Undergraduate Thesis Prospectus

A practical upper-limb soft exoskeleton design to assist patients with amyotrophic lateral sclerosis

(technical research project in Mechanical and Aerospace Engineering)

Racial Disparities in Medical Care: Closing the Gap

(sociotechnical research project)

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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Prospectus

General research problem

How are improvements in healthcare being pursued?

Health has been tied to a person's quality of life. Things like life expectancy, child mortality, maternal mortality, burden of disease, and infectious disease are commonly used to measure a population's health (Ortiz-Ospina, 2022). Global life expectancy has increased drastically from 52.58 years in 1960 to 72.75 years in 2020 (DataCommons, 2022). Despite similar trends in other measurements of global health, there are large gaps in these factors between and with populations. For example, Hong Kong has one of the highest life expectancies at 85.39 years while Central African Republic is 53.68 years (DataCommons, 2022).

Efforts are being made to improve healthcare. Some healthcare providers and organizations have defined goals to improve the healthcare system. Intermountain Healthcare laid out five goals: focus on improving health like underlying chronic conditions, tackle racial disparities, expand telehealth and in-home hospital services, build integrate systems that can adapt and align incentives to changing circumstances, and adopt value-based care instead of fee-for-service approach (Harrison, 2021).

A practical upper-limb soft exoskeleton design to assist patients with amyotrophic lateral sclerosis

How can a textile-based soft exoskeleton be used to maintain the activities of daily living (ADL) of patients with amyotrophic lateral sclerosis?

Neuromuscular disorders include a range of diseases that affect the nerves that control your muscles, the muscle themselves, and/or the communication between the

nerves and muscles (MedlinePlus, 2020). In a study of epidemiologic data of thirty individual neuromuscular disorders spanning over 150 reported studies, the prevalence of neuromuscular disorders as a group is at least similar to that of Parkinson's disease worldwide which is 100-300 per every 100,000 people (Deenen et al., 2015). Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular degenerative disease that affects the brain and spinal cord, causing motor neurons to deteriorate which results in the brain losing the ability to initiate and control muscle movements (ALSA, 2021). Patients often lose muscle control in all parts of their body including the arms, legs, neck, mouth, and even diaphragm. In 2015, over 80,000 Americans were diagnosed with ALS (Arthur et al., 2016).

My technical advisor is Dr. Sarah Sun in the Mechanical and Aerospace Engineering department. I will be working in a team of six: Patrick Evans, Priti Patel, Willis Williams, Lily Xu, and Nicholas Yantiss. Compared to a hard exoskeleton, a soft exoskeleton is lighter, more flexible, and less bulky. The team's goal is to design an upper-limb soft exoskeleton to help patients maintain their ADL. Specifically, to assist elbow flexion and extension and forearm pronation and supination. To achieve those motions, we want to mimic human muscles using twisted and coiled polymer actuators (TCPAs) which expand and contract due to heat. The exoskeleton will use inertial measurement units (IMUs) and electromyography (EMG) sensors to collect data on human motion and motion intention to control the actuators.

Rehabilitation robotics is a new and emerging field. Research on soft-exoskeletons is limited to only about twenty studies. We have not yet found a published paper that used TCPAs on a soft-exoskeleton. The limited data on soft exoskeletons and TCPAs means that extensive experimentation must occur even before designing. Although joule-heating

is the easiest, simplest, and easiest way to heat them, there is not a well-developed method to cool the actuator that doesn't involve something bulky like a fan (Cho et al., 2016). At the University of Virginia (UVA), they're still experimenting with the material to use in the actuator that would have a high enough resistance to reduce the current running through the actuator. Another problem is the TCPA made at UVA only contract around 10% of the original length.

Right now, my team is learning how to make a TCPA. Testing must be done to find the best material to make it with to reduce the current, its expansion and contraction, force that it can lift, amount of heat it generates, and a way to reduce the heat and insulate it from the wearer. Design of the sleeve that will house the TCPAs needs to happen as well. Factors like the geometry of actuators meant to mimic the human muscle placement, placement of the power source, material of the sleeve, etc, must be taken into account before the construction of the sleeve. Finally, protype testing and evaluation must occur to improve the design.

Ideally the team will have a functioning prototype. Because of limitations in the current research, we may not be able to accomplish our goal using TCPAs within the time span we have. A backup plan using Bowden cables as our actuator was also made. However, any documentation of our experimenting on TCPAs could later help others with a similar goal.

