Healthcare Disparities for Patients Suffering from Muscle Loss

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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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STS Research Paper

Introduction:

Volumetric muscle loss (VML) is the massive wasting away of skeletal muscle (which comprises 40-45% of the total body mass) and civilians and military personnel both pay the cost in traumatic events such as car accidents or combative wounds. VML has a devastating effect on service personnel as extremity injuries are the most prevalent type of battlefield injury and contribute the most to long-term disabilities among service members (Liu et al., 2018). For my research, I set out to investigate the following five categories of disparities that patients who suffer from muscle loss face due to their injury (Corona et al., 2015). To better understand the factors at play, my research focused on the medical, functional, rehabilitation, quality of life, and treatment disparities that patients who suffer from muscle loss face. Due to being able to interview a PT and a patient who has dealt with more muscular atrophy, I expanded my research to focus on patients who suffer from muscle loss or reduction of muscle. I was able to interview a physical therapist who works at the UVA orthopedic outpatient clinic. Instead of seeing many patients who suffer from volumetric muscle loss (VML), he sees more cases related to muscular atrophy.

Muscular atrophy, as defined by the Cleveland Clinic is "the wasting or thinning of muscle mass. It can be caused by disuse of your muscles or neurogenic conditions. Symptoms include a decrease in muscle mass, one limb being smaller than the other, and numbness, weakness, and tingling in your limbs. Disuse atrophy can be reversed with exercise and a healthy diet" (*Muscle Atrophy*, n.d.). The key distinction between volumetric muscle loss (VML) and muscular atrophy is that VML deals with the loss of skeletal muscle tissue, whereas muscle atrophy deals with the reduction of muscle mass due to thinning or wasting away of muscle.

The research question that I am attempting to answer by performing case studies on both a physical therapist and a patient is as follows: What are the primary issues that patients who suffer from muscle loss (whether volumetric muscle loss or muscular atrophy) face? To answer this overarching question, I have broken down my research question into five main categories to ask the physical therapist and his patient during interviews. The actors that are at play in this research include but are not limited to: patients who suffer from VML or muscular atrophy, physical therapists, physicians, biomedical engineers, the healthcare system, research entities focused on tissue engineering methods for growing musculoskeletal muscle, and research entities focused on treating patients who suffer from muscular atrophy.

Patients who suffer from muscle loss face many sociotechnical issues that significantly impact their quality of life including navigating social and family changes due to their disability, battling mental health issues due to physical limitations, and struggling with financial difficulties due to complications in finding employment and maneuvering career changes.

Background and Significance:

The purpose of this research is to better understand some of the main categories of barriers that patients who suffer from muscle loss must deal with. When it comes to VML, civilians and military personnel both pay the cost of traumatic events such as car accidents or combat wounds (Testa et al., 2021). Furthermore, patients who suffer from muscular atrophy are subject to many of the same barriers that VML patients face.

When it comes to muscle loss, patients have significant costs that they must face. These costs include monetary costs, opportunity costs, and lifestyle costs. First, the monetary costs that these patients face include both indirect and direct costs. Indirect costs that patients face include the need to forgo working due to barriers to financially advancing in the workplace. Direct costs

that patients must pay include out-of-pocket expenditures such as paying for assistance, medical bills, assistive devices, and delivery of goods if not able to drive (Auchenbach, 2020; Testa et al., 2021). Additionally, patients must pay opportunity costs which include loss of time in the workforce which could directly affect the financial impact that they can have on their life in general and can cause people with disabilities to feel like they have fallen behind (Auchenbach, 2020).

Finally, patients who suffer from muscle loss face a loss of lifestyle. Unfortunately, many victims of VML are forced to live with the life-long effects of losing a substantial amount of muscle and this causes every aspect of their lives to be altered from their activities of daily living (being able to dress, feed, and bath themselves), to being able to provide for themselves financially, to obtaining the proper health insurance coverage to meet their medical bills and financial obligations (Testa et al., 2021).

Methodology:

The STS analytical framework I chose is the Actor-Network theory. This framework seemed to be the most relevant to my research as technology is a product of human/non-human networks. Furthermore, the actors in this framework not only include the current technological advances used to treat patients, but it also includes all the human actors at play—patients, physical therapists, and physicians. I approached the plot by doing a case study of the healthcare issues involved with treating patients who suffer from muscular loss.

