Current Technologies Enabling Communication for ALS Patients: An overview and recommendations for future research

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Abstract

Amyotrophic Lateral Sclerosis (ALS) progressively impairs communication, profoundly affecting patients' autonomy and quality of life. As the disease advances, traditional communication methods become inadequate, necessitating the development of advanced assistive technologies. This paper provides a comprehensive overview of current technologies enabling communication for ALS patients, including eye-tracking systems, brain-computer interfaces (BCIs), and speech synthesis. We give an overview of the current advances of these technologies, offering recommendations for enhancing accessibility, usability, and personalization. Our findings suggest that while significant progress has been made, further innovation is required to address the challenges posed by ALS, particularly in developing affordable and adaptable solutions that can evolve with the patient's condition.

1. Introduction

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disorder that affects motor neurons, leading to the gradual loss of voluntary muscle control. As the disease advances, patients face increasing difficulty with essential functions such as speaking, swallowing, and ultimately, breathing, especially with bublar onset ALS. [Wal99] [EYC*22]Among these, the loss of speech and communication abilities is particularly devastating, as it isolates individuals from their families, caregivers, and the broader world, diminishing their quality of life. [FZDS15]

Communication is not merely a fundamental human need; it is a vital aspect of personal identity and social interaction. For ALS patients, the ability to communicate becomes progressively impaired, creating a profound psychological and emotional burden. The development of assistive communication technologies, therefore, plays a crucial role in preserving the dignity and autonomy of individuals with ALS. [LPP*15] These technologies, ranging from text-to-speech devices to more advanced brain-computer interfaces (BCIs), have provided lifelines for patients, allowing them to maintain their connections with loved ones and participate in social and professional activities despite their physical limitations.

In the later stages of ALS, many patients experience symptoms that closely resemble those seen in patients with Locked-In Syndrome (LIS), a condition characterized by complete paralysis of all voluntary muscles. [MHB*11] Given the significant overlap in the communication challenges faced by individuals in these two groups, it is both logical and beneficial to consider communication solutions designed for Locked-In Syndrome patients as part of our exploration.

In this paper, we address the question: "Current Technologies

Enabling Communication for ALS Patients: An overview and recommendations." Our objective is to provide a comprehensive review of the existing communication technologies employed by ALS patients, critically examine their limitations, and explore how these technologies can be improved. By identifying the gaps in current technologies and proposing enhancements, we aim to contribute to the development of more effective and inclusive communication solutions for those affected by ALS. For this, we will focus on research papers published from 2018 onward to ensure our review reflects the most recent advancements in the field.

To achieve this, the paper is structured as follows:

- Section 2: The Role of Assistive Communication Technologies in ALS - in this section we look into the effects verbal communication loss on the autonomy, dignity, and quality of life for ALS patients.
- Section 3: Existing Technologies In this section, we provide a detailed review of the current communication technologies used by ALS patients, including text-to-speech devices, eye-tracking systems, BCIs, and voice banking technologies.
- Section 4: Critical Recommendations This section offers a analysis of the current technologies, focusing on improvements in usability, accuracy, speed, and accessibility.
- Section 5: Conclusion In the final section, we summarize our findings, giving a final overview of the current state of assistive communication technologies in ALS.

1.1. Methodology

This review focuses on communication technologies for ALS patients based on literature published from 2018 to 2024, ensuring currency and relevance of the findings. The methodology followed these steps:

Literature Selection Process:

- Database Search: We conducted searches in major academic databases including IEEE Xplore, PubMed, and Google Scholar
- Search Terms: Primary keywords included "ALS communication technology," "assistive communication ALS," "eye-tracking ALS," "brain-computer interface ALS," and "speech synthesis ALS"

• Inclusion Criteria:

- Published between 2018-2024
- Peer-reviewed articles
- Focus on technological solutions for ALS communication
- Clinical studies or significant technical developments

• Exclusion Criteria:

- Studies focusing solely on general disability communication
- Technologies not specifically tested with ALS patients
- Case studies with fewer than three participants

Technology Selection Rationale: The three technologies covered in this review (eye-tracking systems, brain-computer interfaces, and speech synthesis) were selected based on:

- Prevalence in Literature: These technologies represent the most researched and documented solutions for ALS communication
- Stage Appropriateness: They correspond to different stages of ALS progression, as illustrated in Figure 1
- Clinical Implementation: Documented evidence of successful implementation in clinical settings
- Active Development: Ongoing research and technological advancement in these areas

Analysis Framework: Each technology was analyzed across multiple dimensions:

- Technical capabilities and limitations
- Implementation requirements
- · Cost and accessibility
- User experience and cognitive load
- Clinical validation and effectiveness

2. The Role of Assistive Communication Technologies in ALS

Effective communication is a cornerstone of human interaction, enabling individuals to express their thoughts, emotions, needs, and desires. For patients diagnosed with Amyotrophic Lateral Sclerosis (ALS), the progressive degeneration of motor neurons presents a significant challenge to maintaining these essential communication abilities. [Mur04] As the disease advances, voluntary muscle control diminishes, leading to severe speech impairment or complete loss of speech, known as anarthria. This loss of verbal communication is not only a physical limitation but also a profound psychological burden, often leading to feelings of isolation, frustration, and diminished self-worth. [FZDS15] Early introduction of assistive communication devices has a positive impact on quality of life for ALS patients and their caregivers. [LPP*15]

A recent study, conducted by Fager et al., investigates the perceived importance of augmentative and alternative communication (AAC) messages in rehabilitation settings, focusing on the communication needs of individuals with disabilities and rehabilitation care providers.

The findings revealed a disparity between individuals with disabilities and healthcare providers regarding the importance of certain messages, with individuals prioritizing more personalized and diverse communication content, especially in categories beyond Basic Needs. These patients also emphasized the need for greater personalization in AAC systems to facilitate better communication during their care.

The results highlight the importance of developing AAC systems that accommodate a wide range of messages to meet the diverse communication needs of patients in medical settings, particularly in ensuring patient-provider communication that goes beyond basic care. [FBPS21]

Aided communication through technology becomes critically important in this context. [DTA*19] It serves as a vital bridge, allowing ALS patients to continue engaging with their environment, maintaining social connections, and exerting control over their lives despite their physical limitations. The significance of these technologies extends beyond mere functional communication; they play a crucial role in preserving the dignity, autonomy, and psychological well-being of individuals facing the relentless progression of ALS. [M.15] Figure 1 illustrates how different communication technologies align with ALS disease progression, providing a framework for technology selection based on disease stage and patient capabilities. This systematic approach ensures that appropriate communication solutions are implemented at optimal times throughout the disease course.

3. Existing Technologies

Table 1: Communication Technology Comparison

Technology	Characteristics	Cost Level
Eye-tracking	+ Non-invasive, early stage – Needs eye control	Moderate
BCI	+ Late-stage viable - Complex, invasive	High
Speech Syn- thesis	+ Natural voice - Early prep needed	Low

Before examining each technology in detail, Figure 2 provides a systematic overview of how these three primary communication systems function, from input to output. Understanding these process flows is crucial for appreciating both the capabilities and limitations of each technology. As we can observe from the diagrams, while eye-tracking systems follow a relatively straightforward path from input to output, BCIs require more complex signal processing, and speech synthesis involves multiple stages of data transformation. ALS patients rely on a range of assistive technologies to

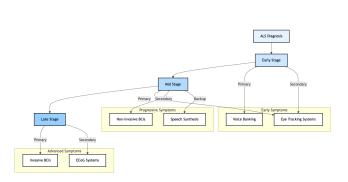


Figure 1: Technology Selection Framework Based on ALS Disease Progression. This hierarchical flowchart illustrates the relationship between ALS stages and recommended communication technologies. The progression from early to late stage (top to bottom) demonstrates the transition from non-invasive solutions (voice banking, eye tracking) to more advanced interventions (BCIs, ECoG systems). Primary and secondary technology options are indicated for each stage, providing clinical decision support for technology implementation. Notably, the framework emphasizes the need for proactive technology adoption, particularly voice banking in early stages, while maintaining backup options throughout disease progression.

maintain communication as their physical abilities decline. In this section, we explore the current state of these technologies, including eye-tracking systems, brain-computer interfaces (BCIs), and speech synthesis devices. Each technology offers a unique solution to the communication challenges posed by ALS, but they are not without limitations. Here, we provide an overview of these technologies.

