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

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science
University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science, School of Engineering

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Spring 2025

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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STS Research Paper

Introduction

Amyotrophic Lateral Sclerosis (ALS) is a progressive neurodegenerative disease that leads to the degeneration of motor neurons. This results in complete loss of voluntary muscle control and impairments in mobility and speech (Zarei et al., 2015). One of the most challenging aspects of ALS is the loss of communication that the patients experience. This impacts both their quality of life along with their caregivers as without the ALS patients' ability to speak, even the simplest interactions can become difficult. Caregivers typically struggle to understand the needs of ALS patients, which can lead to frustration, miscommunication, and increased stress. Approximately, around half of ALS caregivers report that they experience significant emotional exhaustion and anxiety due to the difficulty of taking care of an ALS patient and the communication barriers between the two groups (Lillo et al., 2012).

As a result of this pressing need, there have been recent advancements in assistive communication technologies. Augmentative and Alternative Communication (AAC) devices provide a promising outlook on tackling these communication challenges. These technologies include eye-tracking devices, text-to-speech software, and brain-computer interfaces. With the usage of these devices, ALS patients can communicate independently and efficiently with their caregivers (Chang et al., 2014). Due to this increased ease in communication, AAC devices improve patient autonomy and alleviate caregiver burden by reducing the need for continuous physical presence and interpretation of non-verbal cues (Pugliese et al., 2022).

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. Caregivers experience physical exhaustion from the long hours and lack of sleep, social isolation due to the time commitment of caregiving, and emotional distress due to urgency and difficulty of the situation (Caga et al., 2019). The introduction of further improved assistive communication technologies may offer relief to the caregivers by enabling more effective communication between the two parties.

Ultimately, this paper argues that AAC devices play a critical role in reducing caregiver stress through a variety of means. These include improving patient autonomy, decreasing communication-related frustrations, allowing caregivers more time to engage in social and professional activities, and giving caregivers more time to focus on their personal health and well-being. By focusing on the intersection of caregiving and communication technologies in the context of ALS patients, this STS research aims to emphasize the social implications of AAC devices in ALS care.

Background and Significance

Due to the impact that ALS has on a patient’s motor neurons, they lose voluntary muscle control which includes speech. The patients lose their ability to verbally communicate, which makes their daily interactions difficult. This loss of communication affects their autonomy, quality of life, and emotional well-being on top of the physical toll they face. It also places a heavy burden on caregivers, who must constantly assist patients with their needs. The current and traditional methods of communication, such as letter boards and partner-assisted scanning require constant caregiver involvement which can lead to emotional and physical strain (Linse et al., 2018).

Caregiving for ALS patients is a demanding job, especially if the disease progresses into later stages where patients require full-time assistance. Many caregivers experience chronic stress, emotional exhaustion, and physical fatigue due to the high difficulty and constant responsibility of interpreting non-verbal cues and meeting their patients’ needs (Lillo et al., 2012). It has been reported that 48% of ALS caregivers report high levels of emotional distress, while 30% experience symptoms of anxiety and depression due to the overwhelming nature of their responsibilities (de Wit et al., 2017).

A significant challenge that ALS caregivers experience is the uncertainty in communication. Without clear verbal interactions, caregivers must perform guesswork and trial-and-error methods to determine what their patient wants. This results in misunderstandings, frustrations, and a sense of helplessness for the patient and the caregiver. Additionally, the time-intensive nature of manually assisting with communication means caregivers must always be physically present, leading to chronic fatigue and social isolation (Caga et al., 2019). As a result, many caregivers lose out on time for their personal and professional lives due to the time commitment of caregiving for ALS patients.

Furthermore, it has been noted that caregiver burden is also impacted by the behavioral changes that ALS patients undergo as their condition deteriorates. It has been reported that caregiver burden is influenced more by behavioral and cognitive changes in ALS patients than by physical disabilities (Lillo et al., 2012). When patients develop emotional dysregulation, executive dysfunction, or impulsivity the caregivers must provide both physical and psychological care to the patients. As a result, this increases the burden and stresses the caregiver's experience. It is evident that caregivers also struggle with the emotional and mental challenges of caring for someone who also has minimal physical and communication abilities.

