

Practical Exosuit Design for Patients with Amyotrophic Lateral Sclerosis
How Wearable Robotics Can Affect the Quality of Life of Both Patient and Caretaker

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By
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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 design and creation of a fully soft, wearable exoskeleton for daily use in the rehabilitation of patients with neuromuscular diseases is an important part of the care for these individuals because of the nature of the disease. In the United States, about 250,000 people suffer from neuromuscular diseases at any given time (IQVIA, 2018). ALS, or amyotrophic lateral sclerosis, is a degenerative neuromuscular disease that progressively affects nerves throughout your body and currently has no cure (Understanding ALS). These patients gradually lose control of their muscle function, causing many to rely on a caretaker in order to achieve activities of daily living (ADLs). Because the disease has no cure, the main priority of healthcare workers and family members of the patients is to make the person more comfortable and independent as the disease progresses. Many have theorized that wearable robotic devices could be helpful and efficient tools for people living with ALS because the devices will allow them more autonomy in their daily life, ultimately leading to a better quality of life. However, the number of wearable robotics in use is still very low “due to missing availability on the market, as well as technological acceptance limitations” (Meyer et al., 2021). The market for fully soft exoskeletons is sparse because of the need for each device to be tailored to an individual, so a novel wearable robot is needed in order to better address these patients.

The technical piece of this project will include the design and creation of a novel wearable device that is fully soft for people affected by ALS. In order to achieve this, the project team will work closely with patients at local hospitals to find a suitable design for patients that will be accessible. The socio-technical side of the project will explore the relationship between patients, caregivers and family members. The main goal of this topic is to understand how a wearable device will affect each stakeholder’s quality of life, and if the benefits of the device

outweigh the risks. One way that a patient's quality of life has been shown to increase is by using non-invasive techniques for rehabilitation and living accommodations (Aho-Özhan et al., 2017). The creation of a fully soft, wearable robotic device for rehabilitation will improve the quality of life of ALS patients and their caregivers.

Creation of a Fully Soft Exoskeleton for Upper Limb Rehabilitation

The goal of the technical Capstone project is to create a fully soft, wearable robotic device that will encompass two degrees of freedom, one degree each at the elbow and shoulder. A soft exoskeleton will create a more comfortable, usable and functional robotic device because of its lighter weight and adaptability to different patients (Golgouneh et al., 2021). Using two degrees of freedom, the team plans on designing the device to assist patients in the eating and drinking motions. This seemed to be a more common area of concern for patients because of the regularity of the activity. Soft exoskeletons with both pneumatic and artificial muscle actuators have been created before and are on the market, but a true fully soft device created with only artificial muscles, known as twisted and coiled polymer actuators (TCPA), has never been designed. This is the goal for our design. TCPA artificial muscles are a relatively new technology that uses twisted nylon with a silver finish to act as a conductor (Ho Cho et al., 2016). The length of the thread is sewn into a wearable suit, and, when a current is run through the TCPA, the thread contracts up to 20% of its length in order to create actuation. The threads will be embedded in the suit with insulators to capture any heat that is given off. This actuator looks very promising to our design and future device designs.

Since this design is novel and the research is sparse, the project team has created a backup plan for the design in case the TCPA design is found to be unfeasible. A pneumatically

actuated, two degree of freedom for the shoulder and elbow joint device will be created if this is the case. Zhou et al. (2021) were able to use a pneumatically actuated soft exoskeleton to reduce fatigue in the research participants by inflating an air bladder to mimic human shoulder abduction. This concept and design could be implemented to reach our desired goals for ALS patient rehabilitation. Using either TCPA or pneumatic actuators will ensure that our design will be lightweight and accessible to all patients who need assistance with ADLs. To make the design accessible, the soft suit will use velcro and flexible materials so that each patient will be able to wear the device comfortably and effectively.

