Developing a Comprehensive Assistive Technology Guide for Patients with ALS

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Introduction

Amyotrophic Lateral Sclerosis (ALS) is a uniformly fatal motor neuron disease (MND) characterized by progressive muscle weakness and wasting, as well as substantial loss of motor function. The average life expectancy for someone diagnosed with ALS is 3 to 5 years from symptom onset, during which time mobility, eating, speaking, and breathing may become challenging (Paganoni et al., 2015). Additional challenges can include changes in cognition, loss of social connections and independence, as well as depression (Maresca et al., 2019).

These symptoms and challenges often result in the need for full-time care to complete daily activities before reaching the end of their lives. ALS progresses at varied rates and presents differently for each individual, highlighting the need for a client-centered continuum of care and broad access to information about assistive technology (AT), as well as the technology itself. The use of AT for patients with ALS can greatly improve their quality of life, functional independence, and sense of autonomy (Pousada, 2021).

Processes/Methodology

Due to the individual nature of disease progression, access to healthcare and technology resources, adherence to medical advice, and additional personal factors, the experience of living with ALS is highly variable and needs to be approached with a client-driven model of care. For this reason, patients with ALS and their caregivers were at the forefront of the development of the AT resource completed during this capstone experience. Information and feedback were gathered from patients and the loved ones who came to their outpatient appointments, as well as the interdisciplinary ALS clinics that were held monthly. In collaboration with occupational

therapists, physical therapists, speech and language pathologists, and other members of the ALS care team, I developed a draft early in the process for key stakeholders, the patients, to review.

Feedback was gathered regarding the usability of certain AT devices and resources included in the guide and the list was curated, with the assistance of experts in the field, to provide a wide array of well-liked and professionally-backed devices to patients. Each section of the guide provides a general description of the different devices, why the devices might be used based on symptoms and functional ability, as well as candid "pros and cons" based on patient and provider feedback. The inclusion and review of stakeholder feedback was invaluable to the creation of a resource that would be easily accessible, understood, and utilized by patients and their caregivers.

As my knowledge and experience working with the ALS population grew, I also developed a lecture and AT demonstration for the 2026 Occupational Therapy Doctorate (OTD) cohort at Texas Woman's University (TWU). I coordinated with my agency mentor and an Assistive Technology Professional (ATP) to incorporate a comprehensive snapshot of OT's role with the ALS population into the curriculum for prospective OTs.

Outcomes

Throughout my capstone experience, I was fortunate enough to observe the work of an accomplished and knowledgeable occupational therapist, who has been working with the ALS population for 27 years. I was able to engage with all patients and caregivers who attended the Houston Methodist outpatient clinic, or monthly interdisciplinary clinic during my time there and have developed a well-rounded understanding of occupational therapy's role in caring for patients with ALS. I completed the draft of my AT resource in time to introduce patients and caregivers to it during ALS clinic days, to which I received both positive and constructive

feedback. I used this, in conjunction with input from key informants, to fine-tune the resource for more effective use. The AT guide I created has been approved for publication on the Houston Methodist website for patients all over the world to access.

Toward the end of my capstone experience, I had the pleasure of speaking with the OTD students at TWU about ALS, the role of OT in ALS care, and provided them with a thorough assistive technology demonstration with the help of my agency mentor and another ATP. Our lecture received very positive feedback and my agency mentor and I have been asked to return to teach another cohort about ALS and AT in the future.

Conclusion

Throughout my time working with patients who have ALS and their loved ones, I developed an incredible wealth of knowledge about the challenges they face and how these can be directly impacted by the care they receive from their OT and the other members of the care team. The ALS Assistive Technology Guide I developed during my capstone aims to bridge the gap between quarterly medical visits and the onset of new symptoms and challenges for these patients. By arming them with knowledge and answering some of the questions they may not have realized they had during their clinic visits, this guide is likely to improve the continuum of care for patients with ALS and enhance their sense of autonomy.

Because ALS is a unique population with which to specialize as an OT, not many practitioners are aware of the therapeutic contraindications and overall needs of this population. We presented our lecture on ALS and AT to a group of burgeoning OTs in hopes of sending more practitioners out into the field with a foundational understanding of how to treat patients with ALS and other MNDs.

References

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