Rehabilitative Exoskeletons and Their Implementation

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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

Neuromuscular diseases (NMDs) weaken or break the connection between the nervous system and the muscles in the body (Mary, 2018). NMDs may occur at a young age, but is more prevelant in older stages of life. Effects lead to muscle weakening and atrophy due to their inactivity. One potential solution for limiting these effects is rehabilitative exoskeletons. This paper aims to research the implementation and usage of rehabilitative exoskeletons for patients with NMDs, and how they affect patients' physical and psychological state.

Patients with NMDs face a wide range of burdens including; chronic pain, life expectancy, economic costs, and quality of life (Carter, 2012). These burdens can cause deterioration in their psychological states on top of the physical restraints already set on by the disease. Patients with neuromuscular diseases also tend to lose a sense of individuality, as the loss of motor skills requires help from caretakers in performing daily tasks (Burke, 2017). The reliance on caretakers and therapists takes away from the patient's independence, which can worsen their emotional state. Therefore, when evaluating rehabilitation methods, more than just physical assistance has to be considered to ensure technology's implementation does not cultivate more burdens.

This research paper will evaluate rehabilitative exoskeletons to determine if their implementation does more harm or good for the disabled community. First, it will outline the methods and frameworks to conduct the research and observe the current state of rehabilitative exoskeletons and their effects on the physical and psychological state of users. The next section will provide background information on disability studies, current examples of exoskeletons used in rehabilitation, and common symptoms/burdens of patients with NMD. Then, an analysis of the research results will follow to unpack what was discovered and connect different fragments

using the frameworks outlined earlier. Lastly the conclusion will consolidate finals thoughts towards the central question.

METHODS

To navigate research how the exoskeletons affects patients' physical and psychological state, a method and framework will be used to investigate different aspects. First, case studies will be conducted to gain an understanding of rehabilitation exoskeletons as well as symptoms of patients with NMD. Disability studies will also be included to incorporate the voices of potential exoskeleton users. Following that, Actor Network Theory (ANT) will analyze networks in the studies, which will allow for unique perspectives to be heard and give insight into disability studies. To make research easier, relevant social groups will be identified and used as a guideline for finding information.

The three main relevant social groups are users of exoskeletons, caregivers and therapists, and exoskeleton designers. Neuromuscular diseases worsen over time, especially neurodegenerative ones, resulting in patients acquiring not only physical changes but mental changes as well. According to Burke caregivers also experience lower depressed mental states as patients' conditions worsen (2017). Caregivers witness patients' health worsening, which may bring on feelings of anxiety, depression, etc. Given their stake in the matter, they are a relevant social group that should be looked into. The last relevant social group, exoskeleton designers, produces devices intended to help patients with mobility impairments. Their role in creating and selling the technology gives them a great stake in ensuring the technology is researched and implemented productively.

Research will exclude those at risk for developing neuromuscular diseases, since the focus is on those affected in the rehabilitation stage. Similarly, lower age groups may also be excluded, since many neuromuscular diseases typically set in with older age. However, studying those of younger age and at risk for neuromuscular diseases could help in formulating ways to prepare patients mentally before being too affected by the disease and using assistive technology.

Case Studies

To understand the more personal interactions and experiences between exoskeletons and their users, case studies will be performed. This method researches specific instances to document detailed findings. For exoskeletons, this means investigating specific use cases involving the users to see what occurs between the two. This insight will help substantially in connecting the framework's knowledge to the physical aspect of the research question.

Actor-Network Theory

ANT framework focuses on the interconnections within society, showing that there is a greater network that inspires the design of technology. Through this network, technology and people work together, and no outside forces affect the relationship between two actors. However, these relationships are not stationary; they can evolve and change over time. This applies to the use of exoskeletons. In the realm of exoskeletons, there are both human and nonhuman actors. Human actors include patients with neuromuscular diseases, exoskeleton users, caregivers, and exoskeleton designers. Nonhuman factors include neuromuscular diseases, exoskeleton technology, as well as other rehabilitation practices (physical therapy, other technology, etc.). Prior to exoskeletons, the relationship between rehabilitation patients and their caregivers was much more prominent in rehabilitation. Since exoskeleton usage has increased, this new relationship between exoskeletons and the patients who use them has replaced some of the

caregiver-patient relationships. Though, the relationship between the caregivers and exoskeletons should not be forgotten.

