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RESEARCH

What is It Like to Communicate While Locked-In? First-person Perspectives On Communication and Implications for Design of Brain-Computer Interfaces

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Abstract Brain-Computer Interfaces (BCIs) promise to resolve the communication problems of people who are unable to move and speak due to paralysis (Locked-In Syndrome/State; LIS). Current BCI research focuses largely on improving speed and accuracy of BCI-based communication, but this functional perspective fails to capture the existential importance and richness of human communication. In phenomenological studies of human experience, communication is typically theorized as embodied and relational. Here, we propose to use this phenomenological perspective to capture the experience of the communication difficulties for people with LIS and to assess the potential impact of communication solutions such as BCIs. We present the results of a semi-structured phenomenological interview study into experiences of communication of people with LIS and their daily communication partners. We found that people with LIS and daily communication partners are not only at risk of not being able to communicate with each other, but as a result may not see and perceive each other as full persons. Vice versa, access to and richness of bodily and technological communication are enabling factors for the sense of 'relational personhood' – the extent to which people acknowledge one another as full persons. These findings pave the way for a new outlook on BCI design and urge to further explore the inclusion of relational personhood in the clinical outcome assessment of BCIs for people with communication impairment and their daily communication partners.

Keywords Brain-Computer Interfaces · Locked-in Syndrome · Phenomenology · Personhood · Communication · Ethics · User-centered design

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Introduction

Locked-In Syndrome, or the Locked-In State, (LIS) is characterized by complete paralysis in the presence of intact consciousness and cognition [1–4].[1]LIS can occur suddenly because of a stroke or accident, or gradually as the end-phase of diseases such as Amyotrophic lateral sclerosis (ALS). Clinical literature distinguishes three types of LIS: classic LIS (when only eye-movements are preserved), incomplete LIS (when other residual voluntary muscle movements are possible as well), and total LIS (when movement and communication are completely absent) [2].

People with classic or incomplete LIS typically communicate by making small physical movements such as blinking the eyes or moving a finger to respond to closed questions or select letters recited by a communication partner to form words. Residual movements can also be used to operate Augmentative and Alternative Communication (AAC) technologies, such as eye-trackers, which allow users to select letters, words, and images on a computer screen. However, for some people with LIS, conventional AAC-devices can be hard or even impossible to control because their residual movements are weak, inconsistent or absent [5–8]. Over the last two decades, developments in neurotechnology centered around using Brain-Computer Interfaces (BCIs) as AAC-devices have started to afford people with LIS a form of communication that relies on brain signals, instead of muscle activity [9–13]. Recently, significant successes have been accomplished in demonstrating that implantable BCIs could offer novel approaches to typing and pronouncing words and sentences via a computer [14–22]. These accomplishments are the result of fast progress in neural signal decoding and in the development of implantable BCI hardware and are paving the way for implanted BCIs to become a clinical therapy for the communication impairment of people with severe motor impairment, including those with LIS.

Key questions in these developments concern what functions or experiences BCIs truly restore, and how their clinical and personal impact on users' lives can be meaningfully evaluated and quantified. In the BCI field, there is currently no universally accepted set of clinical outcome assessments (COAs) to evaluate this impact. These issues are of critical relevance for the eventual clinical implementation and reimbursement of BCIs, and therefore a topic of intense discussion and investigation [23–25]. In most studies on implanted BCIs for communication (cBCIs), the success or value of the technology is expressed using metrics such as communication speed, accuracy, or information transfer rate [16, 18, 21, 22, 26]. Also, studies investigating the wishes and needs of potential users of cBCIs typically zoom in on aspects such as speed, accuracy, and control methods [27–32]. Although these are useful performance metrics for quantitatively assessing the effectiveness and efficiency of cBCIs, they do not capture their full impact on the cBCI user. Therefore, cBCI stakeholders emphasize the importance of integrating the subjective experiences of cBCI users in the clinical outcome assessment of cBCIs. Several studies have used (health-related) quality-of-life assessments for this purpose [24]. Yet also these concepts seem insufficient and too generic to capture the full value of a BCI for people with severe motor and speech impairment. In a recent workshop on developing COAs for BCIs, the insufficiency of current assessment metrics was illustrated as follows: "how do we capture that reconnection between father and daughter after using an implanted BCI technology on day two of use?" [23], p. 19, [14].

Indeed, if we think about experiences of communication, it is more than the ability to transfer information to someone else. When we exchange a "hello" with a friend on the street, we do more than sharing the semantic content of the word hello as efficiently and accurately as possible. Phenomena such as the tone of our voice, the posture we take on, where we direct our gazes, and our facial expressions, all shape how we express and experience the communicated hello. Moreover, through communicative exchanges, we establish and maintain relationships, encounter one another as persons who matter and are worthy of address [33, 34], express and regulate our emotions, share our values and opinions, express our inner worlds, etc. These rich embodied dimensions

[1] See [75] for a nuanced and detailed overview of medical terminology, its history, and how it relates to the experience of LIS. In line with contemporary medical terminology, we use the term LIS to refer to 'the Locked-In Syndrome' and 'the Locked-In State' interchangeably, regardless of its etiology.

of communication and their existential significance cannot be captured by performance metrics or generic (health-related) quality-of-life surveys alone. Hence, we propose that the development of actual communication solutions for people with LIS, and the evaluation of their impact, will benefit from taking a more complete perspective on what it means to communicate.

We propose that such a perspective opens up by adopting a so-called phenomenological approach, which offers a systematic study of first-person experiences. Phenomenology has been suggested before as a fruitful method to research the lived experiences and existential situation of people with LIS [35, 36], and, although rare, there is recent work that approaches AAC-mediated communication from a phenomenological approach [34, 37]. Within phenomenological scholarship, communication is generally understood as an embodied and relational process [38–41]. This richer perspective on the phenomenon of communication may shed new light on the meaning and potential of cBCIs for people with LIS. In this paper, we set out to explore what a phenomenological perspective on communication can bring to the development and evaluation of cBCIs for people with LIS. We report the results of an interview-study into the experiences of communication between persons with LIS and daily communication partners, applying a phenomenological approach with an in-depth, open exploration of the lived experience of the interviewee [42–45], and an inductive thematic analysis [46–48]. We address a crucial gap in the literature and ask 1) what are communication-experiences like for people with LIS and daily communication partners, from a phenomenological perspective? and 2) what are the implications of these insights for the clinical outcome assessment and user-centered design of cBCIs?

