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The Integrated and Specialized Interdisciplinary Team as a Differential Factor in the Care of Patients with Amyotrophic Lateral Sclerosis during COVID19 Pandemic

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For neurologists, the COVID 19 illness has two major implications: the first is the protection of the older population which represents the majority of our patients including stroke, dementia, Parkinson's disease, and amyotrophic lateral sclerosis, who are at risk of respiratory failure and multi-organ dysfunction. The second is the protection of patients with immunosuppressive drugs in auto-immune diseases and brain tumors [1].

Amyotrophic Lateral Sclerosis (ALS) is a degenerative disease characterized by progressive loss of neurons in the corticospinal tract, brainstem and cells in the anterior portion of the spinal cord, leading to loss of bulbar function, impairment of functional abilities and weakness of respiratory muscles. On average, survival varies from 3 to 5 years, although 10% of the patients can live more than 10 years [1,2].

Although advances in understanding the pathophysiology of neuromuscular diseases have encouraged the development of new drug therapies, the basis of treatment for these patients remains symptomatic treatment. So the interdisciplinary team has a central role in the therapeutic management of this disease and the integration between professionals is essential for the treatment to occur in a cohesive way to achieve better results. Interdisciplinary care is the standard approach recommended by European and US guidelines [3,4].

Maintaining functionality independently and safely, managing motor, respiratory and cognitive symptoms, maintaining and/or recovering good nutritional status, in addition to providing autonomy and quality of life are part of the goals of the rehabilitation team. As it is a progressive disease, the periodicity and regularity

of the therapeutic follow-up are of fundamental importance, so that strategies and conduct are reassessed for the according to the evolution of the disease [4].

In addition, the team's knowledge and expertise are differential factors in the treatment of ALS patients. The interdisciplinary approach specialized in the management of the disease allows the concentration of the health professional's experience in a rare disease, better communication between team members, facilitating decision making from different points of view and faster and more timely access to the interventions necessary to treatment [5,6].

Individuals with chronic medical conditions, such as ALS, should take extra precautions to minimize the risk of getting COVID-19. In addition to the general preventive measures listed above, patients with these conditions should: - Stock up on necessary medications and supplies that can last for a few weeks. 2- Avoid crowds and non-essential travel. 3- Stay at home as much as possible. Family members and caregivers of people with chronic diseases like ALS should take appropriate precautions and take extra care to avoid bringing COVID-19 home. They should constantly monitor patients and stock medicines and other necessary supplies that can last for several weeks. Storing extra non-perishable food can help minimize trips to the grocery store [7].

There are studies showing that patients followed by an integrated and specialized interdisciplinary team, with experienced professionals in the area, have a better quality of life, in addition to longer survival and lower mortality in the first year, from diagnosis, when compared to the group of patients accompanied by a non-specialized team. In the statistical analysis, this effect has been suggested to be independent of other factors, such as gastrostomy, non-invasive ventilation and use of the drug Riluzol [6]. Multidisciplinary care models have developed as a survival predictor, reducing the risk of death by 45% in five years when compared to patients treated in general neurology clinics [8,9].

ALS patients require comprehensive care with an interdisciplinary approach, which is individually adjusted to each patient and the stage of the disease's evolution. Specialized care is more than a means of providing adequate symptom management to the patient with ALS, as it requires a link between interprofessional practice and clinical research, in order to provide an efficient response to the alteration of each of the functions in an integrated manner. The therapeutic conduct of a professional is only complete when it is integrated with the performance of the other professionals, with a view to understanding the needs of each patient [9].

In patients with Amyotrophic Lateral Sclerosis (ALS), the impact of respiratory infections is expected to be more serious than in the general population, due to the weakness of the respiratory muscles and limitations in coughing. ALS patients with impaired respiratory function and/or rapid clinical deterioration are considered a high risk population for COVID-19, even if no estimates in the different countries are available. Identification of the principal carer it's a fundamental strategy: one principal carer should coordinate care provided to the patient. The principal carer should be someone who is always at home with the patient, to prevent being infected and transmitting the disease to the patient. Foods and medications should be bought through online platforms or by ordering home delivery at local shops. In case of respiratory emergency, first call the neurologist and respiratory physician in charge to finalize the required intervention. If needed, call the 24/7 health support lines that may have been provided and articulate it with the ALS care centres support [10,11].

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