I approached my research questions by conducting a case study on a physical therapist who sees patients who suffer from muscle atrophy and a patient of his. The physical therapist I interviewed had over 15 years of experience as an athletic trainer, and another 15 years of experience as a PT specializing in the rehabilitation of sports-related injuries and orthopedic

conditions. The patient I interviewed was a veteran who had multiple chest muscle injuries due to a helicopter training incident. To understand the sociotechnical issues that affect patients with muscle reduction, I broke my research questions into the following five sections: medical challenges, functional limitations, rehabilitation, and physical therapy, patient experience and quality of life, and barriers to treatment or intervention. These categorical questions were to give a holistic view of the challenges patients who suffer from muscle loss face.

Literature Review:

According to scientific research, the most damaging effect of muscular atrophy is the decrease in quality of life due to increased risk of fractures, reduced mineral composition in the bone, and decreased basal metabolic rate (Jun et al., 2023). Muscle atrophy is defined as the loss of skeletal muscle tissue and damage to the largest organ in the body—skeletal muscle—which accounts for more than 40% of the total body mass. Although traumatic injuries, like the case study I cover below in the discussion section, can result in muscle atrophy, atrophy also occurs when the synthesis of new muscle is exceeded by the rate of protein degradation. This is associated with high-fat and low-sugar diets that are the trademark of the American diet (Jun et al., 2023).

Additionally, online research claims that people with physical disabilities have many life alterations that can affect their mental health due to the impact that disabilities can have on their social life, the lack of integrated care that they may face, and the stigmas that they face (The Impact of Physical Disabilities on Mental Health and Well-Being — Leaf Complex Care, 2023). Physical disabilities may affect a person's ability to be physically active which varies depending on the disability. The social constraints that individuals face due to physical disability often have a more negative effect on the individual than the actual physical limitation itself (The Impact of

Physical Disabilities on Mental Health and Well-Being — Leaf Complex Care, 2023). These claims on disabilities can affect mental health and integrated care are supported by the stories of the veteran I interviewed (discussion section) who shared how the onset of his injuries led to him fighting lots of mental health problems in the early years post-injury. Additionally, the veteran faced integrated care issues not because of a lack of excellent healthcare, but because of peer pressure of being in the military ultimately delayed him in getting the proper healthcare treatment right away.

Mental health issues that people with physical disabilities face include stress and anxiety, depression, PTSD, identity/anger issues, and relationship difficulties (The Impact of Physical Disabilities on Mental Health and Well-Being — Leaf Complex Care, 2023). Research has shown that those with physical disabilities are more likely to face mental health issues that are caused by their social limitations than due to their physical limitations (The Impact of Physical Disabilities on Mental Health and Well-Being — Leaf Complex Care, 2023). This research ties into my own as it showcases and supports the belief that the mind is much stronger than the body—a belief that the wounded veteran I interviewed shared and accredits to having a good outlook on life.

Furthermore, one review claimed that the psychological effects of disabilities on individuals with disabilities in the midlife range (40-65 years) perceived discrimination against themselves more readily than older individuals (65+ years). The research claimed that this was due to society expecting midlife ages to be more able-bodied but did not expect that of the elderly range. Additionally, the research pointed out that persons with disabilities are more vulnerable to having their emotional well-being compromised due partially to their lower levels of social integration and activity which can also entail being less self-sufficient, poorer quality

employment, and reduced work hours that can all lead to financial strain. The study looked at how three distinct markers of psychological well-being—depressive symptoms, negative affect, and positive affect—presented themselves in individuals with disabilities. The results of this study suggested that a slight diminish in the ability of individuals with disabilities to carry out expected roles can be a source of distress in one's life (Namkung & Carr, 2020).

Likewise, the veteran I interviewed expressed that he has felt tension over the need to provide for his family and perform well in his job, but, at the same time recognized that he would not be able to perform his military job description duties long term due to the pain caused from his injuries which ultimately led him to retire from the military. Hence, the relevance of what the literature has to say regarding disabilities can be seen in how the mental, professional, and personal life of the injured veteran I interviewed, were affected.

