements of telemedical tools, not only as stand-alone assessments/interventions but also as a practical complement to the traditional, in-person setting, could help to increase willingness to participate. Only 15% reported being unmotivated, which again largely overlapped with survey participants lacking technical equipment and/or in-house skills. Conversely, up to 85% of the target group showed at least a possibly positive attitude towards medical digitisation. At first glance, surprisingly, and in contrast to both our initial assumptions and the results obtained from PSM-controls, neither age nor any other assessed demographic factor played a significant role in the extent of motivation towards telemedicine participation among HGG patients. This could be due to the strong effects of other parameters, especially non-independent general health status, which may have significantly outweighed weaker effects in the patient cohort. In other words, the real-life challenges related to disability and the efforts related to travelling might render even elderly and less well-equipped or skilled patients interested in telemedicine interventions.

The key findings of the factorial analysis, however, i.e., a significantly higher motivation level among considerably incapacitated patients and, as a trend, among patients with a long distance between home and neuro-oncology treatment unit, are very much in line with our initial assumptions and underline the need for investment in digitisation. Our data may reflect the fact that HGG patients with high rehabilitation needs are unfortunately the least accessible due to their limited mobility. Furthermore, the results suggest that regions with a rather thin network of available treatment units might be particularly worthy of introducing telemedicine assessments and interventions.

4.4 Status-quo of incorporating digitisation into clinical practise: between opinion, experience, and innovative ideas

Although there is growing agreement that digital technologies can be helpful, especially to people with disabilities, digitisation in the field of neuro-oncology is still in its beginnings. Even among the responding speech and language therapists, there is a broad consensus that participation of brain tumour patients through digital technologies in the diagnosis and therapy of speech, language, and communication disorders should be improved. Despite the great awareness of the special needs of patients with limited mobility, poor general condition and long journeys to the therapist, the proportion of speech and language therapists who use telemedicine or other digital tools on a regular basis is very low. In this context, it seems appropriate to point out that only one of the participants indicated having personal experience with video-based telemedical interventions.

The lack of regular use of telemedicine and other digital technologies in our sample of speech and language therapists thus could be caused by lack of personal experience with these technologies in daily practise. Also, a general scepticism about the use of digital technologies in speech and language therapy due to concerns about being replaced by them as well as the assumptions of an assumed lack of suitability for patients of advanced age (Jaecks and Jonas, 2022) could be reasons for non-application. The latter in particular could not be proven in our patient survey data. Another factor seems to be the assumption of 75% of the surveyed therapists that, in a digital setting, both the reliability of diagnosis and the improvements achievable by therapy are inferior to the outcome of an in-person setting. It seems obvious that teletherapy is not the treatment of choice for elderly patients with brain tumours and presumed language-independent cognitive deficits. However, the recent data on the equivalence of in-person vs. telemedical or otherwise digital (diagnostics and) therapy of language, communicative, and cognitive functions do not paint a uniform picture (Kester, 2020; Weidner and Lowman, 2020). Research from the times of the COVID-19 pandemic regarding the this question suggests that the more similar in-person and digital approaches are in terms of, for example, input and output modality or other surrounding factors (special equipment needed; need of e-helpers), the more likely it is that the approaches are equivalent, and that results and effects are comparable (Kester, 2020). In the context of blended teaching concepts, e.g., based on online e-learning, have even proven to achieve better knowledge outcome than traditional strategies (Vallée et al., 2020). These surprisingly clear meta-analytic results might point towards a similarly great potential of blended therapy concepts, e.g., in the context of speech and language therapy. Likewise, recent evidence has been provided regarding the implementation telemedicine among speech and language therapists working with adults with neurogenic communications disorders (e.g., Cacciante et al., 2021; Gherson et al., 2023; Teti et al., 2023).

An important point noted by several responding speech and language therapists is that digital devices alone can hardly replace the in-person setting. However, they can be a great help in providing access to therapy for patients who would otherwise not have access to services and in enabling increased treatment frequency or consolidating treatment effects, e.g., through self-instructed repetition of defined tasks.

Finally, it seems important to distinguish between fully automated/self-directed assessment or treatment tools and video-based telemedical conferences, which offer far more interactive possibilities and make the telemedical intervention almost in-person, providing a major advantage for the two most vulnerable patient groups: patients in poor general health and those living far away. On the other hand, self-instructed tools save human resources on the part of therapists and can thus partly compensate for the imbalance between demand and supply of professional treatment in this field.

Other major challenges for speech and language therapy in HGG patients compared to other cohorts include time management, treatment priorities, and the psycho-oncological burden of the disease. The authors agree with the opinion of some responding speech and language therapists that all these parameters might contribute to the fact that the referral rate of brain tumour patients with communication disorders to appropriate therapy is largely insufficient. Patients with malignant brain tumours are usually overloaded with radio-oncology and neuro-oncology appointments, especially in the early phase after diagnosis, often accompanied by psycho-oncological interventions, physiotherapy and/or occupational therapy sessions due to third party burdens/deficits. In addition, many of them are not allowed to drive due to a clinical history of epileptic seizures, which makes the repeated in-person medical and therapy visits in many cases a major challenge. Therefore, telemedicine interventions might be particularly well-suited to improve access to speech therapy while addressing the special needs of HGG patients.

