



Special Article

Comprehensive Care of Amyotrophic Lateral Sclerosis Patients: A Care Model[☆]

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ABSTRACT

Amyotrophic lateral sclerosis (ALS) is a devastating neurodegenerative disease that presents with muscle weakness, causing progressive difficulty in movement, communication, eating and ultimately, breathing, creating a growing dependence on family members and other carers. The ideal way to address the problems associated with the disease, and the decisions that must be taken, is through multidisciplinary teams. The key objectives of these teams are to optimise medical care, facilitate communication between team members, and thus to improve the quality of care. In our centre, we have extensive experience in the care of patients with ALS through an interdisciplinary team whose aim is to ensure proper patient care from the hospital to the home setting. In this article, we describe the components of the team, their roles and our way of working.

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Atención integral a pacientes con esclerosis lateral amiotrófica: un modelo asistencial

RESUMEN

La esclerosis lateral amiotrófica (ELA) es una enfermedad neurodegenerativa devastadora que se manifiesta por debilidad muscular y produce dificultades progresivas de movilización, comunicación, alimentación y, en última instancia, respiración, creando una dependencia creciente de familiares y de otros cuidadores. La manera ideal de afrontar los problemas derivados de la enfermedad y las decisiones necesarias es a través de equipos multidisciplinarios. Los objetivos fundamentales de estos equipos son optimizar la atención médica, facilitar la comunicación entre los miembros del equipo y consecuentemente mejorar la calidad asistencial. En nuestro centro tenemos una larga experiencia en la atención a pacientes con ELA a través de un equipo interdisciplinario cuya pretensión es asegurar la correcta asistencia del paciente desde el hospital hasta el propio domicilio. En este artículo mostramos los componentes del equipo, sus funciones y nuestro modo de trabajo.

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Palabras clave:

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Traqueostomía

Gastrostomía percutánea

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Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease characterised by the progressive and selective loss of the motor neurons of the cortex, brainstem and spinal cord. The prognosis is fatal, with a mean survival of between 3 and 5 years from the onset of symptoms.^{1,2}

In Catalonia, it is estimated that the annual incidence of the disease is 1.4/100 000 population, and its prevalence is 5.4/100 000 population.³

Patients with ALS present numerous and complex challenges over the course of the disease, such as respiratory, communication and nutritional problems.^{4–9} In this respect, 3 often overlapping phases can be distinguished. The first phase comprises the period of time required to reach the most definitive diagnosis possible. In the second, the patient and their family must adapt to the disabilities that the disease will inevitably gradually cause. Throughout this phase, they must discuss, as far as possible, the decisions that will have to be taken with respect to issues as important as gastrostomy tube feeding and mechanical ventilation, especially invasive mechanical ventilation via tracheotomy. In the third or terminal phase, it is crucial to try to maintain the well-being and dignity of patients, which requires a clear approach, agreed with the patient and their family, on the type of therapeutic measures to adopt.

The consequences of the disease cause serious adaptation problems for the patient and their family. Progressive difficulties in moving, communication, feeding and respiration result in the patient becoming increasingly dependent, generating high costs that are reflected in the household economy and healthcare system.

The absence of a curative treatment does not preclude the possibility of improving the survival and quality of life of patients and their families by applying therapeutic measures such as invasive or non-invasive mechanical ventilation or the insertion of a feeding tube, as well as psychological support.^{6,10–15}

The ideal way to deal with the disease is through interdisciplinary hospital teams, with the external support of primary care teams and patient and family associations.

These teams generally aim to provide comprehensive, joint care by the various professionals involved in the care of ALS patients. There are various care models. The teams usually include neurologists and respiratory medicine specialists, as well as nurses, physiotherapists and social workers, but they can also be more or less extended, depending on the resources of each centre, to include other members including occupational therapists, cardiologists, psychologists, ear, nose and throat specialists, etc., or even in some cases by providing home care.

