

# TECHNOLOGY TO SUPPORT AUTONOMY IN PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

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## ABSTRACT

*Amyotrophic lateral sclerosis is a neurodegenerative pathology, which selectively affects motor neurons of the motor cortex, brain stem and spinal cord, which involves progressive muscle atrophy and weakening of skeletal muscles, spasticity and pyramidal signs, dysarthria, dysphagia and dyspnea. The routine, the normal daily life is completely altered and the impact does not only concern the patient, but the entire personal environment of the patient. In fact, the problems that arise gradually lead the patient to not be able to make any movement in an active and voluntary way and to no longer be able to express himself through verbal communication. Inevitably these deficit aspects also involve the participation and autonomy of the subject, which are increasingly limited in time. The aim of the following study is to demonstrate the validity of the technology as a useful tool for maintaining autonomy in ALS patients. The evaluation, choice and supply of technological devices customized according to the individual needs of the user and his physical and social environment is, in most cases, the most useful and functional solution to improve the quality of life of the patient and those around him. Tools such as electronic wheelchairs and/or eye-controlled communicators can increase the autonomy and participation of the individual, reducing the care burden and allowing the expression of needs, thoughts, social roles and future wills.*

## ■ OBJECTIVE

The objective of the following review is to demonstrate the effectiveness of technological devices to support the autonomy of ALS patients.

## ■ METHODOLOGY AND MATERIALS

The following study is a narrative review of the scientific literature related to the use of technological devices by ALS patients. For the bibliographic search, the Pubmed search engine was used and the following keywords were combined, through the Boolean operators AND and NEAR: ALS, occupational therapy, powered wheelchair, technological device. The search results used in the review were identified using the “free full text” filter. In addition, reference texts of the discipline of occupational therapist were consulted.

## ■ INTRODUCTION

ALS, also known as motor neuron disease, is a rapidly progressing neurodegenerative disease characterized by selective loss of motor neurons, brainstem, and spinal cord. The incidence is currently around 3 cases per 100,000 inhabitants per year and the prevalence is equal to 10 per 100,000 inhabitants in Western countries. Currently, there are about 6,000 sick people in Italy. The disease affects both sexes, although there is a slight preponderance in the male sex. The average survival after diagnosis is 3-5 years, and the most common causes of death are respiratory failure and dysphagia; therefore, life extension measures and, in particular, tracheotomy could significantly increase survival. In addition, it has been reported, that multidisciplinary integrated palliative care not only im-

proves quality of life, but also extends survival. It is characterized by heterogeneous patterns of deterioration: weakness of the limbs associated with frequent falls, difficulty communicating and swallowing up to changes in mood, cognition and behavior.

This disease has a multidimensional impact on the person's life, and the———symptoms imply a significant loss of autonomy that greatly affects everyday life. Early deterioration of language intelligibility and described weakness of the hands and upper limbs may result in difficulties in performing functional tasks that affect communication, leisure, work and social activities. According to the ICF, activity is defined as “the performance of a task or action by an individual” and participation as “the involvement of a person in a life situation.” Studies of activity and participation in ALS patients are surprisingly frightening. The routine is completely altered and the impact does not only concern the patient, but the entire family and social network of the individual, who must learn to manage and support the patient in the various stages of the pathology, considering that the functional, motor and respiratory abilities, autonomy and independence of the person are increasingly limited. Patients and their families engage with a variety of health disciplines, as, in order to fully respond to the wide range of needs of ALS patients, care must be multidisciplinary and the medical and rehabilitation team must make use of diverse clinical specialties, such as physicians experienced in neurology, pulmonology, gastroenterology, psychiatry and palliative care, as well as health professionals such as physiotherapists, occupational therapists, speech therapists, nutritionists, psychologists.

Rehabilitation medicine plays an important role in the treatment of patients with ALS; in fact, it allows you to maintain a satisfactory quality of life for as long as possible. Not least rehabilitation helps the patient and his family to face the limitations that the disease imposes. The goals of rehabilitation at different stages of the disease are to maintain the highest functional levels for as long as possible and prevent complications of secondary damage. The rehabilitation team must therefore evaluate the patient and know his potential, identifying strengths and weaknesses, so as to define an individual rehabilitation project focused on his abilities, without underestimating the critical issues related to the evolution of the pathology.

### ***Focus on the role of the occupational therapist in the rehabilitation team***

The occupational therapist has a specific role in supporting the patient starting from the evaluation, choice and supply of aids and / or orthoses up to proposing environmental changes to make the subject as autonomous as possible and to facilitate assistance by family members. Aids and home modifications are some of the most important interventions in the treatment of ALS. There are several approaches to improve the quality of life of people with ALS, in particular, it is highly recommended to use technology to support personal and social autonomy. The characteristics of the different technological devices allow subjects to communicate, socialize and maintain autonomy and independence, through tools such as:

- Electronic wheelchairs, which support personal mobility;
- Ocular pointing communicators, which allow communication;
- Home automation, which supports the management of the environment.