Recent advancements in AAC technologies have provided ALS patients and caregivers with much needed ease for both of their situations. AAC devices, such as eye-tracking systems, text-to-speech software, and brain-computer interfaces, allow ALS patients to communicate with relatively minimal effort in comparison to the traditional communication methods. As a result, this significantly reduces the burden of the caregivers (Chang et al., 2014). The usage of these devices provides many benefits. They help restore patient autonomy as AAC devices allow ALS patients to communicate by themselves. As a result, they are not as reliant on their caregivers for basic interactions. This helps preserve their sense of self and improves their well-being (Pugliese et al., 2022). Furthermore, using AAC devices, the stress that caregivers face due to poor communication with ALS patients is no longer present. Caregivers do not have to interpret non-verbal cues or perform guesswork for the patient's needs. The patient can communicate by themselves in a clear manner, which decreases the emotional frustration caregivers face and makes day to day interactions efficient (Linse et al., 2018). Additionally, AAC devices minimize the need for direct caregiver intervention in communication and their around the clock presence is not required, which ultimately reduces their workload. This reduction in workload helps prevent burnout, reduces physical fatigue, and improves the caregiver’s overall well-being (Chang et al., 2014). Moreover, caregivers who experience less communication-related stress report higher quality of life and improved mental health (Lillo et al., 2012). On top of the mental benefits, the AAC devices also provide social benefits to the caregivers. With the usage of AAC devices by ALS patients, the caregivers have more time to spend on their personal life. They can engage in personal activities, spend time with family, and interact with social circles to prevent isolation and emotional exhaustion. Finally, another key benefit of the use of AAC devices in ALS is that it improves the patient-caregiver relationship. Due to the easier and less frustrating communication between the two parties, the emotional bond between patients and caregivers improves. The patients and caregivers can engage in meaningful conversations and develop a bond instead of having interactions that revolve around understanding patient needs (Linse et al., 2018).

Overall, AAC technologies in ALS care have demonstrated immense importance for both caregivers and patients. As a result, exploring how they help reduce caregiver burden and enhance the quality of life for the caregivers is important to understand.

Methodology

The research question that this study will be exploring is: How do assistive communication technologies for ALS patients alleviate the emotional, physical, and social burden experienced by their caregivers? To address this research question, this study will use a systematic literature review of existing research on AAC technologies and ALS caregiving. The literature review will focus on three aspects of caregiver burden, including the emotional burden, physical burden, and social burden of caregiving. For emotional burden, studies that examine stress, anxiety, and emotional exhaustion in ALS caregivers will be examined. Furthermore, for physical burden, research exploring how AAC devices reduce the need for direct caregiver intervention in communication and how they decrease physical fatigue will be reviewed. Finally, for the social burden, studies that analyze how the usage of AAC devices by ALS patients affect the caregiver's work-life balance, social interactions, and quality of life will be examined.

The literature reviewed in this study will be sourced from peer-reviewed journals that focus on ALS caregiving and AAC technologies. Additionally, clinical studies that examine the effectiveness of AAC devices in reducing caregiver burden will be used and qualitative interviews and quantitative metrics that record ALS caregiver experiences in the context of AAC technologies will be used. The qualitative content that is extracted from the studies will focus on the positive outcomes (reduced stress, improved patient-caregiver relationships, increased patient autonomy), challenges (learning difficulties, device maintenance, accessibility issues), and long-term implications (changes in caregiver responsibilities over time, technological advancements in AAC design) to analyze the emotional, physical, and social impact of AAC devices.

Additionally, this study will apply Actor-Network Theory (ANT) to analyze how assistive communication technologies function as mediators within the ALS caregiving networks. The main idea behind ANT in this context is that both human actors (caregivers and patients) and non-human actors (AAC devices) interact with each other in various ways, which impacts the patient's and caregiver's experiences. Specifically, in terms of ALS, caregivers rely on AAC devices to facilitate communication, and these devices influence the caregiver's workload, emotional strain, physical strain, and social interactions. By characterizing AAC devices as active participants in the "caregiving network" this study will explore how AAC devices impacts caregiver responsibilities and alters the daily experiences of both caregivers and patients.