3.1. HT-AAC Eyetracking Computer Systems

Eye-tracking technologies have evolved from early, rudimentary methods to sophisticated systems that utilize video-based techniques, such as Video-Based Eye-Tracking (VOG), which offer non-invasive and accurate tracking of eye movements. [EZMS*22] These devices enable ALS patients to interact with computers and other digital interfaces by moving their eyes, thus providing a critical tool to ease communication difficulties with caregivers. [SBCM*22]

Katharina Linse and colleagues have highlighted that the integration of artificial intelligence (AI) into eye-tracking systems has further improved the accuracy and usability of these devices, making them more responsive and adaptable to individual users' needs. [LAJH18] However, they also point out that current research emphasizes several challenges, including issues with calibration, the high cost of commercial systems, and the need for more affordable and accessible options. Moreover, they note the "Midas touch problem," where unintended commands are triggered by the user's

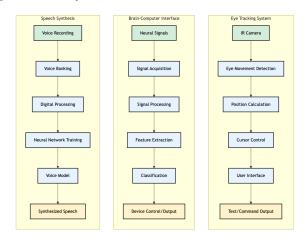


Figure 2: Process Flow Architecture of Current ALS Communication Technologies. This comparative diagram presents the operational workflows of three primary communication technologies: eye tracking systems, brain-computer interfaces (BCIs), and speech synthesis. Input nodes (green) represent initial data acquisition, process nodes (blue) show transformation steps, and output nodes (yellow) indicate final communication outputs. The eye tracking system demonstrates a direct pathway from physical input to text output, while BCIs show a more complex signal processing chain. Speech synthesis illustrates the progression from voice banking to model development. Each pathway highlights the distinct technical requirements and processing complexity inherent to each technology.

gaze, as a significant hurdle that needs addressing, along with the need for these systems to perform reliably in varied lighting conditions and outdoor settings.

The authors Guo-Rui Ma and colleagues propose using a combination of blinks as a more reliable trigger for interactive objects (IOs). Through experiments using a Tobii eye-tracker, they found that double-blinks offer a low task load and a high success rate of 95 percent. Additionally, they determined that larger IO diameters and optimal spacing (55.5 mm and 33.3 mm, respectively) improve user response times and interaction success rates. A prototype eye-controlled multimedia player demonstrated that this approach achieves efficiency comparable to traditional mouse control, successfully addressing the Midas Touch issues and mitigating the interference caused by involuntary blinking, leading to a significant enhancement in system robustness. [MHC*23]

Beyond the technological advancements, research also focuses on the psychological and social impacts of eye-tracking devices. Studies by Linse et al. have shown that these technologies significantly improve the quality of life, psychological well-being, and autonomy of ALS patients. [LAJH18] They also reduce the burden on caregivers by facilitating more effective communication. However, there are barriers to widespread adoption, including patient acceptance, cognitive impairments, and a lack of consistent support from healthcare systems. As Linse et al. emphasize, "enabling complex communication independent of a 'translation' by

caregivers/next-of-kin and thus patient autonomy is crucial for the preservation of psychological wellbeing." [LAJH18]

The Blink-To-Live system, developed 2023 by Mohamed Ezzat and colleagues is a novel eye-tracking system leverages standard mobile phone cameras and computer vision techniques to decode simple eye gestures into synthesized speech, enabling patients to communicate efficiently without the need for expensive, specialized hardware. The system's user-friendly design, combined with its ability to quickly translate eye movements into over 60 daily life commands, makes it highly accessible, particularly in low-resource settings. Blink-To-Live not only enhances communication speed and accuracy but also reduces the cognitive load on users. [EMG*23]

3.2. Brain-Computer Interfaces (BCI)

Brain-Computer Interfaces (BCIs) enable patients to interact with computers and other devices using their brain signals, bypassing the need for motor functions that are often compromised in ALS. BCIs establish direct communication between the brain and external devices, utilizing various brain signals [CD17]. They can be classified as invasive, semi-invasive, or non-invasive based on sensor placement. Non-invasive methods include EEG and MEG, while invasive techniques involve implanting electrodes directly into the cortex [PHP10]. The BCI process typically involves signal acquisition, pre-processing, feature extraction, classification, and interfacing with devices.