Material and Methods

Participants and Setting

We conducted phenomenological interviews with three adult groups of participants (Table 1, 2, 3). All interviews were performed by BVB, and followed a phenomenological approach, where the goal of the interview was an in-depth, open exploration of the lived experience of the interviewee (M. [42–45]. The three groups of participants were 1) people with LIS, 2) loved ones of people with LIS, and 3) healthcare professionals of people with

Table 1 Demographics of participants with LIS

Identifier	Gender	Etiology	Type of LIS	Years since ALS diagnosis/onset LIS	Communication Methods
PU_01	Male	Stroke	Incomplete	20–29	Letterboard, laser pointer on glasses, gymnastic air mouse, eye-tracker, headmouse
PU_02	Female	Stroke	Incomplete	10–19	Letterboard, eye-tracker, headmouse, minimal bodily expression
PU_03	Female	ALS	Incomplete	20–29	Hand-controlled laptop-mouse, residual speech (only intelligible for loved ones)
PU_04	Female	ALS	Incomplete	0–10	Hand-controlled smartphone/tablet speech computer
PU_05	Male	Stroke	Incomplete	30–39	Customizable switch-operated program, letter board
PU_07	Male	ALS	Incomplete	10–19	Eye-tracker, hand-controlled smartphone, residual speech (only intelligible for loved ones)
PU_08	Male	ALS	Incomplete	10–19	Eye-tracker, minimal facial expressions
PU_11	Female	Stroke	Recovered (this person reflected on the period during LIS in the interviews)	20–29	Earlier: letter board, hand-controllable speech computer. Now: speech, hand-controllable speech computer

Table 2 Demographics of loved ones

Identifier	Gender	Relationship to person with LIS	Etiology	Type of LIS	Years being related to the person with LIS	Communication methods with person with LIS
CG_01	Male	Partner	Stroke	Incomplete	10–19	Eye-tracker, headmouse, minimal bodily expressions
CG_02	Female	Child	ALS	Total	10–19	Earlier: letter board, eye-tracker, minimal bodily expressions Now: none
CG_03	Male	Partner	ALS	Incomplete	20–29	Hand-controlled laptop-mouse, residual speech (only intelligible for loved ones)
CG_04	Female	Child	ALS	Incomplete	0–10	Eye-tracker, residual speech, minimal bodily expressions
CG_05	Female	Partner	ALS	Total	10–19	Earlier: eye-tracker Now: none
CG_06	Female	Partner	ALS	Incomplete	0–10	Hand-controlled speech computer, residual speech (only intelligible for loved ones), minimal bodily expressions
CG_07	Male	Partner	ALS	Total	10–19	Earlier: Eye-tracker, minimal bodily expressions, residual speech Now: none
CG_08	Female	Partner	ALS	Incomplete	0–9	Eye-tracker, Hand-controlled laptop, minimal bodily expressions

Table 3 Demographics of healthcare professionals

Identifier	Gender	Healthcare profession	Years of experience working with people with LIS
CP_01	Male	Internist	10–19
CP_02	Female	Respiratory nurse	10–19
CP_03	Female	Respiratory nurse	0–10
CP_04	Female	Rehabilitation specialist	10–20
CP_05	Female	Respiratory nurse	0–10
CP_06	Female	Speech/language pathologist	20–29
CP_07	Female	Physiotherapist	20–29
CP_08	Male	Neurologist	30–39
CP_09	Female	Speech/language pathologist	20–29
CP_10	Female	Speech/language pathologist	40–49

LIS. People with LIS were defined according to the clinical definition of LIS [2]. Three types were distinguished: classic LIS (when only eye-movements are possible), incomplete LIS (when other residual voluntary muscle movements are possible), and total LIS (when no movement at all is possible). Loved ones of people with LIS were defined as people who are close relatives of people with LIS (such as partners or children) and involved in daily interactions and communication with people with LIS. Finally, healthcare professionals were defined as people who are professionally involved in treatment and counselling of people with LIS.

We included 5 Dutch, 2 USA, and 1 Canadian participant with LIS. The median age was 50.5, ranging between 39–63. Three of them participated

in cBCI research.[2]See Table 1 for further demographic information about the people with LIS:

We included 7 Dutch and 1 Canadian loved one. The median age was 60, ranging from 30–75. Three of them were related to a person who used a cBCI in research settings. See Table 2 for further demographic information about loved ones:

We included 8 Dutch and 2 USA healthcare professionals. The median age was 56, ranging from 30–69. Two of them had experience with conducting research into cBCIs for people with LIS. See Table 3 for further demographic information about healthcare professionals:

Recruitment

Recruitment for all interviews was conducted online via the Dutch ALS patient organization, the International Locked-In Syndrome forum, rehabilitation centers, the professional networks of the authors, by directly emailing potential candidates who previously gave permission to be approached for research purposes, and by sharing information about the study during several ALS-centered events in the Netherlands. Given the low prevalence of LIS, we used a combination of random sampling and a purposeful sampling approach, meaning that besides random sampling we also purposefully selected and approached potential candidates that we estimated would be able to provide us with rich information on the matter of interest [49].

Ethics and Consent

The study was assessed by the medical research ethics committee of the UMC Utrecht in accordance with the Declaration of Helsinki of 2024. The committee confirmed that the Dutch Medical Research Involving Human Subjects Act did not apply to our study (non-WMO, protocol number 223/076/DB), because participants were not subjected to acts or imposed rules of conduct that required review (there were no expected risks for the bodily and/or psychological integrity of research participants). By standard procedure the study was then still assessed and approved by the internal quality assurance team and the data manager of the UMC Utrecht. Participants gave explicit informed consent to participate in the research and for the use of their data by signing an informed consent letter. People with LIS signed online via the UMC Utrecht approved tool ValidSign (https://www.validsign.eu). They could sign independently and digitally with a mouse click, using their AAC devices.

Interviews

The interviews with people with LIS were conducted in a written fashion, where questions and answers were typed in encrypted Microsoft Word documents that were sent through email (e-interview) [50]. During the e-interview with LIS participants, BVB shared an encrypted Word-document with the interviewee, asking them a first set of questions, after which the interviewee had the opportunity to respond in their own time. Only the interviewee could open the document with a password that was sent to them per text by BVB. This approach allowed the interviewer to ask follow-up questions, creating a semi-structured, open-ended interview with the interviewee. The interviews with loved ones and healthcare professionals were conducted face to face (two by videocall, the others in person). The e-interviews lasted between 23 and 79 days. The face-to-face interviews lasted between 45 and 1 h and 37 min.