Without the usage of AAC devices, caregivers must put in a lot of manual effort. They must manually assist patients in all communication efforts which lead to physical exhaustion, emotional frustration, and social isolation (Caga et al., 2019). With the usage of AAC devices, caregivers experience a shift in responsibilities, because communication becomes more independent and efficient for patients (Chang et al., 2014). ANT will provide clarity on understanding these shifting relationships and examine the benefits and challenges of the usage of AAC devices in the context of ALS.

ANT will be a useful analytical framework to explore how AAC devices affect the caregiving experience. By examining the interactions between caregivers, ALS patients, and AAC devices, this STS study will evaluate how caregiver workload is reduced by the improved communication process, how caregiver stress is alleviated by reducing miscommunication and guesswork, and how the social relationships between caregivers and patients have improved. It is also important to note that ANT will also reveal the potential unintended consequences of the adoption of AAC devices. This is because these devices also introduce new technological dependencies and learning curves for patients and caregivers. This research will also examine the challenges associated with AAC technologies. This will include the learning curve and device training aspect as caregivers must learn how to use and troubleshoot AAC devices, which requires additional time and effort (Linse et al., 2018). Additionally, the usage of AAC devices leads to technological dependence as some patients become reliant on specific AAC features, while improving their own quality of life. As a result, this leads to new forms of caregiver responsibility of maintaining and adapting the technology (Pugliese et al., 2022). Finally, it is important to assess the access the equity issues as not all caregivers have equal access to AAC technologies due to financial, technological, and healthcare disparities (Caga et al., 2019). By holistically explaining these social interactions, ANT will provide an understanding of how AAC technologies impact ALS caregiving.

Combining ANT with a systematic literature review, this dual methodology will provide a comprehensive view of how AAC devices affect ALS caregivers. It will emphasize the benefits and limitations of AAC devices and how this technology has reshaped caregiving quality of life, roles and responsibilities.

Literature Review

ALS imposes severe physical, emotional, and social challenges on caregivers, who frequently report high levels of burden and stress. Caregiving for ALS patients is demanding, particularly due to the progressive nature of the disease, leading to complete loss of voluntary motor control, speech impairments, and increased dependency on caregivers (Zarei et al., 2015). Caregivers endure emotional distress, physical fatigue, and diminished social interactions due to their continuous involvement in care responsibilities. The disease imposes a severe burden on caregivers, with nearly 48% reporting high emotional distress, and 30% experiencing symptoms of depression and anxiety (Lillo et al., 2012). These stressors occur due to the constant physical care, communication difficulties, emotional toll of ALS progression, and overall difficulty of the job (Caga et al., 2019). A main challenge for caregivers is interpreting patient needs, especially since patients tend to be unable to verbally communicate. Without the use of AAC technologies, caregivers rely on guesswork and trial-and-error methods, which increase miscommunication, frustration, and exhaustion (de Wit et al., 2017).

In response to these challenges, there are a variety of AAC devices that ALS patients use to have more independence and alleviate most of the difficulties their caregiver experiences. These devices include eye-tracking systems, text-to-speech software, and brain-computer interfaces. These devices offer ALS patients an alternative means of communication (Chang et al., 2014). The literature suggests that AAC technologies significantly reduce caregiver burden via a variety of ways. AAC technologies are known to improve patient autonomy as they allow ALS patients to express their needs independently. Additionally, they can help reduce emotional stress as they eliminate any frustration that a caregiver may experience due to communication difficulties and miscommunication. Furthermore, they help decrease physical fatigue as they minimize the need for direct caregiver intervention in communication efforts. Moreover, they also improve a caregiver’s social life. They can engage in more personal and professional activities due to increased free time and less demanding care (Pugliese et al., 2022). AAC devices also allow ALS patients to communicate clearly, thus enhancing the quality of interactions between patients and caregivers. This helps foster a stronger emotional and social connection between the two parties. Also, Linse et al. (2018) found that AAC technologies play a crucial role in palliative care, allowing patients to maintain decision-making abilities while reducing caregiver stress.