Discussion and Results:

For my research, I did an empirical study of all the sociotechnical issues that patients who face muscle atrophy/VML deal with and how that impacts all facets of their lives. To do so, I interviewed both a physical therapist from UVA and a patient of his who is a retired veteran who underwent extensive left shoulder muscular injuries which led to multiple tears and 8 surgeries plus years of physical therapy since his initial injury in 2009. To carry out my research, I asked questions from the following categories to both the PT and the veteran who both brought different perspectives to the discussion.

1A. Medical Challenges: One of the first topics I wanted to analyze was the primary medical complications associated with volumetric muscle loss/atrophy of muscle and what the typical trajectory looked like.

Since one of the primary populations the PT treats are patients with atrophy of muscle, he answered this question from that point of view. In summary, The PT shared that the major problem that patients face concerning muscle strength being lost is that the patient's daily activities—especially recreational activities—are drastically altered depending on how extreme the wasting away of muscle is. According to the PT, one of the classical guidelines in most treatment protocols for calves suffering from muscular atrophy is to have its girth (e.g. circumference of the calf muscle) return to like 80/90% of the other side. However, the PT shared that though those protocols exist on paper, they are often of little relevance to physicians and physical therapists who treat patients. The PT spoke of a consortium that gave guidelines to physical therapy regarding Achilles repairs regarding the trajectory of when the patient is ready to return to work or sports. The consortium found that, while guidelines exist on paper, physicians and physical therapists do not use those guidelines while they see them clinically. This is because the atrophied muscle does not regain much girth and comes nowhere close to approaching the opposite extremity. Rather, when it comes to knees and ACL reconstruction, people might be able to regain their strength up to 90% of the opposite extremity. This explanation of how written standards do not always translate to responsible treatment plans was of particular interest to me as it showcases the disconnect between health treatment protocols and actual practices in healthcare. I found that the overall answers from the PT came from a more technical viewpoint of the injury and not so much from a sociotechnical viewpoint. This makes sense since the PT treats the functional and tangible injury as opposed to delving into how a patient's injury affects all aspects of his life.

The retired soldier I interviewed had a different perspective to bring to the table on this question since he was not on the healthcare side of things but on the receiving end of healthcare.

Due to being in a rigorous 2-year helicopter training program that could have truncated his training if he pushed for time to heal from his injury, the soldier "gutted" through the pain and did not take a timeout to fully address the extent of his injuries until after he finished the remaining 7 months of his helicopter training program. Furthermore, the issues he faced were exacerbated by living with injuries for months before finally getting to start physical therapy following an MRI that revealed a constellation of shoulder injuries and most notably, an anterosuperior rotator cuff tear with biceps tendon subluxation. Immediately following his injury, the veteran recognized that he had a significant loss in dexterity and flexibility which suddenly predominated in his life since simple movements that were once fluid became impossible. Because of this loss in dexterity in his injured (left) shoulder, he had to compensate with the right shoulder side which would eventually lead to similar inflicted injuries on his right side nearly 16 years later. Hence, according to the veteran, the primary medical complications he faced were that he did not get treatment soon enough because of the pressures of the helicopter program he was in to stay injury-free to complete the program. This means that many of the medical issues that the veteran faced could potentially have been curtailed if he had received treatment sooner. The prolongment of getting initial treatment (other than a general medic checkup and X-rays) post-injury was not only unnecessary but also evidence of one of the sociotechnical issues that the veteran faced because of his injury: he was forced to choose whether to grit his teeth in pain to make it through the training, or, face the possibility of being kicked out of the program if marked down as having a medical injury. He, not wanting to be a quitter, chose to push through the pain to become a helicopter pilot – all while suffering from intense pain. To say he was a fighter would be an understatement.