Recent advancements have seen the development of various BCI spellers, including matrix-based P300 spellers and hybrid spellers that combine different paradigms to enhance accuracy and usability. [Li21] These spellers have made it possible for ALS patients, including those in locked-in syndrome (LIS), to communicate at rates of more than 10 words per minute, significantly improving their ability to interact with others. However, challenges remain, particularly in achieving higher speed and accuracy in real-time communication, as well as addressing the cognitive and emotional factors that can influence BCI performance. The ongoing research in this field is crucial, as BCIs offer a promising solution to maintaining communication and quality of life for ALS patients, particularly as their condition progresses and other forms of communication become impossible. [Mur04]

A study by Miguel Angrick and colleagues recently demonstrated the ability of a chronically implanted BCI (invasive) to enable real-time synthesis of intelligible speech in a participant with ALS. This system utilizes intracranial electrode recordings to decode brain activity associated with speech production and converts it into audible words. The BCI, designed with recurrent neural networks, achieved an 80 percent accuracy rate in producing recognizable speech from a limited vocabulary of keywords. [A*23]

The usability of BCIs for people with ALS in daily life remains a major challenge. Factors like the ease of use, comfort, and the ability to maintain consistent communication as ALS progresses are critical. The complexity of BCI signal processing, shown in Figure 2, highlights why these systems typically require more extensive setup and training.

According to Vansteensel et al. (2023), while various brain-computer interface (BCI) technologies show promise, electrocorticography (ECoG) electrodes appear to be particularly promising for communication in individuals with late-stage ALS. [VKvT*23] The authors highlight the success of ECoG-based systems, noting that these systems have demonstrated long-term stability and usability in daily life settings. For instance, they mention a case where an individual with ALS successfully used an ECoG-based BCI system for independent communication over several years, with high user satisfaction. The ECoG approach strikes a balance between being less invasive than intracortical microelectrode arrays and offering more stable signal acquisition compared to other methods, making it a strong candidate for widespread clinical application.

A study by Jonathan R. Wolpaw and colleagues demonstrates that an EEG-based BCI can be reliably and independently operated at home, highlighting the practicality and effectiveness of BCI technology for ALS patients beyond clinical environments. [WBR*18]

Florencia Garro et al. identified issues with the current growth in the BCI-filed: Due to the varied technologies and methodologies involved, assessing the usability of these BCI systems in a consistent and standardized manner presents challenges. This complexity makes it difficult to identify user-related issues and to establish solid metrics for improving and comparing different systems. Additionally, when BCIs are intended for medical purposes, they must meet strict regulatory standards related to design, risk management, and usability to be validated and brought to market. [GM20]

3.3. Speech Synthesis

Over 90 percent of those with severe speech impairment use speech-generating devices. [A*23] Voice cloning technologies, which replicate a patient's natural voice, offer a promising solution to help ALS patients maintain their personal identity and ability to communicate as their speech capabilities deteriorate.

ALS patients often produce limited or distorted speech, particularly in advanced stages of the disease. [KSR*91] The work from Wadoux et al. investigates the impact of limited and extreme phonetic content in speaker embeddings for voice cloning systems, specifically in the context of organic dysphonia. Voice cloning, which replicates a speaker's voice from limited data, is a promising solution for individuals with voice disorders. However, dysphonic patients often produce speech with restricted phonetic content, raising concerns about the system's effectiveness. The study focuses on using a speaker encoder approach, particularly the xvector model, to assess how phonetic content influences speaker embeddings. Experiments were conducted with varying sample durations and phonetic content strategies to determine the effects on voice cloning. Results show that phonetic content has a greater impact on speaker embeddings than duration, suggesting that voice cloning systems need to account for such constraints when applied to patients with voice disorders. This research sets the stage for further studies on enhancing voice cloning for individuals with impaired speech. [WBCL22]