The basic objectives of these teams are: (a) to optimise the treatment and follow-up; (b) to reduce the number of trips to hospital; (c) to improve communication between the various specialists in the team, with the mutual enrichment that this implies, thereby facilitating fast decision-making; and (d) to improve the quality of life and survival of patients.

This interdisciplinary care model therefore offers major advantages over the conventional model of separate, individual visits with each professional, on different days and with little communication between the various individuals responsible for the ALS patient.

Experiences in multidisciplinary units, some of which are in our area, have been published.^{16–20} The main benefits obtained with these teams are improvement in quality of life and optimisation of healthcare resources. These units, although they do not change the neurological course of the disease, encourage more comprehensive patient care and may even improve survival.²⁰

The aim of this paper was to present the organisation of a well consolidated interdisciplinary team for the care of patients with ALS.

Work Methodology

Inception of the Working Group

The Neurology department at Hospital de la Santa Creu i Sant Pau (Barcelona, Spain) has a Neuromuscular Disease Unit, which

is a referral centre for the care of patients with ALS in this area. Since the late nineties, the neurologists in the unit have referred these patients to Respiratory Medicine outpatients when they suspected respiratory impairment related to the disease. In 2000, it was decided to begin working together, with regular meetings of both teams to analyse the progress of patients with respiratory involvement, and to adopt consensual approaches. However, these patients continued to undergo separate check-ups in the Neurology and Respiratory Medicine clinics.

In 2004, we set up the ALS Interdisciplinary Clinic, in which patients are seen simultaneously or in a staggered manner by the different specialists over one morning in the same department (Neurology outpatients).

Members of the Group and Duties

The central core of the group is made up of 2 neurologists, 3 pulmonologists, a physiotherapist, a hospital nurse, 2 home care nurses, a rehabilitative physician, a speech therapist, a dietitian and a social worker. All are directly involved in the consultation and collaborate actively and as a team. Each member has a certain specific function, as shown in Table 1. All of them also collaborate jointly in making decisions, such as when to start home mechanical ventilation (HMV), the need to change the diet or insertion of a percutaneous gastrostomy (PG) tube. When these decisions must be taken, agreed with the patient and their family, a meeting is organised in the clinic with the specialists most directly concerned. Thus, the decision to initiate invasive or non-invasive HMV will be taken by the pulmonologist together with the neurologist. When the diet needs to be changed or a PG inserted, the speech therapist and dietitian also participate. When a decision must be made regarding issues of general or respiratory rehabilitation, or on the need to use specific systems for clearing secretions (In-Exsufflator), the rehabilitative physician and physiotherapist are also involved.

When the patient needs to be admitted for adaptation to the HMV, the person directly responsible is the pulmonologist, and if it is for placement of a PG, the pulmonologist or neurologist are responsible, depending on whether or not there is a respiratory risk; nevertheless, all of the team members are aware of and collaborate in the decision-making.

There is also a team of additional consultants who collaborate with the team when necessary. In this team there is a gastroenterologist/endoscopist and interventionist radiology team, who take part in the placement and follow-up of patients who require PG. One or other team are chosen depending on the patient's condition. In patients with HMV or respiratory risk due to sedation, radiological placement of the PG is usually preferred. The palliative medicine team provides advice and support in end-of-life decision-making. Other specialists may assist depending on requirements, such as psychiatrists, cardiologists, dermatologists, etc.

Finally, there is good communication with external support teams, such as: (a) primary care teams; (b) teams for home care of frail patients, known as PADES (*Programa d'Atenció Domiciliària i Equips de Suport [Home Care Program and Support Teams]*)²¹; (c) augmentative and alternative communication systems: UTAC (*Unitat de Tècniques Augmentatives de Comunicació [Augmentative Communication Techniques Unit]*) and CVI (*Centre de Vida Independent [Centre for Independent Living]*); (d) technical assistance team (Sirius), and (e) home therapy companies. These are contacted depending on the needs of each patient.

The primary care and PADES teams may occasionally attend team meetings or sessions to coordinate efforts in difficult situations, but in general communication is through the home nursing team.