While AAC technologies offer many benefits, they do not alleviate all aspects of caregiver burden and do have some limitations. In the literature, one limitation that has been noted is that caregivers still experience grief, anxiety, and emotional distress as ALS progresses, regardless of whether AAC devices are being used or not (Caga et al., 2019). As the condition of an ALS patient worsens, it can take an emotional toll on the caregiver who may have formed a relationship with the patient. Additionally, there is a learning curve, and technological barriers associated with AAC device use. AAC devices require training and troubleshooting in many cases. This can create additional responsibilities for the caregiver who may already be overworked and overwhelmed (Linse et al., 2018). Caregivers often tend to experience frustration initially with AAC device implementation, which demonstrates the importance of training the relevant parties to use the device. Furthermore, some ALS patients deal with cognitive decline and executive dysfunction. Due to their cognitive state, AAC devices may not effectively assist these ALS patients which lead to increased caregiver burden, responsibilities, and difficult communication (Lillo et al., 2012). These patients tend to experience behavioral symptoms such as impulsivity and emotional dysregulation, which significantly increase caregiver stress. Studies show that behavioral changes in ALS patients are even stronger predictors of caregiver burden than physical disabilities alone, suggesting that AAC devices can only partially mitigate these issues (Lillo et al., 2012; Caga et al., 2019). Another key limitation of AAC devices is that they did not address the physical caregiving tasks such as feeding, repositioning, or medical care (de Wit et al., 2017). This continuous physical care remains a significant source of exhaustion and strain for caregivers. Finally, another limitation of AAC device use is disparities in relation to access. Socioeconomic status, healthcare coverage, and technological literacy often limit caregivers' and patients' ability to benefit from these devices (Pugliese et al., 2022). This creates inequality in terms of device access, especially for patients who may need it the most.

Ultimately, the literature indicates that AAC technologies represent a significant advancement in ALS patient care, helping reduce emotional and social stress associated with communication challenges. However, they do not fully address all the physical and emotional caregiving challenges. Although AAC devices provide a crucial advancement in ALS patient care, additional support mechanisms are necessary to holistically address caregiver burden.

Results and Discussion

This research explored the STS question: How do assistive communication technologies for ALS patients alleviate the emotional, physical, and social burden experienced by their caregivers? After performing a literature review, the analysis demonstrates that AAC technologies significantly alleviate caregiver burdens. However, the devices also have limitations and certain stressors that caregivers endure persist. Additionally, after applying the STS framework of Actor-Network Theory, deeper insights into the sociotechnical relationships between caregivers, ALS patients, and AAC devices were noted. It helped note the relief that the AAC devices provide and the limitations that remain.

The literature review demonstrates that AAC technologies play a significant role in alleviating caregiver burden in a variety of ways. Due to the facilitation of clear and independent communication from ALS patients that use AAC devices, caregivers tend to experience reduced emotional stress (Chang et al., 2014). These devices provide patients with communication autonomy via eye-tracking systems and text-to-speech software. As a result, caregivers have reduced emotional strain that is associated with communication difficulties. The literature also indicates that caregivers who work with patients that use AAC devices report improved mental health, increased emotional stability, and reduced feelings of helplessness due to the elimination of trial-and-error communication (Linse et al., 2018).

Furthermore, AAC devices help alleviate the physical burden that caregivers endure, especially related to communication related tasks. Traditional communication methods, such as manually assisting patients with communication through partner-assistant scanning or letter boards, lead to chronic fatigue in caregivers. This is due to the constant vigilance and effort required to facilitate communication between the two parties. Eye-tracking and gesture-based

AAC devices shift the physical burden from the caregivers to the technology, which decreases direct caregiver involvement and intervention. As a result, caregivers experience less physical exhaustion and are less susceptible to burnout (Chang et al., 2014).

Finally, from a social burden perspective, AAC devices allow caregivers to regain some of their personal time. This allows for a better work-life balance and reduces social isolation (Pugliese et al., 2022). When ALS patients can independently communicate their basic needs, caregivers have more flexibility to engage in social activities, maintain employment, develop their relationship with the patient (due to the increased ease in communication), and develop other interpersonal relationships outside of caregiving. The main benefit of this is that it contributes to an improved quality of life for the caregiver and leads them to be more satisfied overall with their caregiving role.