All interviewees were asked about their own experiences of communication. For people with LIS, this meant their own experiences of communication with others. For loved ones and healthcare professionals, this meant their experiences of communication with, and in the presence of, people with LIS. All interviews were conducted based on topic lists, which were generated following the principles of phenomenological grounding [42, 44, 45], where themes and possible questions are determined based on existing insights into the phenomena under concern. Starting from a phenomenological theory on communication [34, 38–41], multiple existing first-person accounts (published autobiographies, memoirs, etc.) (e.g. [51–53], psychological and phenomenological research publications (e.g. [35, 36, 54–58], and the

[2] BCI users form a very small group [76] , and we need to take the identifiability of our research participants into account for ethical reasons. At the same time, sharing demographic information about our research participants is important for understanding the results. To avoid identifiability, we categorize age and time since ALS diagnosis/onset in LIS in blocks of 10 years. We also do not share age, nationality, and eventual BCI use specifically per participant.

authors' personal experiences concerning communicative experiences of people with LIS informed the drafting of the topic lists. In terms of personal experience that informed drafting the topic lists, three of the authors (BVB, NFR & MVS) had experience with working with people with LIS in a BCI research context, including home-visits, as participants of cBCI research. One author (WY) had experience of working with people with dementia on similar topics as reported on in this article.

A topic list is a list of potential themes and questions to be addressed but that does not need to be followed literally. Rather, the topic list functioned as a possible backbone for the interviewer, only to be used if a participant did not themselves bring up a topic of concern. Every interview concerned the same topics and consisted of three parts. The first part focused on demographic information. The second part assessed the effects of LIS and AAC devices on experiences of communication and personhood. The third part aimed to assess the actual or potential effects of cBCIs on these experiences. If a participant was unfamiliar with the concept of cBCI, we showed them an informative animation video [27]. We have added the topic lists as supplementary material to the paper.

Data Analysis

The audio recordings of the face-to-face interviews were recorded and transcribed ad verbatim including false starts, repairs, and back-channel talk. The transcripts of these recordings, as well as the written interviews, were stored anonymized and coded for all participants. The transcripts and written interviews were analyzed using NVivo software (www.lumivero.com). We conducted an inductive thematic analysis, deriving codes directly from the text, and making sense of the data in an iterative back and forth between the text and the emerging themes [46–48]. We followed the six (intertwined and recursive) phases of thematic analysis as described by Braun and Clarke [46], critically reassessed by [47] and [48]. These phases are familiarization with the data, generating initial codes, generating initial themes, reviewing potential themes, defining and naming themes, and producing the report. Data saturation (the point during data analysis where new interviews do not lead to new insights about the study objectives) was reached for all groups [59]. BVB coded every interview and drafted a first list of themes that covered all the typical characteristics of the experiences of the interviewees. Separate code-lists were generated per group of participants (people with LIS, loved ones, healthcare professionals). Where relevant, the codes were grouped into larger categories. To ensure consensus, the codes and statements were discussed during three days of deliberation involving four of the authors (BVB, JVG, WY, MVS). After reaching consensus on a list of codes for a particular group, all interviews were coded again by BVB, using that list. After this, all authors reached consensus on the themes and subthemes we describe in this paper. The analysis was performed in the native language of our interviewees (in Dutch or in English). When necessary, quotes were translated to English for the purpose of this manuscript by BVB.

Results

We identified three common themes that together described typical experiences of communication between people with LIS and daily communication partners (loved ones, healthcare professionals). While we discuss these themes separately, they should not be taken in isolation as they together capture experiences of communication. The themes are:

1) Communication technology and residual bodily movement signify a highly precarious lifeline for access to basic communication and social interaction between people with LIS and communication partners.
2) The quality of communication and social interaction is shaped by the range of bodily and/or technological expressivity of people with LIS and the adaptive responsiveness of their communication partners.
    a. The extent to which people with LIS are, and feel, perceived as persons is drastically impacted by access to communication technology and residual bodily movement (Theme 1) and range of bodily & technological expressivity and adaptive responsiveness (Theme 2).

b. In social situations where loved ones and people with LIS are present, the extent to which loved ones are, and feel, perceived as persons is impacted by access to communication technology and residual bodily movement (Theme 1) and range of bodily & technological expressivity and adaptive responsiveness (Theme 2).

Below, we describe the themes and related subthemes in detail.

Communication Technology and Residual Bodily Movement Signify a Highly Precarious Lifeline for Access to Basic Communication and Social Interaction Between People with LIS and Communication Partners

The first theme highlights that the ability of people with LIS to engage in interaction depends largely on their remaining physical capabilities and on the design and affordances of their AAC systems. Vice versa, communication partners can only connect with a person with LIS if they perceive sufficiently clear and reliable forms of bodily or technological expressions from that person. If the communicative relation between the person with LIS and their communication partner is limited, the former becomes alienated from the world, and vice versa. The first subtheme we identify here is that *access to communication technology and residual bodily movement determine whether people with LIS can enjoy basic access to the world* (3 people with LIS, 4 loved ones, 2 healthcare professionals). As a participant with LIS states:

> "When communication is restricted by physical impairment, we lose our connection to the world. Using a BCI re-establishes that connection." (PU_07).

A loved one similarly told us that:

> "Luckily, my mother was open to working with a Tobii [AAC device]. She could operate it with her eyes; it was all she could still move. Yes, it was her lifeline to the outside world." (CG_04)

And a medical professional said:

> "With LIS it always comes down to [AAC-devices] being tailor-made. (…) if you can operate even one button, a whole world opens up." (CP_07)

Secondly, the *reliability of residual bodily movement, or of the device that a person with LIS uses for communication, determines whether meaningful interaction can occur* (5 people with LIS, 2 loved ones, 4 healthcare professionals). In the following testimony, a loved one described how they came to distrust the device that the person with LIS was using to call for attention, as there were doubts about whether that person was in fact attempting to communicate, or whether these were false positives:

> "As soon as the reliability disappeared, I got a huge peak of frustration. (…) I thought I was going crazy. That I asked something twice and really thought – can't you hear me? Or – what is going on? (…) For my mother it was very important that the [BCI system] went off quickly, so she could use it quickly. While for me, as a caregiver, reliability is much more important. (…) If she says something is up, I need to know whether it is true. (…) If that thing [BCI] went off… and kept going off… you do not go for every signal." (CG_02).

Similarly, a medical professional recounted a situation where:

> "Sometimes you ask [a patient] to blink with their eyes. And five minutes later you ask it again and they cannot do it anymore. (…) then I think it gets really very complex, because then you cannot rely on what someone does [communicates] is correct. (…) it makes me feel powerless." (CP_07).

The same sentiment was expressed by a person with LIS, who said about cBCI that:

> "Reliability needs to be high, it needs to work perfectly." (PU_08).