Table 1
Team Members and Their Duties.

Team member	Specific duties
Neurologist	<ul style="list-style-type: none"> - Direction of the disease diagnostic process - Communication of the diagnosis and therapeutic options - Monitoring of the neurological evolution - Prescription of aetiopathogenic and symptomatic treatment - Direct responsibility during admissions to the Neurology ward - Final responsibility for consensual decisions with the patient
Pulmonologist	<ul style="list-style-type: none"> - Respiratory evaluation and monitoring - Prescription and monitoring of specific treatments (DCO, HMV, Cough Assist) - Direct responsibility in patient admission for HMV adaptation/other therapies - Change of tracheostomy cannulae
Rehabilitation physician	<ul style="list-style-type: none"> - Functional and therapeutic needs assessment - Instrumental assessment of swallowing - Control of salivation (instillation of Botox, drugs, etc.) - Orthopaedic assessment and prescription
Respiratory physiotherapist	<ul style="list-style-type: none"> - Education, adaptation and monitoring of the patient with HMV - Respiratory and general physiotherapy - Link with out-of-hospital rehabilitation teams
Speech therapist	<ul style="list-style-type: none"> - Clinical evaluation of speech and swallowing disorders - Rehabilitative treatment of speech and swallowing disorders - Guidelines and advice in relation to communication systems
Hospital respiratory nurse	<ul style="list-style-type: none"> - Education and nursing care of the patient - Performing lung function tests in situ - Assisting in changing tracheotomy tubes
Dietitian/nutritionist	<ul style="list-style-type: none"> - Evaluation and monitoring of the nutritional status - Adaptation of food to energy-nutritional requirements - Prescription of oral nutritional supplements - Prescription and monitoring of home enteral nutrition
Home nursing team	<ul style="list-style-type: none"> - Optimisation of the efficacy and comfort of HMV and other treatments. Education - Identification and assessment of the problems of the patient and their family in the home - Change of tracheostomy cannulae or PG - Adaptation to home NIV and mechanical secretion clearance systems - Coordination and collaboration with external support teams in patient care
Social worker	<ul style="list-style-type: none"> - Evaluation of the patient's social situation and environment - Orientation and treatment of social problems

HCO, home continuous oxygen therapy; HMV, home mechanical ventilation; NIV, non-invasive ventilation; PG, gastrostomy tube.

Work Method

Patients

Patients with a suspected diagnosis of ALS are referred to the Neuromuscular Unit for study and follow-up from the hospital itself, the healthcare area and the rest of Catalonia. A second opinion is specifically sought on many occasions, and in this case patients may also come from other regions in Spain.

Our group actively monitors between 50 and 75 patients, considering losses and the inclusion of between 15 and 25 new patients.

Initial Visit

The initial consultation takes place with a neurologist before referring the patient to the interdisciplinary clinic. At this visit, the medical history is taken, and the neurological examination and additional tests required for the differential diagnosis and to establish the diagnosis of ALS are carried out. If the clinical data are suggestive of ALS, the next step is for the neurologist to perform an electromyogram (EMG). This examination is carried out within the following 2 weeks. The main aim of the electrophysiological study is to discard other aetiologies that could explain the clinical and semiological findings. If the EMG is consistent with the diagnosis, an aetiological study is carried out, comprising laboratory tests (haematology, biochemistry, microbiology and immunology), neuroimaging techniques (brain and/or spinal MRI) and, in specific cases, muscle biopsy, lumbar puncture and molecular genetic studies.

Informing the Patient of the Diagnosis

Once the initial study has been completed and the diagnosis confirmed, the following step is for the patient and their family to

visit the neurologist, if the patient so wishes, with sufficient time and without interruptions.

The diagnosis is given at this visit, and the characteristics of the disease explained. The explanation must be clear, using simple, understandable language and avoiding the use of technical terms. The patient should be given the opportunity to ask any questions they consider necessary, and these must be answered clearly. The neurologist must ensure that the patient has understood all the information. The therapeutic options and possibilities of participating in clinical trials or different studies are then explained.