1B. Trajectory of recovery for VML/Atrophy:

The PT said that this spoke to how broken the medical system is. For instance, if a patient were to try to get an appointment at his physical therapy clinic, there would be a three-month wait just to get an initial evaluation-the norm for all PT clinics across the country. Furthermore, upon initial admission to the ER at the time of injury, the ER will not give instructions for how to do simple range of motion (ROM) exercises. Rather, the ER/physicians on site will merely refer one to a specialist (e.g. physical therapists) or primary care physician for follow-ups. In Virginia, seeing a specialist would take at least 2-3 weeks. So, during that downtime, the patient will probably not even try to move that limb since they are waiting to see the specialist or whatever doctor will permit them to do so. The PT said that at UVA, patients are fortunate because when the patient does see a physician assistant (specialist) 2-3 weeks post ER visit, the patient will get top care since the physician assistants (PA) work in close relation with the athletic trainers in their setting. The PA will do diagnostics and decide if he wants to get an athletic trainer to come in and start him with some exercises. The goal of this is to start to try and minimize the loss of muscle, strength, and size of the muscle-or muscle atrophy. From there would be the referral to a physical therapy clinic which takes about three months before one can get into it. Between the initial injury and getting an organized type of exercise program to address those muscles, the patient normally must wait at the very minimum a month if not up to three months. In summary, the trajectory to get proper treatment from the appropriate healthcare professionals is delayed due to the long waitlists to first get into seeing a PA and PT. The good thing for UVA patients is that in the grand scheme of things, a 2–3-week lag time to see a PA is not much time at all. However, if patients are having to take time off work because of the delay in helping due to not getting PT right away, a 1-3-month delay is a long time to wait. The sociotechnical issue of

delays in treatment seems to point to the fact that there is a shortage of healthcare workers not only in the hospital setting but in physical therapy clinics as well. This effect is a sociotechnical issue that is not specific to patients with VML/muscle atrophy, but it is still relevant to them and greatly impacts the timeline regarding how quickly they can begin physical therapy treatment plans.

Likewise, the veteran said that the trajectory of treatment for him was stretched out due to initially not receiving the necessary treatment. Immediately after the incident, the veteran went to a military clinic to have his shoulder examined by the medic to properly document the injury. However, instead of giving him an MRI, the clinic gave him rudimentary scans (most likely an X-ray) and sent him on his way with Motrin 800 mg and a "good luck."

As the veteran recalled: "They would have sent me to the higher care if I had asked for that. But it's just kind of the military environment. I did address it immediately with therapy, Motrin, and a couple of cortisone injections, but if I had known what I know now, I probably would have been more responsible and pushed for getting more rigorous treatment sooner—namely an MRI—but I felt the peer pressure to make it through the program before addressing any more serious issues."

Examining this response from the veteran revealed that he could have received treatment sooner; however, he did not. Why? Because peer pressure to finish the program no matter the pain he felt was stronger than the pain he felt. In most anywhere but the military, the normal course of action would have been to get an MRI and doctor visit immediately. However, due to the veteran being in a high-pressure program, he did not get the necessary help soon enough. This reveals yet another sociotechnical issue that affects a patient with muscle atrophy: the issue of *peer pressure* and how the environment one is in can influence the decisions he makes about

his health. If the veteran were in a civilian job, likely, he would not have felt the pressure to delay treatment and further examination out of fear of getting expelled from his occupation of choice.

2. Functional Limitations: A second section I chose to cover in my interviews was looking at how the patient's daily activities and functional abilities are affected and to what extent.

The PT shared that many times the impact that atrophied muscle will have on a patient's daily life varies contingent on the type of muscle group affected. For atrophied muscles of the lower extremities, patients would have challenging times going up and down stairs and doing motions such as sitting up and down in chairs. Patients with upper body atrophied muscle loss would have a challenging time doing motions like bending over to reach for milk in the refrigerator or opening a cabinet door, to opening a door—the suction on the fridge. Essentially, anywhere strength is required for a particular task, patients' daily activities will be affected.

For the veteran, the main impact that his injury had on his career was the need to retire from being a military helicopter pilot due to too much lifting and reaching in his job description for pre-flight which led to debilitating pain. The veteran shared that "Anytime my left arm had to get anywhere further away from my torso than just maybe a foot, it was debilitating."

Additionally, as a husband and father of two small children, his responsibilities in his family life were met with greater challenges ranging from having to be cautious when picking up his two-and four-year-olds to being able to perform chores around the house without pain.