Thirdly, our interviews showed that *limited communication abilities lead to people with LIS becoming alienated from the world* (5 people with LIS, 4 loved ones):

> "Physical disability separates a person but the inability to talk alienates." (PU_02)
> "The thing I miss the most is being a part of whatever is going on. There is nothing like

going to a party or celebration and being stuck in a corner, totally ignored." (PU_07)

A loved one expressed that about the parent with LIS:

"You become more and more alienated from the world. Your world becomes very different. You no longer have normal conversations with people, because they no longer address you. People are having a conversation, but they do not involve you. At a certain moment (…) you are almost in a different reality. As a kind of passenger in life. Instead of actually still being part of the situation you are in. (…) you have become a passenger of a world." (CG_02).

Finally, we note that the ability to actively partake in the world is also tethered to the physical mobility of the AAC device. Five people with LIS expressed that the *(im)mobility of their devices shapes where and when they are able to interact*:

"I don't communicate with my implant anywhere, other than the office. See, we are in the early stages, and that cannot be done without being connected to the computer by a cable, it would be AMAZING if I could" (PU_01).

Concluding, reliable and ubiquitous access to communication technology and/or residual bodily movement is of crucial importance to establish basic communication and social interaction between a person with LIS and communication partners.

The Quality of Communication and Social Interaction is Shaped By the Range of Bodily And/or Technological Expressivity of People With LIS and the Adaptive Responsiveness of Their Communication Partners

A second common theme that appeared from the interviews was that, once mutual access to communication or social interaction has been established (see Theme 1), the quality and richness thereof is shaped by 1) how well people with LIS can express themselves through their bodies and their technologies but also by 2) the degree to which their communication partners are able to meaningfully adjust to the communicative abilities of the person with LIS. We explain this in more detail with four subthemes.

The first subtheme is that the *tempo of bodily and/or technological expression shapes the quality of communication and social interaction* (8 people with LIS, 8 loved ones, 8 healthcare professionals). People with LIS often describe experiences of lagging behind typical speed and rhythms of unimpeded social communication. This especially makes group conversations during social gatherings more difficult:

"There are times when I only wish to write a simple note or say something in a [group] conversation, that in the end, seems like it is not worth the effort. But if I want to be part of the conversation, I need to make the effort." (PU_07)

Group conversations are particularly challenging because people with LIS struggle with indicating on time when they want to take a turn in a conversation. Turn-taking is a process that usually happens through small, embodied expressions, such as nodding, use of discourse particles such as 'hm', or sharing a look. These cues can be hard to produce in a timely fashion for people with LIS, making it difficult for them to synchronize with the rhythm of a conversation. Moreover, communicative acts in which timing is of particular importance (such as humour) are compromised when tempo of expression is low.

"What I miss the most is to respond ad rem." (PU_05)

Low tempo additionally affects how expressions of people with LIS come across. The other communicator might become uncomfortable, impatient, or perceive the attempt at communication as a directive. Two people with LIS shared:

"When I met my dietician, I had the idea that she felt uncomfortable interacting with me. She did not know how to act. I felt sorry for her. She did not look at me, had no patience when I was typing. Maybe I should have prepared her that I cannot speak or write. (…) There is an uncomfortable silence, I think... Which is why there is little understanding. Most people move on to another subject. Which makes me lag behind again." (PU_08)

> "If communication happens very slowly, it is more like a question or command. Exchanging words is not the same as communication." (PU_03).

Indeed, loved ones and healthcare professionals experience the temporal effects of communicating with a person with LIS as well. A medical professional working closely together with PU_08 said that:

> "I notice that people find it kind of uncomfortable (…) For example, when he wants to say, 'no idea', but then he wants to say something after that. And then I think, oh, he has no idea. But then… that I already… that I move on too quickly. And then [PU_08] says something about the previous…" (CP_05).

And a loved one shared that.

> "It just feels more like at times I'm piling on her (…) while I'm waiting the three or four minutes between her saying her response, I've now said five more things which probably is not helpful in the communication and in the dialogue that we're trying to have." (CG_01)

Secondly, *the output voice of an assistive device shapes how people with LIS and their communication partners experience the quality of their contact*. These voices often are computerized and lack the rich changes in tone of voice, intonation, cadence, and accent that speaking people have in their expressive arsenal (7 people with LIS, 7 loved ones, 5 healthcare professionals). Combined with the lack of full embodied expressions (e.g., facial expressions, body language), this makes it challenging to get across the affective dimension of contact. Two participants with LIS expressed these sentiments for instance as.

> "My tone is a big issue! My husband always thinks I'm mad. My kids always think I am yelling, and my mother thinks I am blaming her for everything." (PU_02).
> "I can use my computer to read a joke, but it might be funnier if told using proper voice inflection. People don't take computer voices seriously." (PU_07).

Also loved ones and healthcare professionals shared how the output voice of the AAC device shaped their experiences of social contact. In the first testimonial below, a loved one shares an experience of her partner losing his "old voice" with which he spoke a regional dialect in the Netherlands. His AAC device could only operate in the standard Dutch language:

> "A Dutch voice. That was very strange. We did not speak Dutch to each other. (…) I missed his voice so much. That's actually what I missed the most *gets emotional* His voice. Yes. Yes, I missed that. And then you have this Dutch voice. Not that I have anything against Dutch people. But a Dutch male voice who tells me that he loves me. Yes, sorry. I thought that was a bit unacceptable." (CG_06)

A medical professional shared a typical experience of less rich communication as a result of the output voice of the AAC device of a person with LIS:

> "You do not have intonation (…) and you never know whether it is sarcastic or not." (CG_05)

Thirdly, *people with LIS and familiar communication partners often find inventive new ways of being responsive towards each other in communication*. (5 people with LIS, 5 loved ones, 7 healthcare professionals). A participant with LIS shared an example of new ways of communicating that she had established with her husband:

> "I blink to communicate numbers and times. To have my nose cleaned with a q tip, I stare cross eyed at my nose. To put on lip cream, I pucker my lips. To show I'm hot, I hang my tongue out like a panting dog. To brush my teeth, I tap my tongue on my front teeth. (…) My husband and I form an O with our mouth to signal 'I Love You'" (PU_02).

We found the same for healthcare professionals:

> "That is the reason I can still completely understand these dysarthric people. I mean, really, if you do it [interacting with them] long enough… it is bizarre how much you can still get out of a conversation. For sure. If you are sensitive enough, you can get very far with that. And then I also understand that their social environment just learns that very well. And that it is about looks or small gestures… it is unbelievable." (CP_04).

And for loved ones too:

> "A small circle of the finger. That was a [specific sausage]. If he wanted a [different specific sausage], then he would go like this *makes a different gesture*." (CG_06).

