Thesis Project Portfolio

Enhanced Communication for ALS Patients

(Technical Report)

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

(STS Research Paper)

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Executive Summary

Amyotrophic Lateral Sclerosis (ALS) caregivers experience overwhelming burdens due to the communication barriers and constant care demands of the patients afflicted with the disease. My Capstone Project involved developing a novel, blink-based communication system by integrating compact Arduino-based cameras onto a BiPAP mask using custom-designed, 3D-printed mounts. The primary benefit of this system is that, with accurate blink detection and future capabilities to translate blinks into communication, ALS patients can independently communicate urgent messages or emergency alerts without requiring continuous caregiver presence. My STS research examined how augmentative and alternative communication (AAC) technologies affect caregiver burden from emotional, physical, and social perspectives. This research was undertaken to understand broader sociotechnical impacts, benefits, and limitations of AAC technologies on ALS caregiving. Both projects are interconnected through their shared goal of alleviating caregiver burden via enhanced patient communication. The technical Capstone project addresses practical communication challenges in the case of patients who use a BiPAP mask, while the STS project contextualizes these solutions within broader AAC device usage along with societal and caregiving dynamics.

The main problem that my capstone project addresses is the communication difficulties that ALS patients who wear BiPAP masks experience, as this limits the effectiveness of traditional AAC devices depend on a clear and unobstructed view of the patient's eyes and face. To overcome this, we developed a system that involves two Arduino ArduCAM modules that are mounted directly onto a BiPAP mask using 3D-printed mounts. These cameras capture real-time video footage of the patient's eyes. This is then processed through a machine-learning (ML) based algorithm that is specifically trained on images of open and closed eyes to detect eye

blinks in real-time. This approach allows ALS patients to potentially communicate more independently and immediately alert caregivers in cases of urgent situations, which significantly reduces the need for continuous caregiver presence.

The development of the ML-based blink detection algorithm and camera mounting system were both successful. The preliminary tests demonstrate that our algorithm effectively detects blinks in real-time when the cameras are directly focusing on the eyes without any obstruction. The construction of the final device on the BiPAP mask, including the cameras with the blink-detection algorithm running and the 3D-printed mounts with the cameras attached, was successfully completed. This device can significantly enhance ALS patient autonomy, decrease caregiver reliance, and has potential for advancing communication solutions for ALS patients.

My STS research explored how AAC technologies alleviate the emotional, physical, and social burdens experienced by ALS caregivers. This topic is significant due to the immense emotional, physical, and social challenges faced by caregivers who manage the general and communication needs of ALS patients daily. I conducted a systematic literature review to examine the interactions and overall network between caregivers, ALS patients, and AAC technologies. This allowed me to analyze how communication devices impacted caregiver responsibilities.

The evidence from the literature suggests that AAC devices significantly reduce emotional stress and physical fatigue, and they improve the social well-being of caregivers due to the increased independence that patients will have. However, the literature also mentioned significant limitations of the usage of AAC devices. These include emotional distress due to ALS progression, persisteny physical demands unrelated to communication, cognitive impairments that challenge AAC effectiveness, and socioeconomic disparities limiting AAC access.

Ultimately, while AAC technologies ease certain caregiver burdens, there has to be other complementary support systems and a focus on equal access to the deivces to fully address ALS caregiving challenges.