HOW ROBOTS CHANGE THE PATIENT-CAREGIVER RELATIONSHIP

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By

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There has been a vastly growing research interest in both the cause and cure of Amyotrophic Lateral Sclerosis (ALS) since the 1990s (Keirnan et al., 2011, p. 942). According to the ALS Association, ALS is "a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord," and someone gets diagnosed with the disease every 90 minutes (Understanding ALS section). Because ALS causes a disconnect between the brain and the muscles, a wearable upper limb exoskeleton would be useful in assisting with everyday tasks, by taking the load off of the user's muscles and putting it onto the device. While upper limb exoskeletons are not new to the world of robotics, most of them are heavy and bulky and therefore, uncomfortable to wear, especially for persons with physical disabilities.

The technical project aims at creating an upper-limb exoskeleton using soft materials that are lightweight and comfortable for the users. Combining sensors, pneumatic actuators, and feedback control will produce a wearable upper limb exoskeleton that is more natural feeling and will provide rehabilitation and motor control for people with ALS and other motor impairments. The prototype for the exoskeleton is shown in Figure 1 on page 2 and includes:

1) A 3D printed shoulder brace that provides an attachment point for the artificial muscles.

2) A strap system that keeps the shoulder brace from sliding out of place and can be adjusted based on the user.

3) A 3D printed muscle mount that guides the artificial muscle's expansion direction.

4) A purchased arm brace that provides an attachment point on the upper arm for the bottom end of the artificial muscle.

This project will be completed with the collaboration of Colton Applegate, Joseph Carley, Marvin Lee, and Nazirah Farach Rojo, and under the guidance of Sarah Sun in the department of

Mechanical and Aerospace Engineering. This exoskeleton has the potential to assist users in their everyday lives by supporting their upper-limbs and making it easier to perform intended actions without the assistance of a human caregiver. The use of this exoskeleton and other robots in patient care will hopefully lead to better-quality relationships between patients and their caregivers.

Figure 1: Exoskeleton prototype. Prototype of the exoskeleton designed in the technical project. (Nazari, 2022).

The technical project tightly couples with the STS research project to discover how a wearable exoskeleton, and robots in general, will affect the relationship between patients and caregivers. The socio technical research analyzing the relationship between patients and their caregivers will be illustrated through John Law and Michel Callon's Actor-Network Theory, that analyzes the complex systems between various actors (2009). To add an alternative approach, this relationship will also be discussed using the Social Construction of Technology (SCOT)

developed by Pinch and Bijker (1984) as a tool used to understand the exchanges between technologies and their relevant social groups (p. 414). As health care for the elderly becomes a more prevalent topic and a "gray tsunami" of older individuals outnumbering children approaches, it is important to recognize the impact that technologies like exoskeletons will have on different social groups (Engelhart, 2021).

WILL ROBOTS IMPROVE THE PATIENT-CAREGIVER RELATIONSHIP?

The STS research aims to determine how the patient-caregiver relationship can be improved to benefit both individuals. In this project, presented in a scholarly paper, the addition of wearable robots and robots more generally will be looked at to see how their presence affects the dynamic between patients and their caregivers. Because this relationship is complex and can have serious effects on people's health and well being, it is crucial to look at all possibilities when introducing robots. This paper will identify the current patient-caregiver relationship and the issues that are involved, analyze the relationship through Actor-Network Theory and the Social Construction of Technology, and look at the introduction of robots into the relationship. While there is a large potential for robots to assist in performing daily activities, being companions, and helping keep people safe, it is also crucial to remember that technologies have serious social implications on the groups that they interact with. The main question that this research is designed to answer is: can robots change the patient-caregiver relationship for the better?