RESULTS

Exoskeletons being used for rehabilitation are fairly new, especially when considering neuromuscular diseases like Amyotrophic Lateral Sclerosis (ALS), Charcot-Marie-Tooth (CMT), etc. The following section will go through various case studies pertaining to disability studies, rehabilitation exoskeletons, and common symptoms or burdens of NMD. Cross analyzing points made in these case studies, should shrink gaps between rehabilitation exoskeletons in conjunction with NMD.

Disability Studies

"Common Cyborg," makes the point of assistive technology taking the focus away from disabled people and recentering it around the device (Weise, 2018). In this, people with disabilities feel underrepresented and betrayed by tech companies. Tech companies mostly focus efforts on creating technology that would help make individuals with disabilities "normal." However "normal" in their eyes is an able person. This separates disabled people, straying away from creating a more inclusive and accepting society. The author states, "Instead they wish for us to lose our language, abandon our culture and consider ourselves cured. They like exoskeletons, which none of us use" (Weise, 2018). She also brings up Haraway's "A Cyborg Manifesto," stating that the work does not accurately depict cyborgs. She describes the work as being, "effective at erasing disabled women that even now, in conversation with many feminists, I am no longer surprised that disability does not figure into their notions of bodies and embodiment," (Weise, 2018).

In Crippledscholar's article, they bring up the dilemma regarding advancing technology rather than advancing society's attitudes toward making accessible spaces. Devices like the stairclimbing wheelchair and Tek Robotic Mobilization Device are marketed as able to replace wheelchairs. However, the author breaks down these types of devices to show a few points. First, they replace things like wheelchairs, but only within certain limitations. For instance, the Tek device can only be used indoors requiring a separate device to be needed for outdoors. The devices are also unsuitable for all mobility impairments, making them single-track in usage and limiting the audience that could benefit from them. Another big mention was cost. These devices (made by able-bodied people) tend to be costly and presume that the disabled user will be able to afford them (Crippledscholar, 2015). Each point connects back to the overarching idea, "The perception is that the problem is solved without any change to society or the environment" (Crippledscholar, 2015). The author stresses this point, that it should not be disabled people needing to adapt to society, but society needs to adopt accessible practices. Lastly, Crippledscholar mentions that an accessible society benefits more than disabled people. Ramps are heavily associated with wheelchair accessibility, however, in reality, they also benefit strollers, carrying heavy objects, etc. (Crippledscholar, 2015). Concluding that society's view on accessibility being too focused on fixing disabled people rather than cultivating an accessible atmosphere limits other groups as well.

Ladau starts off the article by saying, "There is nothing that needs to be changed about my state of being," (2015). The article continues to analyze another article, "In the Transhumanist Age, We Should Be Repairing Disabilities, Not Sidewalks," by Zoltan Istvan. The author describes how Istvan's piece feeds into the discriminating attitudes around disabilities. She brings up the points around exoskeletons, and how Istvan views them as a

solution to fixing the problem. However, in disagreement, Ladau states the real problem is not understanding the full point of view of people with disabilities. Touching on legislation, she brings up Istvan's view, "'Another method would be to just outright cure various physical disabilities.' He believes legislation should be passed 'on eliminating disability via technology and modern medicine.'" (Ladau, 2015). Here, Istvan offends people with disabilities, by saying that there needs to be a cure for disabilities. Though some research and technologies are beneficial for certain aspects of disabilities, they do not replace the societal stigma surrounding disabilities. Forgoing input from disabled people, and presuming their wants and needs enables these discriminative technologies and mindsets. Ladau stresses, that people with disabilities are not broken and do not need to be fixed, but the societal perception around them does (2015).

Rehabilitation Exoskeletons

Vaca Benitez's paper discusses the design of an orthosis exoskeleton system that could allow at-home rehabilitation of stroke or other neurological diseases. The design allows therapists to track patients' plans and progress, as well as the ability to remotely change or assign new rehabilitation plans. The exoskeleton can give the impression that the patient is moving their own arm instead of the device. "Therefore, the combination of the self-initiated movement support and patient-cooperative control strategies can lead to a positive effect on rehabilitation and user-centered support in daily activities" (Vaca Benitez, 2013). The author mentions recovering motor function requires therapy starting early on, "However, this requires a high and efficient deployment of personnel, which can be a limiting factor. In this context, the use of robot-aided therapy is worthwhile" (Vaca Benitez, 2013). The use of exoskeletons can help make up for the lack of healthcare professionals, while still providing adequate care.