Evidence points out that these types of devices can also be used to preserve cognitive autonomy, influence psychological well-being, slow the course of the disease, and guide end-of-life decisions in severely ALS patients and those with locked-in syndrome.

### ***Mobility Devices***

A limitation of mobility significantly affects the lives of people who need technical aids to improve their quality of life, as they are unable to carry out their daily activities normally. A wheelchair could be a solution, and its use significantly improves, in most cases, the quality of life. However, manual chairs require physical skills that turn out to be deficient in ALS patients. The latter, in fact, have a deficit of strength and cannot self-push. They therefore inevitably need the assistance of another person to move. To overcome these limitations, electronic wheelchairs have been designed that allow

the user to move unaccompanied. These include a pair of motors for movement, batteries to drive the motors and a control system that varies according to the needs and functional capabilities of the person. The adoption of an aid of any kind requires a careful analysis of the environment of use, the capabilities, needs and expectations of those who will have to use it, with the aim of achieving independence, active participation and the highest possible functioning. In the case of patients with ALS, the electronic wheelchair

is a useful tool and, in certain situations, essential for maintaining autonomy. The choice of the correct control mechanism of the chair, associated with a suitable posture that supports the residual functionality and the right mechanical characteristics, allows a better quality of life, also increasing participation and social identity. Even when the patient's skills are not adequate for the guidance and management of such an aid, technology facilitates and reduces the level of care. In fact, the electronic device can also be managed by the caregiver who, especially if elderly or weak, takes advantage of the thrust of the motorized chair. On the market there are different types of electronic chairs and in recent years manual wheelchairs have also been designed to which an electric propulsion unit is added. Most electronic wheelchairs can be used to move both indoors and outdoors and are sometimes even more compact in size and maneuverability in tight spaces than manual chairs. The choice of an aid depends on a wide range of factors, starting from the type of traction – front, center or rear – up to the type of control. In support of the limitations present in the SLA, the technology provides special commands that allow the management of the aid even with reduced or almost absent voluntary movements. The most used commands are:

- The mini-joystick: small and ergonomic extremely sensitive joystick that requires minimal force for the activation of the electronic device. It can be calibrated and positioned in a personalized way according to the residual and functional mobility (for example under a finger, near the chin, on a table with handheld support, on a retractable arm);
- Head control: positioned to the side of the headrest, it can be programmed to behave as a push-button control (which acts according to the distance of the head from the sensor) or as a proportional control (which acts according to the force or pressure applied to the sensor);
- Foot control: for those who do not have precise movements with the hands or the head;
- Single sensor control: a single sensor to be placed on the head, finger or elsewhere that is used via a scanning device. This presents, through a display, a series of modes that are confirmed through the operation of the sensor. The management of this type of command can be very slow, which is why it is less and less used;
- Blow-suck control: even this less and less used, is activated with a very slight blow and / or a slight suck.

The aforementioned commands are bound by the presence of an expandable control unit, which also allows us to interface with home automation technologies and allows us to continue to use the aid safely simply by changing the type of special control if the previously functional ability is no longer suitable for driving. The levels of autonomy of the driving of an electronic wheelchair are constantly growing thanks to constant research, design and development of further technologies that allow, even with minimal or no voluntary movements, the management of this. For example, in Seattle, a prototype of an eye-controlled electronic wheelchair was developed for patients with ALS, which integrates a software-hardware technology not dependent on preserved motor or linguistic

function, but only on oculomotor function.

The advantages of using an electronic chair are many and through the control system of the same are guaranteed:

- Autonomy in travel;
- Dynamic postural systems: tilting, reclining, lifting platforms and/ or sitting, verticalization, etc.
- Home automation control through infrared (e.g. remote control of the TV and /or air conditioner) and Bluetooth (e.g. tablet, smartphone, computer).

On the other hand, the disadvantages of choosing an electronic wheelchair are not to be underestimated: if the evaluation does not focus on aspects such as the environment of use, transport in the car and / or the motor and cognitive skills of the individual, the chair could be exploited inadequately, leaving out important aspects such as user comfort and risk situations.

### **Communication Devices**

People with ALS have dysarthria in 80-95% of cases, which makes them unable to meet their daily communication needs through natural language. Patients with this limitation often feel deprived of their judgment, experience a lack of control and a change in social roles. The ability to communicate is strongly associated with patients' quality of life, and communication is considered crucial for adaptation to terminal diseases such as ALS. Communication, in addition to being a fundamental human right, is considered the essence of human life and crucial for the quality of life of patients. According to the Charter of the Rights of the Communication: "every person regardless of the degree of disability has the fundamental right to influence, through communication, the conditions of his life".

