Enhanced Communication for ALS Patients

Alleviating Caregiver Burden: The Social Impacts of Assistive Communication Technologies for ALS Care

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Introduction

The technical component of this Capstone project aims to address the significant communication barriers experienced by individuals suffering from Amyotrophic Lateral Sclerosis (ALS). ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord, which significantly limits voluntary muscle control. As ALS advances, patients lose the ability to speak or move, making traditional methods of communication impossible without the use of assistive technologies. Communication becomes challenging, leaving patients unable to express even basic needs, affecting their quality of life and autonomy (Zarei et al., 2015). Existing eye-gaze devices, commonly used by ALS patients for communication, become ineffective when patients are confined to bed because the BiPAP mask necessary for breathing support obstructs the eyes, rendering these devices useless. This project seeks to overcome that limitation by developing an AI-driven communication system integrated directly into the BiPAP mask. The system will utilize AI/ML-based image processing algorithms to detect eye blinks and translate them into basic communication commands (Ezzat et al., 2023; Dewi et al., 2022). This innovation involves integrating two cameras onto the BiPAP mask to focus on the patient's eyes, enabling communication via blinks even while they are wearing the mask. By addressing the limitations of current communication technologies and providing a bed-compatible solution, this project aims to restore a degree of independence to ALS patients (Fernandes et al., 2023).

The STS component of this project focuses on the sociotechnical implications of ALS caregiving, focusing on the significant emotional and physical burden that caregivers endure. ALS caregivers experience high levels of stress, anxiety, and emotional burnout due to the constant demands of caring for patients who require extensive assistance (Caga et al., 2019). Studies have shown that behavioral symptoms such as impulsiveness, disinhibition, and communication challenges increase caregiver stress, even more than the physical disabilities that accompany ALS. Cognitive impairments, such as executive dysfunction, affect 8–14% of ALS patients, further complicating caregiving (Caga et al., 2019), with reports indicating that 48% of caregivers experience high levels of burden (Lillo et al., 2012; de Wit et al., 2017). This research explores how assistive communication technologies can alleviate some of this burden by allowing patients to communicate independently, thus giving caregivers more freedom and reducing the physical and emotional strain on them.

The connection between the technical and sociotechnical aspects of the project lies in the potential for innovative AI-driven communication systems to transform ALS patient care. The project aims to enhance patient independence and caregiver well-being by reducing the reliance on caregivers for communication. This integration of technology and social considerations demonstrates the broader impact that human-centered design can have in healthcare, addressing not just the technical challenges but also the social dimensions of caregiving.

Enhanced Communication for ALS Patients

The communication difficulties experienced by ALS patients are typically handled with the use of Augmentative and Alternative Communication (AAC) devices. These devices also use eye blinks and other methods to have the computer create speech. However, as the disease progresses, they become less effective, especially for bedridden patients or patients that need respiratory support (Zarei et al., 2015; Fernandes et al., 2023). The project aims to bridge the gap where current communication devices fall short, specifically for ALS patients who rely on BiPAP masks for respiratory support.

The proposed solution will integrate an AI-based system that can detect eye blinks, a form of communication still accessible to patients even at advanced stages of ALS. The key innovation is the integration of cameras onto the BiPAP mask. These cameras will be focused on the eyes and with the integration of an AI-based blink detection algorithm along with image processing software, they will help detect eye blinks. Afterwards, these blinks will be converted into communication signals with a wide variety of possibilities. These signals will represent binary responses (yes/no) or trigger predefined commands, allowing ALS patients to communicate without the need for traditional input devices like keyboards or touch screens (Ezzat et al., 2023).

The system will utilize two small cameras with the appropriate specifications for the task. These cameras will be attached to a custom designed mount which will attach to the BiPAP mask. The mount will connect to the mask in areas where functionality of the mask will not be disrupted. Non-invasive ventilation can extend ALS patient survival by 7 to 15 months, which further emphasizes the importance of integrating communication technology without disrupting respiratory support (Dorst & Ludolph, 2019). The two cameras will specifically focus on the eyes instead of the whole face. This will ensure that eye movements are captured from different angles, accounting for variations in head position and lighting conditions. Current AI/ML-based blink detection algorithms use an eye aspect ratio (EAR) to detect blinks and calculate how open or closed a person's eyes are by measuring the distance between the upper and lower eyelids using Euclidean geometry within the context of the whole face (Dewi et al., 2022). The algorithm this project will incorporate will be built from these open-source blink detection algorithms but will adjust the code and train the model to detect blinks when the video feed only shows eyes instead of the whole face, all in real time. Furthermore, this model will be trained for accuracy and fine-tuning purposes to avoid false positives.

One of the key technical challenges that this project will face is ensuring that the system is functional under different conditions. For example, patients being repositioned during rest and low lighting conditions pose significant challenges to accurate blink detection. The AI algorithms will need to adapt to these factors via providing training images and video feed to improve the model in these conditions.

Finally, this aspect of the project will need to be tested on a variety of participants to gather data on the accuracy of the device. Testing will involve an iterative process that begins with healthy volunteers and transitions to ALS patients in collaboration with healthcare providers. The system will be evaluated on criteria such as detection accuracy early on and will transition to the impact on caregiver involvement (Caga et al., 2019; de Wit et al., 2017). Early tests will focus on ensuring that the hardware components (cameras and sensors) are durable and non-intrusive. Concurrently, the software algorithms will be trained and fine-tuned to recognize a diverse set of eye blinks from different individuals, improving its generalizability.