Besides being inventive with new ways of communication, as a fourth subtheme we found that *people with LIS and their communication partners adapt to newly emerging norms of communication* (6 people with LIS, 7 loved ones, 7 healthcare professionals). A participant with LIS expressed this by stating that:

> "If I know that someone in the group is using an AAC, I would give them a turn speaking. And people really do need to be more patient. I may be slow but I can still communicate." (PU_07).

Similarly, a loved one recounted a situation of group communication in which they had to actively remind other people in the group of the atypical style of communication of the person with LIS, in order to facilitate a good communicative experience for the person with LIS:

> "The conversation went too fast and then... I had to jump in. But that… he needed to teach me that. Because I am… was not really a kind of… I am also a rambling communicator. (…) It took some time getting used to… doing it differently." (CG_06)

And a medical professional emphasized the role of skill and reflectively adapting to the norms of the person with LIS in order to address them as persons:

> "You must remember yourself that there is a person in front of you who communicates more slowly. Who needs time. Who communicates, wants to express themselves. (…) You want that person to be present. They are not stupid. (…). You have to treat that respectfully. Be patient, look at them. Address that person. Ask them the questions." (CP_04)

In conclusion, the quality of communication and social interaction between people with LIS and their communication partners is strongly influenced by the richness of the available communication technology, the person's remaining bodily abilities, and the degree to which partners can adapt to one another. Design choices, technological possibilities, and the skill of both communication partners thus strikingly color experiences of communication.

The Extent to Which People With LIS Are, and Feel, Perceived As Persons is Drastically Impacted By Access to Communication Technology and Residual Bodily Movement (Theme 1) and Range of Bodily & Technological Expressivity and Adaptive Responsiveness (Theme 2)

Thirdly, we found two themes relating to dehumanizing experiences of both communication partners, which we discuss separately because they are different for the person with LIS and their loved ones.

First, we found that for people with LIS, *reduced access to and quality of communication and social interaction critically affects how they are, and feel, perceived as persons by their communication partners* (8 people with LIS, 7 loved ones, 9 healthcare professionals). We found for instance that *people with LIS often experience situations where others talk about them instead of to them* (8 people with LIS), *others acting uncomfortable or awkward around people with LIS* (6 people with LIS), and *others treating them as if they have additional impairments* (such as speaking extra loud and simplistic to them) (6 people with LIS). This leads to people with LIS being and feeling perceived less as full persons:

> "At times, I felt inferior, like I was less of a person (…) If you are talking to me, then talk to ME." (PU_07)
> "A nurse asked another nurse about my private affairs whilst I was sitting next to them. Besides the fact that it wasn't appropriate, I felt ignored and belittled. I spoke to her directly. She did not do it again." (PU_08)
> "Once you're in a wheelchair, people assume you have multiple disabilities. In my experience, people speak louder, or ask my caregivers if I can hear them. It makes me angry. (…) Most people don't look beyond my ALS." (PU_08)
> "They scream at you, talk childishly, pinch or stroke your cheeks (…) I think to myself: keep your hands off me or I shoot out with my arm. Sorry, spasm;)" (PU_11)

In the testimony below, a participant with LIS expressed the experience of not being seen and

valued as a person and its relation to communication as follows:

> "Before my stroke, I never thought much about communication. The first 3–5 years, no facial muscles worked and it was truly awful to not show emotion or character. I cried a lot because it was so difficult not to be able to express myself (…) Communication allows you to feel included like you have value. Society sees you but discounts that you can contribute. Why shouldn't I have hopes and dreams like everyone else.. I now have a much greater appreciation of what is all involved in speaking. (…) Without the ability to communicate, you might as well be a statue in the corner." (PU_02)

For loved ones it becomes harder to see the person with LIS as the full person that they are as well. Here, a loved one told us about a drastic change in perception when her mother became completely locked-in:

> "I notice that sometimes I start to fill in what she wants or needs. As if I create some kind of fake relationship. As if we are talking. The step from very little communication to nothing at all… Yes, so a BCI system really is *long silence* so important. If the door really closes, you become imprisoned. (…) For me... I no longer see my mother. That is what it is. I cannot interact with her whatsoever. It was a huge change for me. It has become harder to see her as a person and as a human being. When all communication disappeared… I have to say that until then… Even if it was the smallest thing, I still saw my mother very much as a person." (CG_02).

A medical professional shared an experience of not perceiving someone with LIS as a full person by stating that:

> "What must that mother be thinking, you know. Because then I am there fiddling with her son... essentially, it is a kind of rag doll. And that must be weird to see for outsiders." (CP_05).

We encountered metaphors similar to the rag doll in four interviews with healthcare professionals, describing people with LIS as bodies without personhood or inner worlds.

Limited quality of communication also plays an important role in this dehumanization. Two healthcare professionals shared that:

> "Of course, emotions and intonation make someone more human. I mean, the Tobii is great. Even if the voice is robotic, it is at least a voice." (CP_05).
> "I went to a meeting once where everyone was using, all the men were using this voice that was called Perfect Paul. You could not tell who was talking." (CP_10).

Besides experiences of dehumanization as a result of communication impairment, we found experiences of the opposite, humanizing, kind, related to adaptive responsiveness of the communication partner. *People with LIS can be, and feel, perceived as persons despite their communicative impairments* (8 people with LIS, 6 loved ones, 8 healthcare professionals). Importantly, this experience critically depended on the person with LIS having a basic ability to express themselves, and on the learnt skills of the communication partner to become familiar with these expressions. Of importance here are adaptation to the tempo of communication of the person with LIS, acknowledgement of how their bodies are still expressive and being familiar with technological expressions. A medical professional who had a long history of communicating with the same person with LIS describes how technological communication can revive the perception of personhood:

> "Her body looks like a dead body. Very cold, very white, very… almost scary to touch. You almost do not want to touch it. But she looks bright [from her eyes]. She communicates with apps. And I communicate with her in the same way that I communicate with you.
> (…) So I am at... I am just at that level with her. I see... I no longer see her [physical] body. Because I am having a conversation with her. I have no trouble communicating with a computer in between." (CP_03)

Loved ones also told us that they could perceive the humanity in persons with LIS through minimal residual embodied interactions, for instance by gazing into each other's eyes. In a similar vein to the quote above, a participant told us:

"Sometimes I even forgot [about their condition] … Because we were still in contact. I did not have the idea that we had less… Less contact with each other. We were still in contact, but in a different way." (CG_06).