THE COMPLICATIONS THAT ARISE WITH PATIENT CARE

A caregiver has the ability to provide crucial support to their patients and improve patient lives overall, but there are also downfalls that occur in this relationship. Between the unclear job definition, rigorous workload, and stress put on both groups, the patient-caregiver relationship

has room to progress. The main role of a caregiver is to assist patients with whatever they require. Because this general definition can range from a vast variety of tasks, oftentimes, caregivers are unsure of their role in a patient's life. In an essay discussing the role of caregivers for patients with dementia, Given (2008) and her coauthors express their concern that most caregivers do not have a solid understanding of their job, and they do not know how to access the resources needed to learn about their jobs (p. 115). This uncertainty is thought to cause additional stress to their lives.

In addition to the inability for caregivers to fully understand the tasks that their patients require of them, caregivers also tend to feel overwhelmed from the workload that comes with taking care of elderly and sick individuals (Engelhart, 2021). The combined stress of traditional work and taking care of family or friends "leads to a variety of physical, psychological, and financial consequences for the caregiver" (Swangerg et al., 2006, p. 419). In an article describing the factors that contribute to the quality of life of caregivers, Glozman attempts to understand the effects that taking care of patients with chronic disabilities has on the mental health of caregivers. Because of the workload associated with providing constant care to patients, caregivers are at a high risk for decreased quality of life (Glozman, 2004). They also tend to face emotional stress related to the amount of emotional support needed for their patients. Glozman found that "caregivers suffer a significant burden that threatens their physical and emotional well-being and is detrimental to their health", clearly demonstrating that there is a large issue at stake (2004).

Like many other issues surrounding health care, the COVID-19 pandemic has only added to the enormous stress placed on both caregivers and their patients. With a shortage of care takers in hospitals, patients do not receive the attentiveness that they need and deserve, all while

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the caretakers are working tirelessly to do their jobs (Jacobs, 2022). Andrew Jacobs, an experienced writer in the Health and Science department of the New York Times, attempts to address this issue and demonstrate the domino effects that the pandemic has had on health care workers by interviewing them directly (2022). He found that after all of the countless hours that caregivers have spent trying to save lives, their physical and mental health have started to diminish.

While caregivers are overwhelmed from the workload of taking care of their patients, those patients tend to feel like a burden on others and do not want to have other people taking care of them (Engelhart, 2021). Although there is significant research discussing the work that caregivers perform, McPherson and coauthors focus on the effects of caregiving for the care recipient or patient (2007). It was found that concern about being a burden is not an uncommon feeling in care recipients, especially those who require physical assistance (McPherson et al., 2007). While the issues are different for each individual, both the caregiver and care receiver's issues are intertwined.

AN ACTOR-NETWORK THEORY LENS

The patient-caregiver relationship is an important part of the well-being of both groups. John Law and Michel Callon's Actor-Network Theory analyzes the complex systems between various actors (2009). Figure 2 below on page 6 describes the network of patient-caregiver relationships, the motivations behind various actors' actions, and the connections that they have with each other. From a socio-technical perspective, the main motivations of motor control technologies are to improve patient-caregiver relationships and reduce the stress that arises for both groups. Ideas including independence and human connection provide a link between the technologies and human actors in the network. The robot/exoskeleton can provide the