Overall, the final goal is to create a system that is not only technologically advanced but also accessible and reliable. This system would make a profound impact in clinical settings and home care, where communication is often the last remaining ability for ALS patients.

Alleviating Caregiver Burden: The Social Impacts of Assistive Communication Technologies for ALS Care

The central question of this STS research is: How do assistive communication technologies for ALS patients alleviate the emotional, physical, and social burden experienced by their caregivers? This question is important to explore as ALS not only impacts patients but also places overwhelming burden and stress on caregivers. The introduction of further improved assistive communication technologies may offer relief to the caregivers by enabling more effective communication between the two parties.

Due to the loss of voluntary muscle control and communication that patients with ALS typically endure, they lose their autonomy and rely on a caregiver for continuous assistance. Research shows that 48% of ALS caregivers experience significant levels of burden due to the high emotional and physical demands of caregiving (Lillo et al., 2012; de Wit et al., 2017). The burden is further exacerbated by the cognitive impairments found in 8–14% of ALS patients, such as executive dysfunction and behavioral changes, which contribute significantly to caregiver stress (Caga et al., 2019). According to de Wit et al. (2017), behavioral impairments, rather than physical disabilities, are the primary contributors to caregiver burden. This highlights the complexity of caregiving, where managing communication and emotional support often outweighs the physical care demands.

Caregivers face a great emotional toll, with caregivers reporting high rates of anxiety and depression due to the constant care that is required (Caga et al., 2019; de Wit et al., 2017). Additionally, according to Londral (2022), 80 to 95% of ALS patients lose the ability to communicate naturally as the disease advances. As a result, this leads to increased responsibility and burden on caregivers, leading to them feeling overwhelmed. It is evident that improving communication for ALS patients could significantly reduce caregiver burden, particularly in terms of emotional strain and time spent managing communication-related tasks.

This research question and problem will be analyzed by examining the qualitative and quantitative data present in existing studies on caregiver burden, assistive communication technologies, and patient-caregiver interactions. Qualitative data from interviews with caregivers who utilize assistive technologies, like eye-gaze or blink-detection systems, will also be analyzed with the focus being on their perceptions of relief after using these technologies. These studies employ tools such as the Zarit Burden Interview (ZBI) to assess emotional tolls that caregivers experience, including anxiety and depression Caga et al. (2019). Additionally, there are studies that provide statistical and quantitative data on the burden caregivers endure. These include the percentage of caregivers that experience mental difficulties and burdens along with what types of factors specifically contribute to the burden and stress the caregivers endure.

The technical efficacy, accuracy of the blink detection of the algorithm, and user satisfaction of the overall system will be explored using data from surveys along with system evaluation. Studies like Ezzat et al. (2023) demonstrate how these systems translate blinks into communication signals which reduces the frequency of caregiver intervention. To accurately quantify this aspect of addressing the research question, metrics such as the number of caregiving hours, emotional strain, and perceived communication effectiveness before and after adopting assistive communication technologies will be evaluated. This analysis of the impact of the technical aspect to the project will help address the potential of these technologies in reducing the caregiving burden, providing a sociotechnical understanding of their broader impact.

The evidence for this research question will be gathered from patients in terms of how technology has improved their autonomy with the increased communication capabilities and how this affected the emotional and physical strain on the caregivers. In a previous study, Gruis et al. (2011) found that ALS patients using assistive technologies reported a significant improvement in their ability to communicate, which correlated with reduced caregiver stress. Additionally, de Wit et al. (2017) highlighted that managing behavioral impairments in patients, rather than just physical disabilities, is crucial to easing caregiver burden. By analyzing this evidence, this project will demonstrate how communication technologies can transform ALS care. This will allow for a technically driven project to address social challenges and difficulties that the caregivers face.

Conclusion

The Enhanced Communication for ALS Patients Capstone project aims to deliver an AI-powered communication system integrated into a BiPAP mask, allowing ALS patients to communicate through eye blinks while in bed. The technical deliverable is specifically a blink-detection system optimized for eye-only tracking. The expected result of the project is a working blink detection system that is integrated into the BiPAP mask via small cameras that ALS patients will use to communicate while in bed. This communication system will help improve patient autonomy and decrease the emotional, mental, and physical strain that caregivers endure by reducing their constant involvement in communication tasks. Ultimately, the deliverable of this project will help the communication barriers that ALS patients face in advanced stages, helping increase their independence.

The STS aspect of this research explores how assistive communication technologies like the technical deliverable of the Capstone project, can alleviate caregiver burden. The main deliverable of this question will demonstrate how caregiver burden was relieved due to the improved patient communication. The expected result of this project is a deeper understanding of the relationship between technology-driven patient autonomy and reduced caregiver strain in the context of ALS.

Ultimately, the combined societal impact of the technical and STS deliverables will demonstrate the significance of designing healthcare technologies that address both patient needs and caregiver challenges, providing a more holistic approach to ALS patient care.

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