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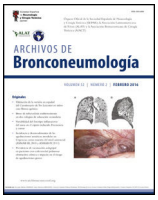

Editorial

The Role of the Pulmonologist in a Multidisciplinary Amyotrophic Lateral Sclerosis Unit. Challenge, Opportunity, and Privilege☆

El papel del neumólogo en una unidad multidisciplinar de Esclerosis Lateral Amiotrófica. Reto, oportunidad y privilegio

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The respiratory management of complex and frail patients is a clinical challenge for the practicing pulmonologist. Patients with amyotrophic lateral sclerosis (ALS) are both complex and frail, so it is absolutely essential that treating physicians work in a multidisciplinary team composed of independent professionals trained in different areas, collaborating on common ground. In fact, we can go even further and form teams that could be called interdisciplinary, in which all participants pool information and define action plans, dissolving the rigid barriers that delimit the responsibility of each specialist, fostering areas of common action and avoiding gaps in care. This is the setting in which multidisciplinary units (MU) are created, and this model has already demonstrated benefits in many medical and surgical areas. In ALS in particular, MUs have demonstrated their cost-effectiveness[1] and their ability to improve not only the patient's quality of life,[2] but also control of symptoms and life expectancy.[3,4] The key to their success is that they are centered around a patient-family unit, far removed from the traditional hierarchical pyramids of the health system. The most important participant in the MU is the patient, and MU team members must remain alert and constantly in contact with their colleagues, and be ready to step forward or intervene to provide individualized solutions to problems inherent to the progress of the disease. It is essential therefore that all professionals cooperate as components of a well-oiled machine, overcoming communication barriers between specialists and promoting collaboration.[5] The basic challenge of pulmonologists working in this scenario is to offer high-quality care based on scientific evidence, in a clinical situation that may involve invasive and non-invasive ventilation. The challenge becomes greater when decisions must be made in areas in which some uncertainty still exists. Perhaps the most pressing questions for the clinician at the moment are the following: how should lung function be evaluated, and what do the different tests tell us?[6]; what data can be provided by image testing?; when should sleep studies be performed and how should they be interpreted?[7]; when is the best time to start ventilation and what is the best modality?[8]; how should monitoring over time be protocolized?; and, how should we identify the best candidates for invasive ventilation with tracheostomy?.[9] It is indisputable that while the implementation of ventilation has led to a change in the progress and the survival of patients with ALS,[10] pulmonologists must constantly update both their knowledge and their technical skills to keep pace with the continuing evolution of ventilatory therapy equipment.

Another consideration is that while the treating neurologist will always provide the ALS MU team with an integrated vision of the disease, all members will take the lead from time to time. It is at that point that the initial challenge becomes an opportunity for the pulmonologist. Firstly, it is a care opportunity: with the support of the rest of the team, the pulmonologist can focus more efficiently on respiratory care, and decisions that are often complex can be made more easily, with input from different perspectives, saving time and energy.

On the premise that all ALS patients should be referred to a pulmonologist for assessment and periodic monitoring,[11] the specific functions of that professional include assessing the impact of the disease on the respiratory system, preventing and treating respiratory complications,[12] assessing the patient's capacity to manage secretions, indicating and adapting invasive or non-invasive ventilatory support,[13] assisting in the training of caregivers, providing care during hospital admissions, supporting the decision-making process, and finally, collaborating in palliative care. Pulmonologists can also play a key role in developing and implementing protocols to ensure safety during invasive procedures that require sedation, such as endoscopy and percutaneous gastrostomy, in managing the patient in the emergency room, in end-of-life care, and in helping facilitate organ donation.

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Finally, to close the circle of ALS care, we believe that the pulmonologist can play an essential role in home care, although very few centers have specialists who can visit patients with mobility problems at home. A model in which hospital-at-home units provide a care support structure that includes a pulmonologist who is also a member of the MU has shown benefits in both care indicators and resource management.[14] However, in the majority of cases this work is undertaken by general practitioners; therefore, we also believe that an exciting opportunity for growth and development of the specialty is the specialized management of patients who are receiving home ventilation.

Another area that can potentially be developed is the relationship with healthcare providers. Here, the pulmonologist can be a key player in passing on the message that MUs are the best solution for the patient, the team, and the institution itself, in terms of quality, efficiency and satisfaction. Moreover, the role of the pulmonologist in implementing consensus documents that ensure the best care for these patients, irrespective of the regions in which they are applied, is essential. Growing social awareness and governmental recommendations that support the management of ALS patients in MUs[15]have led to the development of regional care networks that focus on resolving the problems of each patient in the setting in which the best conditions, skills, and outcomes can be provided.[16,17] Finally, we must be able to take advantage of the fact that, although MUs are driven by a desire to provide optimal care, they have matured in clinical experience and will open up exciting opportunities for learning, improvement in carrying out individual responsibilities, and collaborative research. Participation in clinical trials, a process that is inseparable from efforts to find effective treatments, may also be viewed as a niche opportunity.

Our shared personal impression, then, is that while our commitment is to provide the best care to the patient, we are also receiving a great deal in return. In good company, this is a privilege.

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