The article “Rethinking the Robotic Rehabilitation Pathway for People with Amyotrophic Lateral Sclerosis: A Need for Clinical Trials,” states there needs to be more research about using robotic devices on patients with neuromuscular diseases like ALS (Calabrò, 2019). Therapy treatments have proven to slow disease progression, limit complications, and allow for independence (Calabrò, 2019). A major concern amongst neuromuscular diseases is muscle atrophy. Studies have proven that “moderate-intensity exercise is beneficial in ALS and decreases the deconditioning and muscle atrophy that can result from progressive inactivity” (Calabrò, 2019). The author brings up robotic rehabilitation in connection to ALS. Robotic rehabilitation, like exoskeletons, typically works in repetitive or task-oriented activities to train motor skills. For ALS patients, performing these kinds of movements early on can have major benefits in slowing the disease. Currently, studies show positive results for robotic devices treating neurological diseases, “However, few studies have paid attention to rare neuromuscular disorders such as ALS” (Calabrò, 2019). Even though therapy research for ALS aligns well with rehabilitation activities involving exoskeletons, there has not been much research on the two.

The study conducted by Postol had nine participants who suffered from a chronic stroke and used a lower limb exoskeleton in rehabilitation therapy. People with stroke suffer from diminished quality of life, mobility impairment, and reduced functional ability (Postol, 2021). This study’s goal was to perform repetitive and specific tasks to allow neural systems to form pathways. Along the way, track both the functional and health-related improvements in patients. After the study, all participants shared positive responses to the device. “Positive responses were grouped into physical benefits, including the experience of more ‘normal’ movement, and experiences different to those in conventional physiotherapy; and emotional and cognitive benefits such as confidence, motivation and improved focus” (Postol, 2021). Results showed that

participants enjoyed using the device, felt independent performing daily tasks and showed physical improvements.

Neuromuscular Disease Symptoms

Féasson's article, "Fatigue and neuromuscular diseases" discusses how fatigue is shown in NMDs as well as the domino effects it carries on someone (Féasson, 2006). Fatigue is defined as the loss of strength after performing an exercise or task. For people with NMD, fatigue is one of the main symptoms experienced (Féasson, 2006). Beyond the physical weight of fatigue, there is a psychological aspect. "In this context, pathophysiology of fatigue often implies the motor component but the disease evolution and the physical obligates of daily life also induce an important psychological component," (Féasson, 2006). Fatigue induces a psychological drop since the patient's body communicates to the mind its inability to perform tasks. The article mentions, "Acute fatigue can be defined as an increase in neuromuscular, psychological or physiological cost necessary to realize a given task and/or the incapacity to perform this task," (Féasson, 2006). These psychological costs tend to worsen over time as the disease progresses, and muscles weaken.

Bos's article, "The Prevalence and Severity of Disease-related Disabilites and their impact on Quality of Life in neuromuscular diseases," discusses the study conducted on six hundred sixty-two individuals who filled out a questionnaire on their quality of life since being diagnosed with an NMD (Bos, 2019). Various questions on certain health and life aspects regarding the disease were asked. These were used to evaluate the patient's quality of life. "Commonly, general quality of life is the perceived quality of an individual's daily life, including physical, psychological, social and environmental aspects of the individual's life" (Bos, 2019). Bos mentions how people with NMD tend to experience lower levels of quality of

life compared to those without NMD. Three of the main causes for this are “impairments of muscle function,” “impairments in mental functions and pain,” and “restrictions in participation in life situations,” (Bos, 2019).

ANALYSIS

Actor-network theory investigates the relationships and dynamics around exoskeletons and patients with NMD in rehabilitation, providing a unique framework. ANT focuses on the interactions between human and non-human actors within the network, highlighting how society perceives and implements assistive technologies. ANT unveils the intricate web of interactions between patients with NMS, exoskeletons, NMDs, exoskeleton designers, rehabilitation movements, therapists/physicians, and the disabled community(Figure 1). Each actor prioritizes actions differently which affects other actors in the network, given their different goals.