The answers from both the PT and the veteran supported each other and revealed yet another sociotechnical issue patients who suffer from muscle atrophy face: the issue of not being able to perform normal and, usually, instinctive tasks. This impairs the quality of life and makes

it harder to perform home activities and job descriptions on a relevant timeline let alone to the same level as those who do not have an injury.

3. Rehabilitation and Physical Therapy: The third category of sociotechnical issues I wished to explore were 1) the roles of rehabilitation and physical therapy in recovery, 2) specific treatments and tactics to aid in recovery, and 3) the typical goals and outcomes of rehabilitation for patients.

The PT shared that for VML patients, there is nothing in physical therapy that talks about wanting to change the volume of the muscle. Rather, the big measure of recovery is how much strength recovery is seen—for example, the capacity to generate force is more of what you are looking for, because cosmetic appeal is not the focus nor the long-term goal.

The veteran, however, had a different perspective to add to this question. Instead of trying to answer this question considering the biomechanical issues at play, he mentioned the variation in physical therapy in early versus later surgeries. In his earlier surgeries, the veteran shared that his left arm would be wrapped with an ACE bandage taped to his body and told not to move it for up to 8 weeks. However, such was not the case in his later surgeries (such as a pec tendon transfer) in which the surgeons encouraged him to do lots of stretching and strength training with tubular bands' internal external rotation overhead to aid in regaining strength as soon as possible. As for the relief that the veteran gets from physical therapy, he shared that the most effective PT treatments he has received have been having the PT do scrapping (a technique that involves using a blunt end of plastic to dig into the tissues to induce better circulation by breaking up the scar tissue formation) and cupping, which involves using heat to improve blood flow and reduce pain and inflammation (Tannenbaum, 2023).

Comparing both the PT and the veteran responses, I noticed that the PT kept giving more of a broad/technical to answer how VML/atrophied patients are affected. However, the veteran

gave more specific examples of the types of rehab protocols used on his injuries by the same PT. Based on the response of the veteran, one sociotechnical issue that he faced in rehabilitation and physical therapy was the need to do his own research to find a PT who could perform fire cupping and scrapping. Thankfully, the veteran knew how to seek out help for this expertise, but others with injuries like his might not be as knowledgeable and quick to find the right specialist. This showcases that another sociotechnical issue patients with muscle atrophy/VML may face is whether they have the ability and education to be their advocate.

4. Patient Experience and Quality of Life: The fourth category of sociotechnical issues I explored was the impact on the overall quality of life for patients including how this affects the psychosocial health of patients.

The PT said that whenever patients cannot get that full activation back, there is a significant hit to the quality of life that patients have, and it can have quite a lot of psychological impact on the patient. This is largely because a lot of patients cannot do what they want to do anymore and so that weighs on them emotionally. Within The PT's realm, when looking at patients who suffer muscle injuries due to ACL injuries, there is only a third who return to the same level of recreational activities as they did before their injury. Two parts to that are 1) the physical achievement of getting back to the level they were at before, and 2) how it affects them psychologically. Several tests exist that help to assess the psychological effects that injury can have on patients. One of which is the Tampa Scale of Kinesophobia which is a self-reporting questionnaire that patients can use to quantify fear of movement, or (re)injury they might have (Tampa Scale of Kinesiophobia, n.d.). This fear could be related to the movement or just how comfortable/confident they are about performing movements. Another similar test is the Short Form-12 survey (SF-12v2) which is one of the most widely used tools to assess the self-reported

quality of life for individuals (Neubauer, 2021). The PT shared that using this tool enables one to see how a person perceives their physical capacity and their mental capacity at a given moment. It is a general quality-of-life assessment. The tools that the PT spoke of are just that--tools. They have limitations and are not as beneficial at giving a comprehensive view of the psychological and quality of life impacts. This is largely because they rely on so few questions without exploring the various facets of a more comprehensive assessment from individuals.