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independence that patients desire all while relieving the caregivers from performing daily tasks including feeding and picking up objects. By looking at the system of patient-caregiver relationships as a whole and incorporating all of the actors that affect this relationship, the main issues involved can be identified, and eventually these issues can start to be resolved. The goal of this research is to understand how the robots can change the dynamic of caregiving and in turn improve other factors of life including mental health and human connection. While this analysis includes many of the actors involved in the existing patient-caregiver relationship, it is important to note that there may be other connections that arise with the addition of various robots.
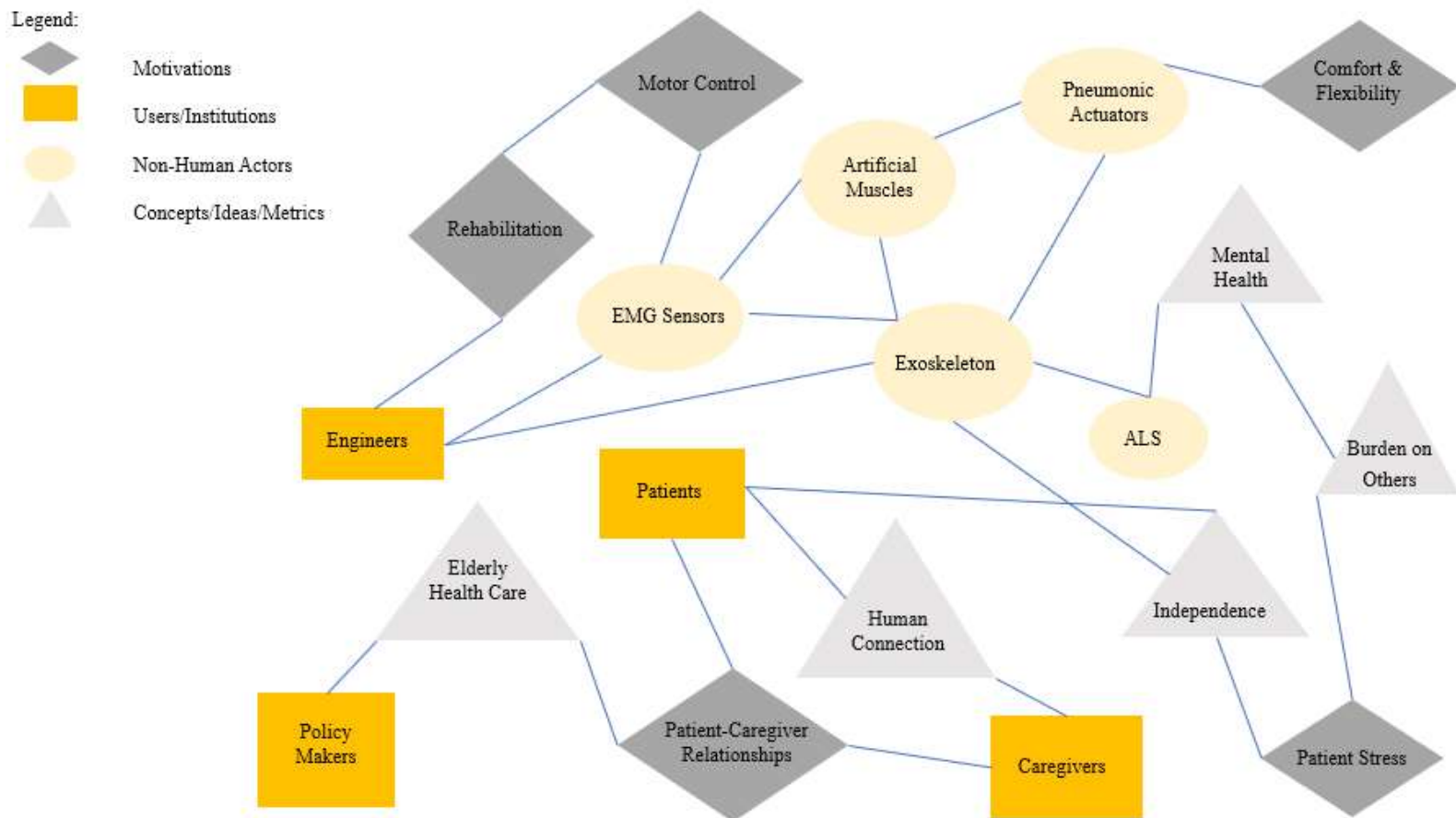

Figure 2. Network of patient-caregiver relationships. Visual representation of the connections between actors and motivations. (Nazari, 2022).