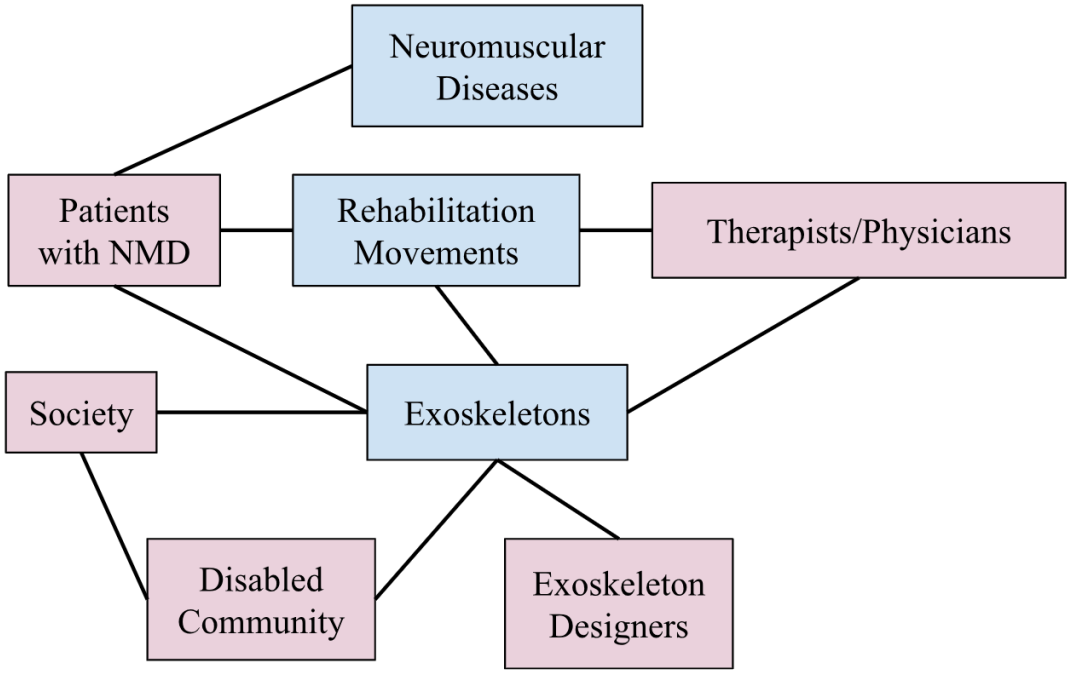

Figure 1: Diagram of how Actors are Connected in ANT Network (Pettit-Pokora, 2024).

Disabled people have a close relationship with assistive technology, as it aims to assist them in performing tasks they may not be able to do alone. However, their main goal is to feel accepted as society members, and assistive technology's goal often takes away from this. "Common Cyborg" points out, the goals of assistive technology and its creator's biomechanical breakthroughs, take away from disabled people (Weise, 2018). The technology becomes praised by society since they believe the technology makes major improvements for the disabled community. However, technology achieving its goals feeds into the stigma that disabled people need to be cured. Glorifying technology's capabilities overshadows disabled people's goals, which leads to them being treated differently by society. There becomes this preconceived notion that they need a cure, or want to conform to society's norms. When in reality they just need a society that accepts and welcomes them as they are. This relationship between disabled people and technology shows when used as a cure, exoskeletons add to the unrest in the disabled community, and achieving either side's goals results in the other not meeting theirs.

Another dynamic that inhibits disabled people from reaching their goal, is between disabled people and society. Society would rather cure disabilities than make accessible spaces, inhibiting disabled people from reaching their goals. This is seen through the creation of technologies, like exoskeletons, but also discriminatory attitudes towards disabled people. However, if society's goal shifted to changing legislation and public areas to be more accessible, the societal view could evolve. This idea is expressed in Crippledscholar's article where they mention the dynamic between society's norms and disabled people. Commonly it is seen that assistive technology's purpose is to make disabled people non-disabled. Currently, initiatives of such technology tend to be costly and limited in their functionality, becoming additional burdens for disabled people to take on (Crippledscholar, 2015). If societal norms were redirected to more

accessible public practices, society's view of the disabled community could be centered around inclusion rather than help. This would benefit both sides of the relationship, allowing them to achieve their respective goals. Currently, the network between disabled people, assistive technology, and society's perception shows a cycle of technology trying to cure disabilities for a community that wants acceptance, prolonging discriminatory attitudes in society.

In the rehabilitation realm, however, exoskeletons may offer hope for assistive technology doing more good than harm. Patients with NMD tend to suffer from a variety of burdens, a major one being fatigue, according to case studies on symptoms of NMDs (Féasson, 2006). For patients with NMD, their goal is to reduce these burdens and alleviate pain. Exoskeletons have been used to help patients with ALS slow disease progression, as mentioned in the article from Calabrò (2019). In the case of rehabilitation, the relationship between patients with NMD and exoskeletons has shown positive physical results, reducing some of the major physical burdens faced. In the rehabilitation realm, the exoskeleton's goal is to assist in performing physical therapy plans on patients as set up by the therapists. To achieve this goal, exoskeletons are sent programs and perform repetitive movements. Rehabilitation for people with NMD utilizes these repetitive tasks to test muscle activation and keep usage of the neurological connections. Case studies indicated that exoskeletons are useful in assisting with these repetitive movements. For patients, these rehabilitation successes with exoskeletons have reduced fatigue and pain, which according to Féasson's article, is associated with psychological cost (2006). Thus, rehabilitation exoskeletons can reduce both physical and psychological ailments caused by fatigue. Postal's study also shows that respondents reported positive results, both physical and emotional (2021). Exoskeletons following through with their goals can help users regain some sense of individuality, which is a common challenge faced by people with

NMD. This security can raise their quality of life and their psychological well-being. Exoskeletons and patients with NMD working together can help achieve the other's goals. This shows to be fairly promising not just in the physical abilities, but psychological as well.