All participants with LIS also shared experiences where they felt seen as a person and how this was dependent on the relation that they had with their communication partner. For instance:

"It depends per person, you have people that do not even begin to try and there are people that can look under my skull." (PU_05).
"A recent example is that the captain of my flight approached me after the flight. We had a pleasant conversation. We talked about what I was going to do during my vacation, etc. For once, it wasn't about my disease. It was a conversation at a high level, as equals. Not patronizing. I felt like he saw me as a person." (PU_08)

Thus, the lifeline of communication technology and/or bodily expressions between people with LIS and their communication partners (Theme 1) does not merely affect whether communication occurs, but they fundamentally determine whether people with LIS are and feel seen as persons at all. Moreover, the richness of communication technology, bodily expressions, and the adaptability of communication partners, shape more than the quality of communication and social interaction (Theme 2). These factors shape to what extent people with LIS are and feel treated as the full persons with rich inner worlds that they are.

In Social Situations Where Loved Ones and People With LIS Are Present, the Extent to Which Loved Ones Are, and Feel, Perceived As Persons is Impacted By Access to Communication Technology and Residual Bodily Movement (Theme 1) and 2 Range of Bodily & Technological Expressivity and Adaptive Responsiveness (Theme 2)

Finally, our results indicate that also loved ones are impacted by the communication impairment of the person with LIS. This impact is less ubiquitous as for people with LIS, since loved ones can have access to effortless communication relations with others. Yet, as is clear from earlier quotes, loved ones may experience feelings of frustration, powerlessness and the need to adapt. The overarching theme in the experiences of loved ones was, however, that also they felt less treated as the full person they are because of the way that a person with LIS communicates (7 loved ones).

The first subtheme is that c*ommunication of people with LIS towards their loved ones can be predominantly instrumental, focusing on basic (care) needs, rather than being affective* (7 loved ones).

A loved one shared:

"At a certain point, the less communication you have, the more factual, businesslike, and practical it becomes. (...) The human aspect, the personal touch, 'how are you', or 'thank you', or whatever (...) is increasingly being replaced by 'cold', 'warm', 'drink', 'pain'" (CG_02)

The focus (by necessity) on brief and cold transfers of information diminishes the acknowledgement of loved ones as the full person, partner, parent or friend they are.

"I think that during that entire period, for myself, I only had one day as a daughter." (CG_04).

The second theme was *the need for loved ones to become the body or mouthpiece of the person with LIS* (7 loved ones). People with LIS often become dependent on their loved ones in a way that can be experienced as dehumanizing for the loved one.

"Yes, what I'm saying is, you become an extension *gets emotional* you live… I was also just becoming his body. Because his body was not working anymore, I had to take on a lot of extra stuff. So, at one point I was like, I'm kind of living two bodies. But from within one body, I am working for two." (CG_08)
"Then it would be really, really, really nice if she can communicate on her own. Yes, because now I have to be there. Constantly. Yes, that's not so bad in itself, but sometimes she wants to talk to someone about something that doesn't interest me at all, and then I have to sit there. Then I am brought in and have to listen, and I have to sit there like that, and she has to say it four times, because for

me there is also noise. Often the other person she is talking to has already lost interest, because they are already talking to someone else, and that is really bad. I think that... if real communication with third parties could be possible. Yes, that would be fantastic." (CG_03)

Concluding, the limited communication abilities of people with LIS lead to a certain degree of dehumanization of their loved ones. We can assume that the person with LIS wishes to acknowledge their loved one as their spouse, child or friend, like they did before communication became a challenge. Yet, their communication impairment prevents them from doing so. In addition, loved ones often need to act as an instrument or mouthpiece for the person with LIS. This limits opportunities to engage in meaningful social interactions with the person with LIS, as well as with others in circumstances that involve the person with LIS. As a result of these factors, loved ones are and feel less acknowledged as the person that they are.

Discussion and Implications for Care and cBCI Design

In this paper, we asked, first, what experiences of communication between people with LIS and their daily communication partners are like from a phenomenological perspective and, second, what the implications of these insights are for user-centered design of cBCIs. Our interview results showed that what is at stake between people with LIS and their communication partners is not only the ability to communicate in the sense of efficiently transferring semantic information, but also the more fundamental ability to be understood and to perceive and treat each other as full persons. The possibility of reliable and rich communication is an enabling condition for people with LIS to be seen and treated as a full person by others, and to acknowledge the personhood of their loved ones. Thus, cBCIs can be considered as key enabling tools for the experience of "relational personhood" between people with LIS and their daily communication partners. Relational personhood as we understand it is a concept from philosophy that expresses whether and to what extent people are and feel perceived as full persons by each other [38–41].[3]We expect the impact of cBCIs on relational personhood to be potentially profound, as usability of conventional AAC is limited for an important portion of people with motor and speech impairments, and because cBCIs have the potential to offer unprecedented usability and richness in communication.

Communication, Relational Personhood, and Technology

We have shown that people with LIS often fall outside typical norms for interpersonal contact. Their minimally expressive bodies, the absence of speech, the temporal delays, and technological form of expressions (e.g., computerized voice) can make it more difficult for others (especially unfamiliar others and others during group-contact) to perceive the personhood of people with LIS. This results in a feeling of being ignored and alienated. At the same time, our results show that minimal and diverse interactions, through residual movements or using technological solutions, can enable communication and a minimal experience of relational personhood (the blink of an eye, or a reliable cBCI utterance can make a drastic difference). Yet, the richness (or lack thereof) of the communication offered by AAC-technologies (including cBCIs) and the skill of social others to patiently wait for, and understand, the often limited communication utterances, are additional crucial factors in how people with LIS appear as persons towards others and how others feel seen and treated as persons by them.

Our finding that LIS may result in experiences of dehumanization on both sides are in line with phenomenological theories about communicative

[3] The notion of 'relational personhood' does not literally appear in these works of Husserl and Merleau-Ponty. However, their ideas about embodied and relational communication and its relation to subjectivity formed the basis of our topic lists. Both authors write about communication as a process of two consciousnesses unifying in experience ([38], p. 476; [39], 201, [40], p. 215,[41], part 2, IV). Through these works, it becomes apparent that people perceive each other's personhood in communication. See [34] for a detailed discussion on this. It is worth highlighting that the concept of relational personhood is also important in feminist bio-ethics (e.g. [77],[78]. It has moreover been developed from an anthropological perspective, see for instance [79], [80], and [69].

experiences [34, 38–41, 60]. Phenomenologists have always paid attention to the role of the moving body in the expression and perception of personhood or subjecthood. Understanding communication in phenomenological terms means that a non-moving body can even cease to appear as alive [61]. People with LIS are severely limited in their capacity to move, and, in turn, in how they can express themselves to others, not only through words, but also through intonation, facial expressions, and bodily gestures. According to phenomenological theories on communication, it is constitutive for an experience of communication that both communication partners perceive each other's embodied expressive behavior as meaningful expressions of an inner world [34]. As one of our interviewees put it: *My definition of communication is different from pointing out what you need (bread, drink, itching, cold,* etc.*). For me, communication is the mutual exchange and understanding of thoughts, emotions, and feelings.* (PU_03). The sentiment that communication is about more than sharing facts and basic needs is also widely understood in AAC literature [62, 63]. Our interview data indeed showcases the importance of the role of the moving body as expressive of relational personhood yet also highlights that bodily expression can be extended technologically when the body is no longer able to move.[4]It is through communication that relational personhood takes shape: that we see and treat each other as the persons we are to one another.