The advisability of making an advance directive is then discussed with the patient and their family. This issue is readdressed at subsequent visits, particularly when a therapeutic approach such as initiating mechanical ventilation or inserting a feeding tube is suggested.

Upon completion, the patient is informed that the treatment and follow-up will take place through the interdisciplinary clinic from then on.

Respiratory, Dysphagia, Speech and Nutritional Assessment

These are presently performed when the patient is admitted to the interdisciplinary clinic.

The pulmonologist makes the initial respiratory assessment based on the medical history, physical examination, chest radiograph, and chest radioscopy to assess the diaphragm movement and a lung function study which includes spirometry, lung volumes, peak respiratory pressures, arterial blood gases and cough peak flow. A nocturnal pulse oximetry study is also carried out in the patient's home.

The rehabilitation physician assesses the motor impairment, walking ability, manipulation of objects, level of dependence and

the need for technical aids, in order to sustain the quality of life and maintain the highest degree of independence.

The speech therapist carries out an initial evaluation of speech and swallowing, and provides strategies and guidelines for optimising communication and ensuring good nutrition without a risk of bronchoaspiration.

The dietitian makes a clinical assessment, stressing the dietary aspect (eating habits, ability to swallow, motor difficulties for handling utensils, characteristics of their environment), carries out an initial diagnostic nutritional evaluation (anthropometric and biochemical parameters) and calculates the energy-nutritional requirements considering spontaneous ingestion. Finally, dietary recommendations are indicated for optimising the qualitative and quantitative composition of the patient's food. The texture of the diet may be adapted based on the type and severity of the dysphagia.

Interdisciplinary Clinic

Two interdisciplinary clinics are held, on the second and fourth Thursday of each month. Patients are seen every 2–4 months according to the disease progression.

On the day of the visit, before seeing the patients, a clinical session is held attended by all the team members. At the session, patients who are to be seen that day are presented, their clinical condition is discussed and it is agreed whether it is necessary to deal with any specific problems or take any major decisions, such as HMV or insertion of a PG. If a patient is unable to attend the visits, the home care team raises any questions that could require joint decision making.

Patients are seen in outpatients simultaneously or staggered over the entire morning. The clinic is held in three outpatient consulting rooms in the Neurology department. The direct care team is made up of 2 neurologists, one of 3 pulmonologists (who alternate each month), a rehabilitation physician, speech therapist, dietitian, a respiratory nurse (responsible for patient education, lung function tests and in situ arterial blood gases) and a respiratory physiotherapist (who is also responsible for supervising the general physiotherapy programme). The order of the visit and type of care is prioritised depending on the patient's needs.

During the afternoon of the second monthly clinic, a joint session is periodically held where a specific issue is discussed, possible clinical protocols are presented or approaches to management of the disease are agreed. All members of the team attend this session, as well as some consultants and often members of the external support teams, for example in cases in which attendance by the primary care team or PADES is requested.

Home Care

An important point to highlight within the interdisciplinary team is the support given to these patients by the home nursing team. This team is composed of 2 nurses who form part of the hospital Respiratory Medicine department. They are in direct contact with the pulmonologists and, if necessary, with the other members of the interdisciplinary team, so that they can solve many problems, thus avoiding additional trips to hospital which may be pointless and difficult. In addition to attending urgent situations, they make routine visits at intervals determined by the needs of each patient.

Among their activities are: (a) to check the ventilation systems and to make changes in the ventilator, ventilation mode or parameters if necessary, and to treat all complications derived from the ventilation, as well as having direct contact with the home therapy companies; in very selected cases, they perform adaptation to non-invasive ventilation (NIV) or mechanical assisted cough equipment in the home; (b) to change tracheostomy cannulae and PG tubes when required; (c) to deal with acute events, such as respiratory infections or other causes of respiratory exacerbation, and (d) in the

case of very frail patients, to try to avoid transfers and to attend any possible complications in the home. In this case, the PADES team is also contacted to begin joint follow-up and palliative treatment, if indicated.