SOCIAL CONSTRUCTION OF ROBOTS ANALYSIS

The Social Construction of Technology (SCOT) developed by Pinch and Bijker (1984) is an approach to understand the exchanges between technologies and their relevant social groups (p. 414). When applied to the issues in patient-caregiver relationships, a clear image of the importance of social groups can be displayed. Figure 3 on page 8 relates the engineer that designs an exoskeleton/robot to the social groups of caregivers, family and friends of patients, patients with lack of motor function, and policy makers. The arrows are pointed in both directions to depict the mutual exchange of information. For the patient, engineers are creating exoskeletons that will assist with muscle control. In order to customize the exoskeleton for the patient's needs, they will need to give feedback to the engineers. The engineers provide family, friends, and caregivers some relief from the tasks they perform to assist patients. By having the robot complete these tasks, caregivers can focus more of their time and energy into developing meaningful relationships with their patients. In turn, the caregivers will help engineers understand what type of tasks are most important and how they can be replaced with the technology. Finally, policy makers work with engineers to make the technology readily available. By highlighting the importance of quality health care for the elderly, policy makers have the ability to push the technologies made by engineers through the design process. In order to address the problems that the STS research is attempting to solve, the engineers must listen to feedback and meet the requirements of the various social groups.
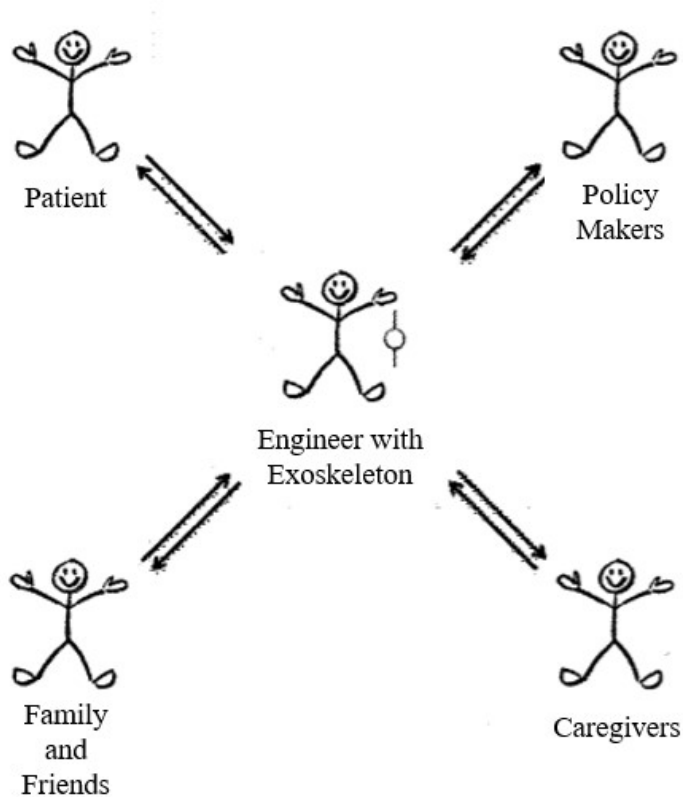
Figure 3: Social construction of exoskeletons. Diagram of the relationships between the engineers and other social groups. (Adapted by Nazari (2022) from Carlson, 2009).

A WORLD WHERE ROBOTS ASSIST CAREGIVERS

The rise in the field of robotics has more recently started to affect the healthcare industry. As the elderly population expands and the COVID-19 pandemic persists, health care workers and caregivers are being loaded with tiresome work with not enough staff to maintain healthy work lives. This results in an increase in the amount of robots in the medical world, and the addition of these robots can provide serious improvements to various aspects of patient care. Specifically in cases regarding patients with cognitive impairments, more resources can be allocated to patients with more severe conditions that may require assistance from a human caregiver (Koutentakis, 2020).

SOCIAL ROBOTS FOR EMOTIONAL SUPPORT

There are various types of robots that could help improve the patient-caregiver relationship. Social robots are now a mechanism for elderly people to receive aid both mentally and physically. Many elderly people often feel lonely, and these robots offer emotional support. The thought behind this idea is to create companions for this population without causing additional stress for caretakers and healthcare workers (Moise, 2018). Loneliness in the elderly population has been an issue for a long time. These people do not want to "bother" their family and caretakers with annoying and inconvenient tasks or feel like a burden on them. Koutentakis and coauthors from the department of psychiatry at Massachusetts General Hospital and Harvard Medical School believe that social robots will have positive effects on the quality of life of both the patients using them and their caregivers (2020). They discuss the possibilities that their own socially assistive robot has for patients and caregivers by highlighting the need to create robots that are capable of meeting the desires of the patients. The robot is user centered in order to provide patients and caregivers the most rewarding experience (Koutentakis, 2020). Robots have the ability to provide independence for the elderly population, especially those who are living autonomously but still need extra support, both physically and emotionally. So if robots offer care that is believed to be falling short, why is there a concern in the use of robots for the elderly?