Although AAC technologies can alleviate certain aspects of caregiver burden, they are not able to remove all the stressors. The emotional toll of ALS progression on caregivers is still a significant challenge regardless of communication improvements. Caregivers face grief, anticipatory loss, and emotional distress due to the progressive, incurable nature of ALS. The harsh reality of the patient's declining condition, deterioration in physical capabilities, and end-of-life considerations are emotionally taxing and cannot be properly addressed by AAC devices (Caga et al., 2019). Additionally, tasks such as feeding, bathing, repositioning, medication management, and respiratory support continue to be physically demanding responsibilities. AAC devices do not provide direct assistance in these caregiving activities. As a result, caregivers still experience physical fatigue and exhaustion to a degree (de Wit et al., 2017).

Furthermore, caregivers still face cognitive and behavioral challenges in ALS patients that cannot be fully addressed by AAC devices. ALS patients frequently experience executive dysfunction, emotional dysregulation, impulsivity, and behavioral shifts that AAC technologies alone cannot manage effectively (Lillo et al., 2012). As a result, caregivers must be more emotionally involved and vigilant which leads to additional burdens beyond communication difficulties.

AAC technologies also introduce new forms of caregiver dependence on technology. These devices require frequent training, maintenance, and troubleshooting. Caregivers must learn new technical skills to manage any device malfunctions and issues. This creates additional responsibilities that can increase caregiver stress, particularly among those who are already burdened or are not technical proficient (Linse et al., 2018).

Finally, disparities in AAC technology access are another critical limitation. These include socioeconomic factors, poor healthcare coverage, and varying levels of technological literacy among caregivers. These factors limit access and use of AAC devices. These disparities highlight the importance of addressing structural and economic barriers that prevent equal distribution of AAC-related benefits among ALS caregivers (Pugliese et al., 2022).

Actor-Network Theory provides a view of AAC devices as both enabling agents and new sources of caregiver responsibility within caregiver networks. As non-human actors, AAC devices transform the caregiving landscape by redistributing communication responsibilities away from caregivers, which allows patients to regain autonomy. ANT also illustrates how the introduction of technology creates new and unanticipated situations. In this case, caregivers are required to develop new technical skills, troubleshoot device issues, and adapt continuously as ALS progresses. An analysis of this problem using ANT explains how ongoing caregiver support and technological innovation are crucial to ensure AAC devices provide relief rather than additional stressors to caregivers. Overall, while AAC devices alleviate caregiver burden related to communication, physical, social, and emotional burden, they cannot fully address all aspects of ALS caregiving challenges. As a result, these devices are a partial solution within the broader solution to reduce caregiver burden.

Conclusion

The key takeaway of this research is that AAC devices significantly ease ALS caregivers' emotional, physical, and social burdens by improving a patient's ability to communicate and granting the patient more autonomy than without the device. AAC devices alleviate caregiver stress and frustration associated with interpreting patient needs. As a result, the social life and mental well-being of the caregiver is improved and physical exhaustion related to communication assistance and round-the-clock care is reduced. However, AAC technologies have many limitations and do not address all caregiving challenges. Issues such as emotional distress caused by witnessing ALS progression, physical caregiving responsibilities like feeding and repositioning, and cognitive and behavioral changes in patients remain persistent despite device usage. Finally, AAC devices can also introduce new tasks and responsibilities for caregivers such as technical training and maintenance tasks. This can provide unexpected stress and increase caregiver burden if not properly managed. As a result, it is evident that AAC technologies are a partial solution to the overall problem of ALS caregiver burden.

Future research should explore other solutions alongside AAC devices to relieve caregiver burden. These can include psychological counseling for caregivers, targeted caregiver training programs, and more robust policies that help tackle the socioeconomic disparities in AAC device access. Furthermore, innovations within the AAC device design can make these devices more intuitive and accessible for caregivers and patients. This can include an interface that uses current artificial intelligence technologies to help reduce the technical barriers that caregivers might experience with AAC device usage. Finally, it is critical for policymakers and healthcare companies to prioritize inequalities in AAC device access to ensure that the benefits of these devices reach all ALS caregivers equally.

Ultimately, AAC devices are a vital advancement in ALS patient care; however, the limitations of the devices demonstrate the need for additional support strategies to fully alleviate ALS caregiver burden.

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