All changes in ventilation modes, parameters, interfaces, as well as states of exacerbation, are discussed with the team of pulmonologists from the ventilation unit, with whom they are in constant, open communication via a business mobile phone. The nursing team helps to dispense the oral medication, but does not administer intravenous treatment if it is required; instead the patient is transferred to hospital for admission. Patient assessment by the nursing team is essential for deciding when transfer to hospital is necessary, and if it is, they accompany the patient.

One limitation in this team is their working hours: from 8 in the morning to 5 in the afternoon, Monday to Friday. Out of hours the patient can contact the Respiratory Medicine doctor on call.

Furthermore, for logistic reasons, patients can only be seen in the Barcelona metropolitan area. Patients living outside the city who have very complex issues (e.g. tracheotomy) have the telephone number and email of the home nursing team and the Respiratory Medicine ward, so that they can contact the respiratory team at any time. Before discharge from the Respiratory Medicine ward, the team responsible for the patient's care are contacted, whether it is primary care or PADES, and a contact phone number is provided. The patient is sometimes accompanied on discharge, and a meeting is organised in the patient's home with the teams who will be responsible for their care. Less complex patients (NIV, isolated PG, etc.) can also contact the Respiratory Medicine and Neurology team by telephone or email.

Comment

Our opinion, shared by other authors, is that patients with a disease like ALS, which is a multidimensional, progressive condition with a very serious prognosis, requires comprehensive care with an interdisciplinary concept that covers care from the hospital to the home.

Several experiences have been published in the literature that present models very similar to ours, principally multidisciplinary units in Ireland,¹⁸ Italy¹⁹ and Madrid.²⁰ All have a long history in the multidimensional care of patients with ALS. Some have shown that patients attended in these units have higher survival rate.^{18,20} Factors that favour this may be the application of early respiratory and nutritional care, as well as the close interdisciplinary clinical follow-up, which facilitates the early detection of any symptoms.

However, unlike these working groups, the special feature of our model is the fact that patients are attended on the same day and by the entire team at the same time, with the possibility of performing specific tests and treatments if necessary. Furthermore, we have strong home care participation, which is considered in only some of these units, although through community care and not a nursing team from the hospital itself.

Therefore, the strength of our model is defined by several aspects: (a) optimisation of care in the sense that in one single day, patients are assessed by the various specialists and healthcare personnel who take part in their follow-up, reducing trips to hospital, which are sometimes very complicated, especially in advanced stages of the disease; (b) the possibility of performing necessary respiratory studies in situ, such as lung function tests, arterial blood gases, radiology or others; (c) the support of respiratory physiotherapy during the day, which enables patient assessment as well as starting respiratory physiotherapy treatment, adaptation to mechanical secretion clearance systems and review of ventilation systems in situ; (d) having a home team who actively participate in the group activities and who provide much day-to-day information,

as well as being a link between primary care and PADES; (e) achieving smooth communication between all members of the team responsible for the patient, crucial when it comes to taking critical decisions and explaining them to the patient and their family, such as the indication for ventilation or placement of a PG tube, and (f) encouraging joint projects and enriching discussions not only from a clinical but from an ethical point of view, which aids consensual decision-making, often very difficult.

On the other hand, it is important to highlight that this care model has some weaker points, such as the time that the patient must remain in outpatients, which can become excessively long, or the fact that there is a risk of loss of privacy as several members of the team attend the patient at the same time, especially when decisions to be taken must be discussed. However, this point can be overcome by taking preventive measures to maintain privacy during the conversation, which should be limited to the patient and their family with the specialists who are most directly related with the decision to be taken, the neurologist with the pulmonologist in respiratory issues or the neurologist with the dietician in dietary aspects.

Conflict of Interests

The authors declare that they have no conflict of interests.

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