4.5 Limitations

This study summarises the opinions and experiences as well as the technical possibilities of both the target group (of HGG patients) and the speech and language therapists in order to shed light on the opportunities and obstacles linked to telemedical applications in speech and language diagnostics and therapy of those patients. Unfortunately, due to the anonymous character of the surveys and our attempt to limit the survey length to the necessary minimum in order to achieve a high compliance rate and avoid missing values, only very little clinical data have been obtained from the interviewed patients. Additional information, for instance on the nature and the degree of eventual communication impairments or on the status of therapy and disease, would have been of great value to widen the field of interpretation of the survey results.

Moreover, it must be considered that the interview statements of healthy controls, patients and therapists might not readily translate to the effective daily clinical practise, which reflects a common assumption in market research. Accordingly, previous studies in the field like the BIG CACTUS randomised-controlled trial have demonstrated that positive effects of digital treatment strategies might (i) not necessarily improve daily-living communication skills or health-related quality of life (Palmer et al., 2020), and might (ii) be biased by the therapists' and the patients' attitude and knowledge regarding the implementation of digital technologies into therapy practice (Burke et al., 2022).

Another major limitation of the surveys is the relatively limited number of participants, linked to a certain regional bias, as the HGG patients and probably also the therapists were mainly recruited from the mid-west of Germany (a highly developed region with a relatively dense network of medical and speech and language therapy services) due to the affiliations and the regionally focused professional network of the authors.

Thus, the data are not sufficiently powered to demonstrate small effects and might not be readily transferable to a different socio-geographical background. In the authors' opinion, however, the core message of a profound need for expanding telemedical infrastructure and access might be rather underestimated due to the assumed socio-geographical bias.

4.6 Outlook

Given the encouraging openness of HGG patients to telemedicine and the broad consensus among the therapists that the access to speech and language therapy and digital participation in this context need improvement, it seems timely to develop strategies for such progress. Efforts may involve public and social media, patient, caregiver, and therapist (professional) organisations and networks to raise awareness and increase openness for telemedical and other digital assessment/therapy approaches by highlighting the wide variety of possible digital solutions and critically discussing their respective benefits and limitations. Moreover, it seems advisable for researchers and interested clinicians in the field to join forces in order to further elaborate on the available spectrum of tools that enable user-friendly telemedical and other digital assessment/therapy options tailored to the target patient population. In this context, it might be of great advantage to achieve non-commercial and free release of the respective tools. However, not only the recent legislative advances regarding data safety issues as well as the subjection of medical software products to approval for clinical use, but also the increasing automatation of the respective tools, turn their design and validation process so complex and cost-instensive that a purely non-commercial development has become challenging.

Such efforts could not only represent a major advance in the treatment of language and communication impairments *per se* but could also be used to facilitate other medical applications such as a more comprehensive and regular testing of neurocognitive functions, which is currently rarely implemented in routine clinical practise (Weiss Lucas et al., 2021). Early detection of cognitive decline in HGG patients may not only help to better identify treatment/support needs, but also to anticipate suspected tumour recurrence (Armstrong et al., 2003; Meyers and Hess, 2003; Butterbrod et al., 2019), and thus possibly even improve the survival outcome of those patients.

5 Conclusion

The morning after the pandemic leaves us with the reverberations of the increasing acceptance of telemedical tools that can be sensed across generations from the response behaviour of the surveys presented here. However, the great potential that lies in amending digital technologies to the in-person setting seems to have hardly found its way into the daily practise of speech language therapists, thus leaving the substantial problem of under detection and under treatment of speech and language disorders in brain tumour patients widely unchanged. Achieving a paradigm shift in this context may be particularly important for HGG patients who not only struggle with neurogenic speech, language and communication disorders, but also with mobility and time limitations due to the impact of further neurological deficits as well as the side effects and time schedule associated with tumour treatment. An expansion of accessible (and ideally free) telemedicine applications could serve as crucial support, empowering the therapists' answer to the currently underestimated need for assistance. Therefore, joint efforts to newly develop and further improve digital tools tailored to this patient population seem timely and worthwhile.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors upon reasonable request, without undue reservation.

Ethics statement

The studies involving humans were approved by Ethics Committee of the Medical Faculty of the University of Cologne (File No. 14-109). The studies were conducted in accordance with the local legislation and institutional requirements and according to the guidelines for good clinical practise as well as with the Delaration of Helsinki. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin because, the data consist of anonymous survey data. According to legislation and its interpretation by the Local Ethics Committee, no written informed consent is necessary in this case. None of the participants received financial compensation for the participation in the survey.

Author contributions

CW: Conceptualisation, Data curation, Formal analysis, Investigation, Methodology, Supervision, Visualisation, Writing – original draught, Writing – review & editing. SK: Conceptualisation, Investigation, Writing – review & editing. JJ: Investigation, Writing – review & editing. RL: Investigation, Methodology, Writing – review & editing. MK: Methodology, Writing – review & editing. RG: Resources, Writing – review & editing. DW: Conceptualisation, Investigation, Writing – review & editing. KJ: Conceptualisation, Investigation, Methodology, Resources, Supervision, Writing – original draught, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1287747/full#supplementary-material

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