A more comprehensive assessment of how quality of life can be affected can be seen by examining the veteran's responses. The veteran recalled how much his surgeries had helped him and especially noted his 4th surgery: "You don't realize how much pain you are in until somebody fixes you...I remember one of the surgeries I got at West Point—there was such a good surgeon up there—I remember getting emotional with him on one of the follow-ups several months post-surgery. Because he took me out of such bad pain, I was in that I was like hugging him and thanking him in his office." Because of the severe pain the veteran had endured for so long, he forgot what it felt like to be painless.

Additionally, the quality of life affecting the veteran was noticed by his healthcare team. One PA said the following during her checkup with him:" 'I know you're still trying to fly helicopters but we're just kind of confused as to how you're still doing what you're doing with what you got?' The veteran's reply to this was "Because. Flying, that's what I know how to do. And I have a family to take care of." Hence, he persevered and mentally learned how to adjust and make peace with his injuries. The veteran shared that the alternative to adjusting would have been to easily just shut down and quit. However, the veteran chose not to quit, shut down, or feel sorry for himself. Rather, he expressed a very thankful attitude as evidenced in his response: "You can either just go into a corner and feel bad for yourself, or just keep going. And I try to

keep going." The veteran seemed to have recognized the impact of that perspective and how strong the mind is. Rather than feeling sorry for himself, he chooses to fight against having a defeatist mentality and to persevere. A sociotechnical issue that affects patients' quality of life largely relates to the impact their injury plays on their emotional well-being and the mental outlook they choose to have on their injury. The mind is a powerful force and can greatly impact the perspective and quality of life of individuals as it did with the veteran.

5. Barriers to Treatment or Intervention: The last sociotechnical question I wished to explore was what barriers patients face to receiving proper treatments and interventions.

The PT shared that barriers to patients getting treatment can be caused by several factors such as cost, time, and personal recovery goals. First, he shared how cost can be a big reason for preventing patients from continuing to get physical therapy since insurance rates drive a lot of the costs associated with receiving PT. Not to mention, co-pays can be ridiculously high, so often, patients eventually start asking themselves, "How much money do I need to put into this?" Additionally, the barrier of costs can be caused not only due to not being able to afford physical therapy, but also to be able to afford general fitness care. Another major barrier the PT spoke about was regarding the amount of time a patient must continue with physical therapy. Unlike athletes whose job is to train, condition, and recover, the average patient has a normal 9-5 job in addition to all the other responsibilities of life. In short, lack of time, money and good insurance can all serve as sociotechnical barriers to a patient getting proper healthcare treatment.

In the veteran's case, he shared that he had a positive experience with the accessibility and availability of treatment. The veteran had a surplus of specialists who wanted to help and were dedicated to his recovery. This is not the case for every patient, but thankfully it was for him. Furthermore, when it came to economic barriers, due to being a retired soldier, the veteran

said he had great healthcare coverage that is accepted almost everywhere. Additionally, the veteran shared that if he chooses not to use that part of his insurance, there is the Richmond VA Medical Center for Veterans—where he has two of the best doctors in his life. Overall, the veteran seemed to have a very positive experience with insurance, coverage, and accessibility to a plethora of healthcare professionals. The only time that the veteran faced issues with accessibility to excellent healthcare was when he was deployed during the military to rural and third-world countries.

The physical therapist focused more on the time, motivation, and cost aspects of barriers to patients receiving proper healthcare treatment, whereas the veteran added the perspective of geographical location playing a huge role in accessibility for military personnel. Hence, the overall sociotechnical issue that some patients may face includes economic limitations and limitations to specialists due to geographical location and health insurance coverage, as well as patients having the time and motivation to pursue treatment.

Conclusion:

The takeaways I gleaned from my research were that military pressure to stay in a program can lead to more extensive injury for veterans and that the life of injured veterans is forever changed by musculoskeletal injuries. Additionally, I learned that the fortitude of the mind to persevere despite suffering plays a pivotal role in a patient's outlook on life post-injury and post-surgery. From the physical therapist, I learned about the different types of sociotechnical issues like economic, social, and accessibility barriers patients with muscular atrophy or volumetric muscle loss may face. The next steps for continuing this research would be to look at the different technologies that are out there for treatment and explore what types of

sociotechnical barriers stand in the way of patients receiving stellar procedures, care, and physical therapy for recovery.

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