Racial Disparities in Medical Care: Closing the Gap

How do interest groups, advocacies, and others strive to lessen the racial disparities in medical care?

The World Health Organization (WHO) stated in a report that "rates of COVID-19 morbidity and mortality are significantly higher among people of African descent, ethnic groups experiencing discrimination, indigenous peoples, migrants, stateless persons, refugees and internally displaced persons" (WHO, 2021). This disparity in treatment of certain communities can be seen throughout healthcare.

At Congress's request, the Institute of Medicine (IOM) looked into racial and ethnic differences in the quality of healthcare received by patients, outside of factors like access to care, ability to pay, or insurance coverage. Several sources they looked into consisted of the role of bias, discrimination, and stereotyping at the provider, patient, institutional, and health system levels (Nelson, 2002). In a speech by past president of the American Medical Association (AMA) Alan Nelson, MD, he summarized the key findings and recommendations from the study to close the gap in the healthcare received.

General recommendations included increasing awareness of racial and ethnic disparities in healthcare among the general public, key stakeholders, and healthcare providers. Legal, regulatory, and policy interventions were to

1. avoid fragmentation of health plan along socio-economic lines,
2. increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals, and
3. provide greater resources to the U.S. Department of Health and Human Services Office for Civil Rights to enforce civil rights laws.

Heath system interventions recommended were

1. promote the consistency and equity of care through the use of evidence-based guidelines,

2. structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities,
3. enhance patient-provided communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice,
4. support the use of interpretation services where community need exists,
5. support the use of community health workers and multidisciplinary treatment and preventive care teams.

Data collection and monitoring recommendations included

1. collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language,
2. include measures of racial and ethnic disparities in performance measurement, and
3. monitor progress toward the elimination of healthcare disparities.

Educational recommendations included

1. implement patient education programs to increase patients' knowledge of how-to best access care and participate in treatment decisions and
2. integrate cross-cultural education into the training of all current and future health professionals. (Nelson, 2002)

The National Academy of Sciences (NAS) is a private, non-profit society of distinguished scholars. The IOM is a part of the NAS which works “outside of government to provide unbiased and authoritative advice to decision makers and the public” (IOM, 2009). The publication *Unequal Treatment: Confronting Racial and Ethnic*

Disparities in Health Care that Congress requested is one such example of IOM providing advice to decision makers.

The AMA is a professional organization of physicians and medical students whose mission is to "promote the art and science of medicine and the betterment of public health" by lobbying court and legislative bodies across the nation (AMA, 2022). The American Public Health Association (APHA) is also a group of public health professionals whose mission is to "improve the health of the public and achieve equity in health status" (APHA, n.d.). They hold meetings to discuss new ideas, best practices and the latest research.

Local establishments like the non-profit Center for Achieving Equity (CAE), in Cuyahoga County, Ohio play major roles towards health equity at the local level. The Center's mission is to "engage all levels of community to ensure systems, structures, policies and practices create and sustain equitable opportunities for all" and participates in a national network called the National Collaborative for Health Equity (CAE, 2017). Since the Center's start, there's been a shift from prevention approaches centered on behavior modification and access to healthcare to those focused on socio-economic factors, institutional decision-making, and policies that can improve community conditions (Cuyahogo County, 2013).

Smaller national advocacies, like the non-profit National Compadres Network, whose mission is to "strengthen and re-root the capacity of individuals, families, and communities to honor, rebalance, and redevelop the authentic identity, values, traditions, and indigenous practices of … communities of color..." can also decrease the racial disparities in medical care (NCN, n.d.). By working within the community and with local government, initiatives focused on policy and system changes based on the "healing-

informed racial justice framework" that trains community leaders as city leaders and staff can improve health outcomes for residents (Dieng et al., 2014).

The concept of taking community action to promote health equity is also seen with the Thunder Valley Community Development Corporation (CDC), whose mission is to "[empower] Lakota youth and families to improve the health, culture, and environment of our communities through the healing and strengthening of cultural identity" (Thunder Valley, n.d.). The Thunder Valley CDC engaged in hundreds of hours of discussion within the community that led to a community development plan to addressed the lack of physical, political, and economic infrastructure by building local skill and leadership capacity with the ultimate goal of "improving health outcomes in our community by creating a healthy community and environment as a catalyst to decreasing health disparities across the reservation" (NAS et al., 2017).

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