As mentioned above, Miguel Angrick presents a significant advancement in brain-computer interface (BCI) technology, demonstrating the successful online synthesis of intelligible speech in an

individual with amyotrophic lateral sclerosis (ALS) using a chronically implanted BCI. The study employed electrocorticography (ECoG) recordings to decode and synthesize spoken words, preserving the participant's unique voice characteristics. The research marks a breakthrough as it shows, for the first time, that a speechimpaired individual with ALS can produce synthesized speech that is intelligible to human listeners, with an accuracy of 80 percent. This development holds promising implications for augmentative communication technologies for individuals with severe speech impairments. [A*23]

The study by Francis R. Willett and colleagues demonstrates speech neuroprosthesis capable of decoding attempted speech into text with high accuracy and speed. Using high-resolution recordings from intracortical microelectrode arrays in a participant with ALS, the system achieved a word error rate of 9.1 percent for a 50-word vocabulary and 23.8 percent for a 125,000-word vocabulary, with a speech rate of 62 words per minute. This performance surpasses previous speech BCIs, showing that speech articulation is robustly represented in the brain even years after paralysis. [WKF*23]

Recent research on speech banking for ALS patients highlights its importance in maintaining personalized communication. Custom synthetic voices created using statistical parametric synthesis were found to be more intelligible, natural, and preferred compared to waveform concatenation. [HMLC*23]

4. Critical Recommendations

While existing technologies have made significant strides, they are not without limitations. Issues such as high costs, calibration challenges, and cognitive load often hinder the widespread adoption and efficacy of these tools.

Based on our analysis of current technologies, we propose the following ALS-specific recommendations for each technology category:

4.1. Eye-tracking Systems Enhancement

- Adaptive Calibration: Develop machine learning algorithms specifically trained on ALS eye movement patterns to address the progressive nature of motor deterioration
- Fatigue Compensation: Implement dynamic sensitivity adjustments that account for ALS-related eye muscle fatigue throughout the day
- Environmental Adaptation: Create systems that automatically adjust to varying lighting conditions in hospital, home, and outdoor settings, particularly crucial for mobile ALS patients
- Multi-modal Integration: Combine eye-tracking with voice banking technology for early-stage patients, allowing seamless transition as speech deteriorates

4.2. Brain-Computer Interface Improvements

 ALS-Specific Signal Processing: Develop algorithms that account for ALS-related brain signal changes over disease progression

- Minimally Invasive Solutions: Research ECoG approaches that balance signal quality with surgical impact, particularly important for ALS patients with respiratory challenges
- Adaptive Learning Systems: Create BCIs that automatically adjust to changing neural patterns as ALS progresses
- Emergency Communication Protocols: Implement rapidaccess commands for urgent medical needs specific to ALS patients (breathing difficulties, positioning needs)

4.3. Speech Synthesis Advancement

- Early Voice Banking Protocol: Establish standardized voice banking procedures immediately upon ALS diagnosis
- Emotional Content Preservation: Develop synthesis models that maintain emotional inflections crucial for personal communication
- Limited Data Adaptation: Improve voice cloning technology for patients with already impaired speech
- Context-Aware Synthesis: Create systems that adjust speaking style based on social context (medical, personal, professional)

4.4. Cross-Technology Integration

- Seamless Technology Transition: Develop standardized data formats allowing patient communication preferences and patterns to transfer between systems as disease progresses
- Unified Control Interface: Create a consistent user experience across technologies to reduce cognitive load during transition periods
- Progressive Technology Planning: Establish clinical protocols for timing technology transitions based on quantitative assessments
- Cost-Effective Modularity: Design systems with upgradeable components to adapt to disease progression without complete system replacement

4.5. Implementation Strategy

- Early Technology Assessment: Implement standardized evaluation protocols at diagnosis to plan technology adoption timeline
- Caregiver Training Integration: Develop comprehensive training programs that include both patients and caregivers
- Remote Support Infrastructure: Create specialized technical support systems for ALS patients using these technologies
- Cost Reduction Strategies: Research open-source alternatives and insurance coverage pathways specific to ALS communication needs

