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

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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. Because of the limited market and use of the technology, more research needs to be done not only on the creation of these devices, but also the implementation of them in roles of rehabilitation and daily use.

This research 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). By studying different instances of where wearable robotics have been used successfully can help us better understand how they can improve quality of life. The creation and implementation of a fully soft, wearable robotic device for rehabilitation will improve the quality of life of ALS patients and their caregivers, and therefore change the patient-caregiver relationship in a beneficial way.

Case Context

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. The middle ground between these two actuators is found in the use of a Bowden cable. Research supporting Bowden cable actuators for use in wearable robotics is more abundant, with multiple research teams creating similar designs with only one degree of freedom. By using this unique type of actuator, the design will be low cost, lightweight and accessible for many people for both rehabilitation and activities of daily living.

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.

STS Theory

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 Bjiker’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.

Table 1

How Different Stakeholders Affect a Wearable Robotic Device

Stakeholders	Stakeholder Input and Feedback
Patients	Communicate with engineers to ensure a comfortable and viable design
Caregivers	Communicate to engineers which tasks the patients need the most hep with
Family Members	Gives feedback to engineers about which design elements alleviate the most familial and caregiver stress
Engineers	Listens to each stakeholder in order to create the most helpful design for all parties

Research Questions and Methods

How can data from human motion experiments and case studies regarding 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 (IQVIA, 2018). 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, further research and testing of our prototype designs will be conducted 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, the second stage of design testing will begin by placing our model on human beings to mimic the motions of people affected by ALS.

I will use two different case study methods in order to conduct research for this project. By studying the implementation of wearable robotics in rehabilitation and activities of daily living, I will be able to understand the intersection between the technology and its impact on society. Two recent cases have shown how these different applications of wearable robotics can have a beneficial effect on caregivers and patients. A device created by Columbia University allows ALS patients to regain up to 70% of their range of motion in their neck movements (Robotic Neck Brace Dramatically Improves Functions of ALS Patients, 2019). This study shows how patients can resume activities of daily living without the need of a caregiver. Another study focused on the impact of robotics on rehabilitation of patients. A wearable robot for gait assistance helped people not only walk farther on their own, but also use less energy in doing so (Kim et al.). By using these two case studies, I will be able to better understand the sociotechnical impact of wearable robotics. Through my research and testing, I will seek to understand which devices patients have the most success with, whether they can use them at home or not, and if my research team's model could help.

Results

By using different academic papers and case studies of rehabilitation centers, our research team can understand exactly which movements and activities of daily living are needed for people with ALS and other neuromuscular diseases. ALS patients, when newly diagnosed, begin meetings with their neurologists and specialized therapists so that a course of action can be created for their rehabilitation. The specialists set up in-patient and out-patient rehabilitation work so that the patients can learn how to adapt to their new lives and strengthen their muscles so they can prolong their quality of life. Using data from multiple case studies on the rehabilitation of people diagnosed with ALS, our Capstone group was able to design and prototype a wearable robotics device that fit the specific needs of out-patient therapy. In these studies, it was found that multiple avenues of therapy, including limited exercise, stretching and the use of adaptive equipment, gave patients the best results in maintaining their autonomy.

These case studies also emphasized the fact that, although rehabilitation can increase the quality of life of the patients, the progression of ALS symptoms can not be fully stopped at this time.

In a 2014 study on rehabilitation of ALS patients, lightweight braces were cited as a common example of out-patient therapeutic devices that people with ALS were given as a way to aid in discomfort and daily movements (Majmudar et al., 2014). The therapeutic devices used for activities of daily living, however, are mostly splints that fix either the patient's foot or hand in certain positions to conserve energy and give them better stability. The downside of these splints and orthotics is their cumbersome and stiff designs. A review on the use of these devices does give us a view into what is most needed by patients. The data in the study showed that patients need the most help in activities such as eating, drinking and grooming, which our device is designed to achieve, but in a fully-soft design. A comprehensive 2018 study on physical therapy for ALS patients showed that the most common symptoms reported by patients in their daily lives were muscle fatigue and muscle stiffness (Bello-Haas, 2018). To combat this, stretching of the muscles and range of motion exercises were prescribed both in therapy sessions and at home.