Finally, electromyography (EMG) and inertial measurement unit (IMU) sensors will be embedded in the wearable device to track muscle actuation and the human motion of the wearer. EMG sensors measure the electromyographic of human muscles by recording the electrical signals that occur on the surface of the skin (Gielen, 1999). These sensors sit on the human skin and track the muscle's activity, which in turn will allow the robotic device to give feedback. This feedback tells the device the motion that the wearer is trying to produce, and in turn will create that motion through the use of software. IMUs are sensors that can collect nine degrees of freedom from its accelerometer, gyroscope and magnetometer, and can be widely used in aeronautics, robotics and human activity (Botero Valencia et al., 2017). The IMUs will be used in order to estimate the user's acceleration and angular velocity so that we can get feedback on the motion of the actuators. Using data from both sensors, Arduino software and Matlab, we will be able to program the device to create the desired motion.

How Wearable Robotics Can Affect the Quality of Life of Both Patient and Caretaker

ALS is a progressive, neurodegenerative disease that currently has no cure. Because of this, many patients require a caretaker, usually a family member, to help them with all of their

daily needs. As the disease progresses, the work of the caretaker becomes more important as the person becomes less independent. This takes a mental and physical toll not only on the patient, but also on the caregiver. Research by Burke et al. (2017) showed that caregivers had higher levels of anxiety and depression and a lower quality of life when taking care of patients whose disease had progressed. Also, a recent study found a beneficial relationship between patients and the use of a device for rehabilitation, stating that ALS patients who participate in rehabilitation have a higher quality of life than those who do not (Soofi et al., 2018). By looking at these studies it is clear to see the positive impact that this technology has on the stakeholders and how the technology will be shaped by those that it impacts. Researchers believe that wearable robotics can help fix this problem. I will try to show which stakeholders will be affected by the new technology.

Pinch and Bijker's (1984) Social Construction of Technology (SCOT) will be used to show that all technological artifacts have stakeholders that influence the design and creation of a product, and that there is an inherent relationship between them. In this situation, the stakeholders are the patients, family members and caregivers that are affected by the disease, and who will hopefully be impacted in a positive way by a wearable robotic device. With the creation and implementation of this device, ALS patients will be able to more easily complete ADLs without the help of a caregiver, alleviating some of the stress that a caregiver may feel. The engineers creating the device will be able to receive feedback from the patients so that they can cater to each patient's individual needs. Also, the designers will use this framework to address the desires of the family members and caregivers of the patients. Using the framework of social construction, I will be able to better understand the role of wearable robotics in the rehabilitation

of people affected by neuromuscular diseases and how technology should be created in order to meet the requirements of all the social groups involved.

Research Question and Methods

How can data from human motion experiments and input from ALS patients be used to create a wearable device for rehabilitation? Neuromuscular diseases affect nearly 250,000 Americans, and those who care for them are affected in a multitude of other ways. It is important that this device is researched and created so that the patients, family members and caretakers can have a higher quality of life. To do so, different methods of research and data analysis must be conducted. The first part of the team's research plans included literary analysis of studies regarding ALS, rehabilitation for the disease, and the use of soft exoskeletons in rehabilitation. In the spring semester, hospital visits will be planned in order to get feedback from patients and doctors so that we will have a better understanding of the types of ADLs that are most common. The methods that the group will be using to collect data and analyze results will come from using human test subjects. The first part of this method will be collecting data from outside sources in order to code the actuators, and then get feedback from the test subject, which will be one of the group members. The data we collect from our own procedures will be used to modify our code and design. We will use Matlab programming and the collection of IMU and EMG sensor data using the Arduino IDE interface to control the robot. Finally, we will use standard testing metrics including repeatability, accuracy and safety to create a viable device. Once we have a baseline for the movements that we want, we will then go on to hospital visits in order to test the device on the patients that we hope to help.

Conclusion

Neurodegenerative diseases like ALS cause patients to lose control of their muscular functions, creating a need for a caregiver to help with their activities of daily living. To alleviate this problem, a fully soft, wearable robotic device is being designed and created so that people affected by ALS can have more independence. More autonomy for the patient will allow both patient and caregiver to have a higher quality of life. This is significant because the creation of this device will go beyond just the ALS sufferer and a caregiver. The device will be able to help other people with neuromuscular diseases, and also people who need rehabilitation for common injuries. And finally, the device will reshape the patient and caregiver relationship for the better. In the research paper, a wearable device with TCP actuators will be utilized to show how a rehabilitation device can be used to change the dynamics of the patient-caretaker relationship.

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