Therefore, in these patients where verbal and non-verbal communication skills deteriorate, alternative augmentative communication (CAA) strategies and technologies become increasingly important to support a wide range of issues such as one's own needs, social interaction, and to express personalities and feelings. Alternative augmentative communication systems complement (augmentative) and replace (alternative) verbal communication. CaA can be no or low tech (e.g. gestures, writing, tables) or high tech (e.g. tablets, touchpads, computer devices based on eye tracking, brain-computer interfaces). High-tech communication technologies offer the possibility of maintaining, with minimal movement, complex communication independent of the caregiver and environmental control, even in the advanced state of the disease. Mobile phones, touch screen tablets with software that incorporate symbols/words, frequently used phrases, synthesized speech and text prediction, improve communication and quality of life in ALS patients when introduced in the early stages of the disease.

The most functional HT-CAA devices in the advanced stages of the disease are eye-tracking computer systems that allow control of the cursor through eye movement. Eye movements are often the least strenuous and are sometimes the only residual movements that allow communication. These systems are based on a technique, that of eyetracking, which has at its base the idea of generating reflexes on the user's ocular surface and calculating the direction of the gaze

starting from the relative position of the pupil with respect to those reflexes. Several studies demonstrate the positive impact of using technological eye-tracking devices for severely disabled people. User acceptance and satisfaction are reported as high in the SLA. It was found in a study of 50 patients with ALS that 96% of those who were recommended CAA technology, due to increasing communication difficulties, accepted the device immediately or after a certain delay. The three main reasons for their decision for the CAA were the maintenance of communication, participation in the community and employment. Patients are encouraged to use these devices for a variety of activities such as face-to-face communication, email contact, Internet access and other computer functions and programs, as well as for controlling the environment. Even with respect to social media, access via HT-CAA is an additional help to allow connection with the outside world and thus support patients' social networks. Therefore, HT-CAA can allow social and intellectual stimulation, independent leisure activities and express even complex

thoughts. Interestingly, the worse the clinical condition of patients, the greater their acceptance of the technological device for communication seems to be. The computer eye tracking system preserves the patient's autonomy and therefore psychosocial well-being, in particular by allowing social activities that patients have defined as the most important area of life for their quality of life. It is disputed that psychological well-being could even change the course of the disease in ALS and could change patients' attitudes towards life extension measures. Secondly, caregiver-independent communication, enabled through the offer of HT-CAA is crucial to assess the psychological condition of patients and the actual willingness to ensure self-determination of care. The sick person, in fact, through the use of the eye pointer and without intermediaries, can communicate in a simple way and in full compliance with the law. The independence and dignity of people with ALS who are granted the right to express their will is also protected.

An advantage represented by eye-controlled communicators is the vastness of operations that allow you to carry out with just the look. In addition to access to social media, email and various applications, they also allow the switching on, off and management of home devices connected via infrared. For example, a patient bedridden with an eye pointer is able to turn the TV on/off, change channels, adjust volume, etc. In addition, it is not to be underestimated the management of alarm and emergency devices that can be activated by the user to attract the attention of the caregiver through a sound, a whistle, a noise. The ability to carry out and control various devices within the home affects the level of active participation of the subject within the family. In fact, they help the user to affirm his presence and his active will, as well as to emphasize his role and his identity. Devices of this type must be evaluated and customized on the basis of the individual needs that the user, the caregiver and the entire environment require. Alternative augmentative communication devices, however, may also have limitations and pitfalls in use and supply. User factors, such as psychosocial factors or cognitive and behavioral impairments, can complicate the use of technological devices for communication. Although oculo-

motor movements are generally considered spared in ALS, patients may present with ophthalmoparesis, defective tracking movements, saccadic movements, nystagmus, and abnormal Bell phenomenon.

## ■ DISCUSSION AND CONCLUSIONS

Technological devices are not designed to prolong survival, but to improve the quality of life and autonomy for residual life. According to the literature reviewed in this article, the optimization of communication, personal mobility and environmental control, leads to a better quality of life and better well-being, as well as allowing also the maintenance of social roles and intellectual stimulation. ALS patients represent a human population suffering from a disease that causes progressive physical deterioration that

leads to immobilization while most keep cognition and consciousness intact or slightly involved. Technology offers these patients, mostly young and active, a practical and concrete solution in solving or at least reducing the problems that daily affect their autonomy. It is therefore important to have timely access to adequate, easy-to-use and customized equipment to allow the user to maintain the highest level of autonomy possible according to the residual functionality and personal, welfare and environmental needs. The intervention of evaluation, choice and provision of devices to support the ALS patient should be incorporated as mandatory in multidisciplinary care in order to allow autonomy, ensuring access to the best personalized strategies and their adaptation to the changing needs of patients suffering from this disease.

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