These two cases, however, fail to mention the use of therapeutic robotics in the treatment of ALS in either in-patient or out-patient therapy. By incorporating the successful assistive therapeutic devices for at home use from the study by Majmudar et al., a wearable robotic device can be created that will meet the needs of patients with neuromuscular diseases. The most commonly used devices are mobile arm supports for eating and drinking and long-handled tools for personal hygiene. The use of these therapeutics brings me to the conclusion that the creation of a wearable robotic can be the solution for people suffering with ALS. Dr. Bello-Haas' alludes to the fact that in-patient therapy is not enough, as patients become weaker as the disease progresses, leading to the dependance of a caregiver. The need for a device that can help a patient's range of motion and help complete activities of daily living is in high demand, which is why many researchers are designing wearable robotic devices with these specifications in mind. Finally, both of the cases mentioned the demand for non-invasive devices that do not restrict the user. By using data from these two case studies, a wearable device for in-patient and out-patient rehabilitation can be created.

Discussion

The case studies that I used in my research methods were broad and very similar to the most of the research that I have previously done on ALS and rehabilitation. The majority of studies on the impact of rehabilitation on the quality of life of patients and their caretakers found the same few ideas to be true. For example, a 2017 study found that patients had a much higher quality of life when their assistive equipment for therapy and daily living was non-invasive (Aho-Özhan et al., 2017.) The quality of life of the patient's caregiver is frequently mentioned because of the close relationship between the two. As ALS progresses, patient's lose more and more control of their muscles, ultimately depending solely on a caretaker, who is usually a family member, to provide for their needs (Burke et al., 2017). This research connects back to the STS framework of SCOT through the impact on the stakeholders, including patients, family, caregivers, and now therapists. Evidence from the 2014 and 2018 case studies support the claims by Aho-Özhan et al. and Burke et al. because it showed that patients' quality of life was improved when therapeutic devices were used. This in turn reduced stress of the caregivers and family of the patients, as their care was not needed as much.

Because the field of wearable robotics for use in ALS rehabilitation is small, there are a limited number of studies and research around the topic (Meyer et al., 2021). There have been a few recent studies that show promise with the use of wearable exoskeletons. A 2018 research study conducted in China led to the development of a fully-soft wearable device designed for stroke patients (Wei et al., 2018). This design was then able to be used in the rehabilitation of these patients, which is a fantastic sign for this field of research. However, most of the research that I have conducted has been concerned with either the creation of wearable robotics or ALS rehabilitation as a whole. The two areas have rarely intersected in the literature, which has made it difficult to find data about ALS patient's experiences with wearable robotics. Because of this, I have used data from other neuromuscular diseases or the rehabilitation of any type of muscular ailment that may occur. These limitations may have affected my understanding of what is the next best step for creating a fully-soft, wearable robotic device, and in conducting research on this topic.

Moving forward, it seems that the best way to conduct research around this topic would be to get in contact with rehabilitation centers that specialize in ALS and other diseases. Using doctors and therapists from these centers would give me direct access to what is currently being used to better the lives of those affected by ALS, and it would also give our research team a better understanding of what is needed in an addictive device. To do this, I would need to conduct an interview with the staff to see what exercises and devices are used inside the facility, and then find what would be useful for the patient's activities of daily living. This along with a survey of the caretakers would allow me to better understand not only the extent of how a wearable device would help ALS patients, but also how it would enhance the relationship between patient and caretaker.

With the large extent of the research done, I can now look at how it will change my practices and implementation of our Capstone design in the future. While finalizing the design, an emphasis needs to be made on making it lightweight and non-cumbersome because these were limiting factors in the research when dealing with everyday activities. Many patients were forced to use stiff designs to reduce energy consumption, so a more accessible design will be created. Also, my future work needs to encompass all stakeholders that will be impacted by the design. The patient, their family, caretakers and doctors need to be consulted so that the final product is tailored to each. Using STS frameworks in future work will be of the utmost importance.

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. Using data from different case studies and human motion experiments, a fully soft, wearable robotic device is being designed and created so that people affected by ALS, and possibly others, can have more independence. More autonomy for the patient will allow both patient and caregiver to have a higher quality of life. Because of the close relationship and interaction between these two parties, alleviating stress from either can only improve the quality of both lives. This is significant because the creation of this device will go beyond just the ALS sufferer and a caregiver. In a broader sense, the device will be able to help other people with neuromuscular diseases, and also people who need rehabilitation for common injuries. In the future, there will hopefully be more research about the interaction of wearable robotics and those affected by ALS so that researchers will be better able to create these devices. Through my research in this field of study, I have found that there are solutions to this problem, and, by using STS frameworks, stakeholders can work together to create a solution that is beneficial to all.

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