4.6. Enhancing Accessibility and Affordability:

There is a critical need to develop more affordable and accessible assistive communication technologies. High costs currently limit the widespread adoption of these devices, particularly in low-resource settings. Future research and development should focus on creating cost-effective solutions, such as utilizing standard mobile devices for eye-tracking or developing affordable BCIs, to ensure that all ALS patients, regardless of their financial situation, can benefit from these technologies. Many of the reviewed technologies are

still only used in clinical settings and are not available for most pa-

4.7. Improving Usability and Reducing Cognitive Load:

The usability of assistive communication devices must be a primary focus. Many current systems require significant cognitive effort, which can be overwhelming for ALS patients, particularly as the disease progresses. Enhancements in user interface design, powered by AI, could help reduce this cognitive load, making the technologies more intuitive and easier to use. Research should explore adaptive systems that learn from individual users' patterns, thereby improving speed and accuracy while minimizing effort.

4.8. Addressing Technological Limitations:

Persistent issues such as calibration difficulties in eye-tracking systems and the "Midas touch problem" need to be addressed through innovative solutions. For instance, incorporating AI-driven algorithms can improve the precision and reliability of these systems, making them more robust in varied environments. Additionally, developing hybrid systems that combine multiple technologies, such as BCIs and eye-tracking, could offer more comprehensive solutions for complex communication needs.

4.9. Focus on Long-Term Usability and Adaptation:

As ALS is a progressive disease, assistive communication technologies must be adaptable to patients' changing needs over time. Longitudinal studies and ongoing user feedback should guide the development of technologies that can evolve with the patient's condition. BCIs using electrocorticography (ECoG) electrodes have shown promise in long-term use, but further research is needed to refine these systems for broader application.

5. Conclusion

Assistive communication technologies have emerged as vital tools in addressing the loss of speech and communication abilities, offering ALS patients a means to maintain their autonomy, dignity, and social connections. Through devices such as eye-tracking systems, brain-computer interfaces, and advanced speech synthesis, patients can continue to interact with their environment and loved ones even as their physical abilities deteriorate.

This comprehensive review of communication technologies for ALS patients reveals a complex landscape of solutions that must adapt to the progressive nature of the disease. Through our analysis of eye-tracking systems, brain-computer interfaces, and speech synthesis technologies, we have identified both significant achievements and crucial areas for improvement in current assistive communication technologies.

The comparative analysis presented in Table 1 demonstrates that while each technology offers unique advantages, no single solution adequately addresses all stages of ALS progression. As illustrated in Figure 1, the optimal communication strategy requires a dynamic approach, transitioning between technologies as the disease advances. The technical processes detailed in Figure 2 highlight the

varying complexity of implementation, from relatively straightforward eye-tracking systems to sophisticated brain-computer interfaces

Our recommendations emphasize five key areas for advancement:

- Enhancement of existing technologies with ALS-specific adaptations
- Development of seamless transitions between different communication systems
- Integration of early intervention strategies, particularly for voice banking
- Implementation of support infrastructure for both patients and caregivers
- Creation of cost-effective, modular solutions that evolve with disease progression

These targeted recommendations move beyond general technological improvements to address the specific challenges faced by ALS patients. The focus on adaptive systems, early intervention, and integrated solutions reflects the unique needs of the ALS community, where communication abilities change dramatically over time.

Future research should prioritize:

- Development of more affordable and accessible solutions
- Creation of standardized protocols for technology transition timing
- Integration of artificial intelligence for improved adaptation to disease progression
- Enhancement of user interfaces to minimize cognitive load
- Establishment of comprehensive support systems for long-term technology use

By implementing these recommendations and research priorities, we can work toward more effective, accessible, and adaptable communication solutions for ALS patients. The goal remains to maintain patients' ability to communicate throughout all stages of the disease, preserving their autonomy, dignity, and quality of life despite the challenging progression of ALS.

We suggest that future of assistive communication technologies for ALS patients lies in continued innovation and interdisciplinary collaboration. Researchers, healthcare providers, and engineers must work together to develop more affordable, accessible, and user-friendly solutions that can adapt to the progressive nature of ALS. By focusing on personalization, ease of use, and long-term functionality, future developments have the potential to enhance the quality of life for ALS patients, enabling them to maintain their independence and emotional well-being throughout all stages of the disease. It is imperative that future research emphasizes not only technological advancements but also the human experience, ensuring that these tools serve as a lifeline for communication and connection.

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