Our results are largely in line with earlier empirical surveys and questionnaires about subjective experiences of people with LIS [55, 57, 58], which show that communication is of crucial importance to the wellbeing of these individuals. [57] also found that people with LIS feel treated as objects and progressively regain a sense of relational personhood enabled by the recognition of their caregivers. Our study adds novel and rich insights into the value of different dimensions of communication, the impact of communication technology, and of the adaptive responsiveness of communication partners for the experiences of relational personhood of people with LIS. We also show that the experience of diminished relational personhood is not limited to interactions with caregivers but affects people with LIS in social situations in general.

Our study provides a unique insight in the first-person experiences of communication and personhood of daily communication partners. Their perspectives have received only limited attention in literature (except from [64] but form a pivotal part of the experience of communication and relational personhood of people with LIS. In a sense, people with LIS and their loved ones become entangled in that the person with LIS cannot live without them. Our data demonstrate that it is not only the personhood of the person with LIS that is at stake, but that daily communication partners experience dehumanization too. An important nuance here is that a person with LIS is critically dependent on their communication partners for a sense of relational personhood, but that loved ones perceive diminished personhood particularly in situations that involve the person with LIS and still have access to enriching communication where they feel seen and treated as persons with others. The perspective that we provide in this paper is new and may affect how we evaluate the impact of LIS and how cBCIs could play a role in the experience of LIS.

Relational personhood as Clinical Outcome Measure for cBCIs

cBCI research is at a point where the technology is becoming ready to leave its academic nest and enter the commercial and clinical world. An important ongoing challenge for achieving regulatory approval, reimbursement, and clinical adoption of communication-BCIs is establishing clinical outcome measures (COAs) that capture and quantify their impact [23–25]. The field of BCI research is currently exploring the most appropriate COAs for cBCIs. COAs are standardizable assessments that describe or reflect how an individual feels, functions or survives as an effect of an intervention (in this case cBCIs). The subjective 'feels' aspect of COAs for cBCIs is thus far discussed in terms of (health-related) quality-of-life assessments. These, however, fall short for several

[4] It is in fact an interesting theoretical question whether to conceptualize BCI-mediated expressions as movements or not. The majority of BCIs require brain activity that is generated by voluntary embodied movement attempts by users, since what is decoded from the brain is sensorimotor activity. This however does not manifest as visible bodily movements in the typical sense. The answer to this question is also dependent on whether BCIs are conceptualized as part of the body of people with LIS, and on what notion of the body one employs. We refer the reader to [81] for an extensive discussion on this.

reasons [65], and do not capture the full impact cBCIs can have on users. Recount the question from the FDA/NIH workshop that we highlighted in the introduction about how to articulate what it means for a father and daughter to reconnect through a cBCI. Our results show that communication technologies such as cBCIs enable both the primary user and their loved ones to see and treat each other as the full persons that they are for each other. The inner world of the father becomes more visible for his daughter, and he is able to acknowledge his daughter as the person that she is for him. Not only 'his' ability to communicate is restored, but 'their' relationship as father and daughter is rekindled by their restored ability to interact [65]. The quote from CG_02 on p. 16, where she shared that the existence of a cBCI was the difference between her seeing her mother or not, speaks precisely to this point. Indeed, when asked to speculate about the potential of cBCIs in the future, PU_07 told us that *"Using a BCI has been a game changer. I am no longer just a warm body in the room, to only be paid attention to when necessary."*

BCI technology has been suggested as a way to support the "relational underpinnings", or the "intersubjective experience", of personhood of people with LIS before [66, 67]. However, the exact nature of this support for relational personhood has not yet been articulated. The interview results reported here provide a clear articulation of the relation between communication impairment, communication solutions such as cBCIs, and relational personhood. Our findings thus represent a solid scientific basis for considering the concept relational personhood in the COA of cBCIs, as it reflects an aspect that is highly relevant for both the primary users and their loved ones/caregivers and because this experience can be expected to change as a result of using a cBCI. As a next step towards that goal, we strongly suggest the BCI community to participate in the development a Communication and Relational Personhood questionnaire (CRPQ). This questionnaire would quantifiably measure the effects of a cBCI on the relational personhood experienced by primary cBCI users (and their loved ones) [65]. To validate the construct of relational personhood and its relation to communication ability afforded by communication technology, the CRPQ may be administered to a large number of users of conventional AAC. Eventual correlations between CRPQ scores and metrics such as cBCI-use and the ability to digitally conduct activities of daily living using a cBCI may help to quantify the full impact of cBCIs on the lives of their users.

Importantly, relational personhood is closely connected to human rights. According to fundamental principles in the UN convention on the rights of persons with disabilities [68], people with disabilities should be "3a) respected as dignified and independent individuals"," 3c) allowed to fully and effectively participate and be included in society" and "3d) respected as part of human diversity and humanity". These rights presuppose the perception of all people as fully human. Our findings demonstrate that this perception is highly precarious in contexts of LIS. Vidal has critically described two cases in Spain of people with LIS who were deprived of their civil rights because they were deemed incapable of 'governing themselves' due to the way that they communicated, which shows how notions of individual autonomy inscribed in law might exclude people with LIS from legal personhood [69]. Our notion of relational personhood and the role that AAC tech (including BCIs) have in mitigating the vulnerability of not being perceived as a person, shows that access to AAC/BCIs, particularly ones that are reliable and maximally supportive of rich communication, directly serve the protection of human rights. In this sense, the experience of relational personhood can be tied to the concept of legal personhood in law. Arguably, in line with the Communication Bill of Rights [70], people with LIS have a right to cBCIs, considering that they can support the underpinnings of their perceived personhood.