Vaca Benitez's paper discusses an important relationship between rehabilitation exoskeletons and therapists. The design discussed is for at-home therapy, where the therapists can track progress, and send new rehabilitation plans virtually to the exoskeleton (Vaca Benitez's, 2013). In this case, the therapist's goal is to create and track movements for patients in rehabilitation, whereas the exoskeleton's goal is to perform the programmed movements to assist patients. Both can work together to achieve their goals. This relationship has a positive byproduct which allows patients to receive care from the comfort of their own homes, promoting a sense of independence. Patients had a positive impression of the device, as it minimized their need for assistance from others. Moreover, therapists were pleased with the remote therapy as it allowed them to help patients in ways that were not initially expected. Since in-person therapy is very hands-on, technology can replace the physical needs of the therapists, enabling them to help multiple patients simultaneously. By working together, exoskeletons and therapists can achieve their goals in rehabilitation, while reducing some of the challenges that exist with direct therapist-patient therapy.

Rehabilitation exoskeletons do not aim to cure disabled people; rather, they aim to offset the effects of diseases, making them a promising form of assistive technology. The disabled community has expressed displeasure with society and technology focusing on curing disabilities instead of accepting them. However, rehabilitation exoskeletons may be an exception, as shown by the relationships demonstrated in ANT. Patients with NMD often experience pain and fatigue, which rehabilitative repetitive tasks can alleviate (Calabrò, 2019). Therapists' views and

interactions indicate that exoskeletons can administer tasks effectively, yielding promising results for both the therapist and the patient. In addition to physical benefits, psychological benefits have been discovered. Patients can feel in control of their movements without requiring another person's assistance, and in some cases, they can perform movements from their own homes, restoring their individuality and capability to accomplish tasks independently. The goals of each actor assist each other, empowering patients with NMD through rehabilitative exoskeletons. However, this discovery is inconsistent with disability studies' reports on exoskeletons, indicating limited research on how the disabled feel about rehabilitative assistive technology specifically.

CONCLUSION

In conclusion, the implementation and usage of exoskeletons for individuals with neuromuscular diseases reveals a complex dynamic between a variety of factors. While going through numerous case studies and frameworks, there became a clearer image that assistive technologies offer more than just physical assistance but can restore a sense of self and individuality within users.

Case studies, disability studies, and Actor-Network Theory highlight the relationships and networks around assistive technologies with disabled individuals. Disability studies show that technologies tend to try and cure disabilities, creating this image that disabled people want to be fixed. However, rehabilitation exoskeletons offer a break from this paradigm. The goal shifts from altering the identity of disabled people to alleviating burdens associated with NMDs. Which allows patients to regain some capabilities that may have been lost.

Analysis showcases the physical benefits of exoskeletons used in rehabilitation. By administering repetitive movements, these devices reduce fatigue and pain. Which alleviates some of the accompanying psychological costs. Exoskeletons also proved to restore a sense of control and independence, improving the psychological state of users. The ability to perform tasks independently, in conjunction with the convenience of at-home therapy, has a positive impact on the patient's emotional well-being. The relationship between exoskeletons and therapists shows a collaborative duo for rehabilitation for patients with NMD. The devices are not limited to assisting patients but can extend the outreach of help from therapists. Through virtually sending therapy plans, and being able to personalize plans for a larger number of patients. All of which contradicts the stance outlined in disability studies. Disability studies show distaste towards assistive technology, which opposes the reports outlined in case studies. Thus showing there may be missing reports on disability studies in the rehabilitation realm.

While the battle for acceptance and inclusion for individuals with disabilities is still being fought, rehabilitation exoskeletons show a promising step moving forward. With the ability to address both the physical and psychological burdens of NMDs while promoting independence and empowerment, these technologies have the power to change the lives of millions. While continuing to explore their implementation, it is crucial to listen to the voices of disabled people and ensure technology is centered around their needs and desires.

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