UNINTENDED CONSEQUENCES OF SOCIAL ROBOTS

The unintended consequences associated with bringing social robots into homes can include robots' inability to feel emotions and users assuming false intelligence from their robots (Engelhart, 2021). Because robots do not have any emotions, elderly people will often be upset by their lack of compassion. In one particular study, subjects told a personal story to their robot,

and the robot turned away from them. As a result of this, "the subjects were hurt by the robot's pantomime of human indifference, which briefly masked its essential inability to feel" (Engelhart, 2021, para. 38). Users also tend to assume things about their robot's intelligence. When the robots provide a response that makes users happy, they believe that the response was out of complete understanding, but in reality, the response is random. Because the users' "expectations are inflated…, then eventually the disappointments will come" (Engelhart, 2021, para. 41). While these circumstances are definitely concerning and should be taken seriously, the potential for these robots to alleviate some stress from caretakers and patients should also be noted.

PHYSICAL ROBOTS FOR PATIENT CARE

Physical robots, including wearable exoskeletons, provide a different sense of aid to patients and their caregivers. Caregivers believe that if robots can provide help in the physical aspects of patient care, they will then be able to focus on other, more important, parts of their relationships with their patients and even lessen the strain that caregiving can produce on both parties (Wang et al., 2017, p 74). Rather than worrying about feeding patients or helping them with other everyday tasks, caregivers can shift their mindset to be oriented on the emotional parts of their job and help to decrease the sense of loneliness that these patients tend to go through. While the main goal of social robots is to offer company and emotional support to users, physical robots offer support by physically assisting users with motor impairments to complete their intended actions.

In order to analyze the effectiveness of robots on decreasing loneliness and improving the patient-caregiver relationship, it is crucial to include the subjects themselves in the research.

Robots must be accepted by the users in order to be successful, and by including patients in their own research, the acceptance of specific robots into everyday routines can be found (Koutentakis, 2020). Most current research on robots for the elderly fails to include the subjects which causes inappropriate assumptions about the efficiency that technologies provide for the patient (Engelhart, 2021). There is great potential for the use of robots in social and physical care for the elderly, but only if done in an appropriate manner. By including elderly people in their own research studies and asking them what they believe is effective, robots will prove to be an asset in the health care department. While they cannot replace genuine human connections, they can offer support for both the users and the caregivers who can then focus on having more meaningful connections with their patients.

THE FUTURE OF ROBOTS ASSISTING CAREGIVERS

In order to fully encompass the potential that robots hold in improving the patient-caregiver relationship, many other circumstances need to be analyzed. As previously mentioned, there are always unintended consequences when new technologies are introduced, and in order to avoid adding more harm into these relationships, the introduction of robots needs to be well planned out. This includes taking a deeper look into the interactions that caregivers have had with robots in the past and also making sure that the research done includes the patients themselves. In the paper "Robot Caregiver or Robot-Supported Caregiving?" Pfadenhauer and Dukat (2015) argue that "what a technology actually is can be decided only when it is applied" (p. 393). In order to benefit from social robots, caregivers must work with them to provide the best level of support to their patients. This might come from having a caregiver present with the robot, at least in the introductory phase, to guide patients and make them feel more comfortable.

After looking at the potential improvements that robots bring to the patient-caregiver relationship, it is quite obvious that there is a promising solution to the issues that have arised. In the future, research centered around subject feedback of robots in clinical settings would be most appropriate in providing engineers, patients, and caregivers the best chance at a strong, healthy relationship. Overall, the patient-caregiver relationship is a complex web that can be affected by many different factors. Robots can provide this relationship with more opportunities that will revolutionize the mental and physical health of both individuals.

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