Future Research and Design of cBCIs

Our research paves the way for a new outlook on user-centered design, and evaluation, of BCIs [71]. The cBCI field has for a long time expressed the desire to incorporate user-experience into the design of cBCIs but the low prevalence and communication impairment of people with LIS render studies on user preferences challenging [27–32, 72]. Our results show that a cBCI user is not merely an individual, but part of a network of communicators that shape whether and how both people with LIS and their communicative partners are mutually acknowledged as full persons. In this

sense, daily communication partners of people with LIS are also users of cBCIs. In other words, if we want to design cBCIs that support relational personhood, the perspectives of persons with LIS as well as their communication partners should be integrated into the design. Based on our results, we propose that (the network of) cBCI users stand to benefit from a focus on 1) access to communication per se (if, when, and where is a cBCI available) and 2) quality and richness of communication (tone of voice, intonation, tempo, emotional and embodied expressions).

If, when, and where a cBCI is available can be of constitutive importance for if, when, and where people feel they are acknowledged as the person they are. This implies certain fundamental requirements for designing cBCIs that support people with LIS and their communication partners: they should be reliable (otherwise others lose trust in the device, which means no contact is possible), available at all times [19, 73], mobile (not tied to a large computer that makes it impossible to transport and hence lose access) [19, 20], and affordable (equal access for everyone and covered by insurance). Moreover, understood as a basic right of people with disabilities, access to meaningful communication requires that all communication partners, including for example healthcare professionals with limited time, should be able to easily become familiar with the device and the expressions generated with it.

Once the ability to establish reliable communicative contact is facilitated, the next step is to improve the quality of contact. We found that the speed of communication contributes to such quality for both the person with LIS and their daily communication partners. Slower communication leads to more exclusion from social contact, especially if the communication occurs in a group and the person with LIS is lagging behind the rhythms of normal contact. Faster cBCIs have the potential to enhance the relational personhood of the person with LIS (becoming able to participate in conversations) and their loved ones (not needing to be the mouthpiece of the person with LIS). Another specific aspect that we want to draw out here is that it would be very helpful for people with LIS to have a way to indicate that they want to take a turn in conversations, as it could smoothen the communicative process. Third, our data indicate the relevance of the output voice. Our voice is closely tied to our identities, and a voice that lacks an authentic tone, a characteristic accent, or familiar cadence will more readily lead to dehumanization [74]. Recent findings in cBCI literature [21] that showcase an instantaneous voice-synthesizing cBCI represent a promising development in this respect. Our results also show that it is important to design a cBCI that allows a user to express emotions. A computerized voice combined with the lack of bodily expressions makes it more difficult to get across the affective dimension of communication. Being able to express emoticons on the backside of the screen, or by controlling an embodied avatar [16], are useful directions here.

Implications for Healthcare Professionals

We believe that healthcare professionals should be aware of the potential transformative value that cBCIs can have on the lives of people living with LIS as well as their daily communication partners. Our findings also show that people with LIS often are capable of a variety of communicative acts with familiar communication partners. These acts might not be visible at first glance for inexperienced observers and may be taken less seriously in medical contexts. Our research, however, shows the value of systematically studying subjective experiences for medical care. There may be instances where it is no longer possible for an unfamiliar healthcare professional to easily perceive the expressions of someone with LIS, but where a loved one or familiar healthcare professional is able to communicate. Rather than dismissing this as 'too subjective', healthcare professionals should be open to the possibility that there are forms of communication that they do not immediately have perceptual access to and that more time may be needed to learn to communicate with the person with LIS.

Limitations, Strengths, and Recommendations

Any study of this kind will have some notable limitations. A first limitation is the number of people we interviewed. Although phenomenological literature is typically based on 1–10 interviews, larger groups will benefit the generalizability of findings about the subjective experiences of people living with LIS and their daily communication partners. For future research, we recommend including as many people

as possible, but also wish to emphasize that detailed descriptions of lived experiences are of great value for research, no matter how many one can find. We did reach data-saturation for all groups, meaning that including more participants would not have led to more insights. A second limitation is that the data in this paper was interpreted by people who do not have complex communication needs themselves. This difference in positionality possibly affects how well we have interpreted the data. A third limitation is that we did not study the differences in experiences between people that enter LIS gradually because of ALS and people that enter LIS suddenly because of a stroke or accident. It has been argued that this difference in etiology deeply shapes illness experiences [75]. This comparative dimension, and its implications for experiences of communication, personhood, and technology are an important venue for future research.

A unique feature of our research is that it is, to our knowledge, one of the first to interview people with LIS with semi-structured interviews (see [56, 69, 75] for earlier work). Empirical research into first-person experiences of communication and personhood of people with LIS have thus far been limited to survey-style studies into experienced changes in personhood [57, 58] and a life-history study with one participant [55]. A common belief/assumption was that it is not possible to interview people with LIS in an in-depth, open format. We have shown that this is in fact possible when offering the option to take unlimited time (interviews took between 23 and 79 days) and interviewing through digital interactions, which facilitates a more equal communicative process. One of our participants expressed this sentiment by stating that: *"If you and I were to conduct this interview live, it would take much more time. And there might be a lot of repeating or misunderstood words." (PU_07)*. Every participant expressed at the end of the interview that they were happy with this format and with the opportunity to formulate longer responses than usual. Some even stated that they felt heard and seen because they did not feel hurried in this mode of communication. In a way, this underscores the message of this article: email allows for a form of communication with a shared temporality between the interviewer and interviewee, making it easier to be and feel perceived as a person for the person with LIS. We thus recommend our method of phenomenological e-interviews for future research into experiences of people with LIS and their social surroundings.

Conclusion

In this paper, we have shown the value of an empirically informed phenomenological perspective on communication between people with LIS and their daily communication partners. Rather than seeing communication as a single person's ability to efficiently transfer information, we have started from the position that communication is a relational experience that is shaped by bodily abilities and technologies. Applying philosophical concepts to a neuroscientific area of human-technology interaction research has allowed us to demonstrate that what is at stake for people with LIS is not only the ability to efficiently transfer information, but also the fundamental and existential experience to be seen and treated as a full person by others, and to treat those others as full persons. This brings a novel perspective to the potential meaning of AAC technologies, including cBCIs. These technologies have the potential to support the experience of relational personhood of people with LIS and their social surroundings. The risk that communication impairment poses to relational personhood, and how AAC/BCI is potentially able to mitigate this risk is crucial with regards to the rights of people with disabilities. Guided by these findings, we recommend that relational personhood is included in the COA of cBCIs. With this, we have paved the way for a new outlook on the future of cBCIs, the design and evaluation of which should do justice to the fundamental right to be seen as a person by incorporating dimensions of access and quality in a relational way.

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Data Availability Audio files and transcripts are not available for review because of the risk of participant identification. Upon expressed interest, anonymized parts of the transcripts may be shared through a data sharing agreement.

Declarations

Competing interests Mariska Vansteensel has been a consultant for GA Capital.

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