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Short Communication

Rehabilitation in Amyotrophic Lateral Sclerosis: "Prudence and Limit of Programs"

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Abstract

The rehabilitation treatment approach for patients with Amyotrophic Lateral Sclerosis should be individualized, held in submaximal limits and changed according to the stages of the disease. The spectrum of presentation and disease progression speed may vary according to each patient and the transdisciplinary approach promotes measures focused mainly on improving the quality of life of patients. Symptomatic therapy is the most appropriate to be used in palliative care related to Amyotrophic Lateral Sclerosis and its association with the multidisciplinary care improves survival of patients. The installation of palliative care should follow some conditions presented by the patient, and must comply with normal stage of the disease. In neuromuscular involvements, physical therapy seems one of the main methods for reducing pain and loss of strength or function of the members, besides assisting in the promotion of the quality of life of patients. However, despite the knowledge about the disease, further studies are needed to promote advances in knowledge of appropriate treatment and application of new methods of treatment.

Keywords: Physical therapy; Amyotrophic Lateral Sclerosis; Rehabilitation

Short Communication

Our understanding of prudence? I believe it is a combination of wisdom, patience, calm or consideration with regard to certain situations. Conducting researches and meeting patients with Amyotrophic Lateral Sclerosis (ALS) daily, makes me humble enough to accept my limitations on what would be considered the gold standard for these patients. Undoubtedly the motor rehabilitation brings several benefits for patients with ALS.

Most scientific papers suggest, however, that the rehabilitation treatment approach for this population should be individualized, held in submaximal limits and changed according to the stages of the disease [1,2]. Although we know that ALS has a natural history, the spectrum of presentation and the evolution rate of the disease may vary among patients, hence is not suitable to protocol activities / exercise therapy. Unfortunately we add to it, the lack of randomized controlled studies with a significant number of patients and follow-up in the long run. A major aspect that should be taken into consideration is the fact that when the first signs / symptoms of the disease begin to manifest, about 80% of the population of motor neurons of the weakened region have already been devastated. We should not cause a metabolic burden on an already compromised system, since all the attempts to restore function, for example compensatory axonal budding, have been automatically carried out by our central nervous system [3,4].

The management of muscle weakness / fatigue should include energy maintenance techniques, changes in lifestyle as well as regular periods of rest between activities. Stretching techniques are useful in managing the range of motion, and the use of assistive equipment and support are also important to facilitate certain basic and instrumental daily life activities besides providing greater security [4,5]. The aquatic environment may also be a good treatment strategy for these patients. Importantly, the work of swallowing, speech and breathing muscles are also part of this process and ought to work together with other systems [6].

The main therapeutic pillar in ALS is a trans-disciplinary approach, including health professionals and related areas by promoting focused measures mainly to improve the quality of life of patients, a role developed by physicians, nurses, speech therapists, physiotherapists, nutritionists, psychologists and occupational therapists [7]. From a medical point of view, therapeutic measures practices are basically symptomatic, whose therapeutic basis is primarily dependent on observation and appropriate implementing measures for the demands referred by family members, by members of the multidisciplinary team and exceptionally by the patients themselves. Proper nutritional support is also essential in these cases, since about one-third of patients with ALS are found in state of malnutrition [8] and will not be addressed in detail in this text.

Symptomatic therapy, one of the pillars of palliative care related

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to ALS and its association with the multidisciplinary care, guarantees improved quality of life and optimizes patient survival [9]. In spite of the discussion with families about palliative care to be applied, the following variables are considered as absolute indications for the installation of palliative care: (i) significant threatening complications , as septic episode (including severe sepsis and pyelonephritis), persistent and recurrent fever after antibiotic therapy and recurrent aspiratory bronchopneumonia; (ii) critical nutritional and protein-energy commitment, including continuing weight loss, dehydration, hypovolemia, lack of alternative feeding method and insufficient energetic and hydric intake; (iii) progressive neurological disabilities such as progressive dysphagia (from soft diet), functional dependence in activities of daily living, moderate or severe dysphonia and progressive tetra paresis with ambulatory disability; and (iv) significant reduction in respiratory capacity, including vital capacity less than 30% of normal, dyspnea at rest, supplemental oxygen and objection in the use of noninvasive or invasive ventilation methods [10,11].

Promoting individual's adaptation to reality is the responsibility of professionals working with rehabilitation. To outline an appropriate rehabilitation program, it is essential to know neuromuscular diseases, their causes and pathophysiology. Although each neuromuscular disease is different with regard to the presentation, course and impact on life expectancy, all of them involve essentially multiple organs and systems, resulting in the limitation of daily life activities (DLA) [12].

Taking into consideration the natural course of ALS, according to *Dal Beelo-Haas* (1998) [13], the disease can be divided into six stages, and it may help the physiotherapist to determine a specific intervention through the disease process.

In stage I, the functional independence and mobility are still preserved. There is only slight weakness in specific muscle groups. Thus, active-free exercises, resistance exercises (not compromised musculature), aerobic exercise (walking and swimming), stretching, patient and family education, and psychological support are indicated.

In stage II, there is already moderate muscle weakness and involvement of a greater number of muscle groups. Therefore, the continuation of the exercises of stage I is oriented and the addition of active-assisted exercises, passive exercises in the most affected muscles, as well as the use of orthotics and adaptations.

In stage III, there is a worsening of muscle strength in some specific groups, functional impairment from mild to moderate and greater susceptibility to fatigue. Level II exercise and use of the wheelchair are indicated, in order to reduce the energy expenditure and fatigue of the patient.

In stage IV, there is a worsening of muscle strength in the arms and legs and the therapy used in stage III is recommended, except for the completion of resistance exercise, which should be avoided. From this moment on, respiratory therapy is also indicated and emphasizing the care in the prevention of decubitus ulcers (positioning in bed), since the patient will have difficulties to change it [14].

In stage V, there is a moderate functional dependence and a moderate to severe level of weakness. The physiotherapeutic treatment is the same as stage IV, associating with techniques and methods for the treatment of pain relief [4].

Finally, in Stage VI the patient needs maximum assistance for being in bed and dependent on invasive ventilator support. At this time passive and stretching exercises are indicated to delay the onset of contractures and deformities or to avoid progression of existing ones. With regard to respiratory physiotherapy it is essential the use of mechanical ventilation and tracheal aspiration.

Other authors as Piedmont and Ramirez (2001) [6] also suggests a classification (functional) in three stages (independent, semi-independent and dependent) associated with specific physical therapy procedures for each phase. These authors also recommend that daily exercises be taught to patients and their caregivers. The three stages are divided as follows:

- Independent: a motor skill is preserved, and the patient was able to walk normally and execute his DLA. There is a slight decrease in muscle strength and fatigue resistance. The main objectives are to maintain motor function as long as possible, avoid muscle retractions and joint deformities, re-educate the posture and provide guidance on the use of orthoses.
- Semi-independent: the patient presents difficulties in carrying out the DLAs and can make use of the wheelchair. At this stage, the respiratory compromise begins, with dyspnea on moderate exertion. Stretching, muscle strengthening, postural exercises and respiratory kinesiotherapy are recommended.
- Dependent: the patient needs a caregiver to assist him in carrying out the DLAs due to disease progression. The preservation of joint mobility with emphasis on scapular and pelvic regions, the preservation of the respiratory system and postural changes are recommended.

Regarding communication, symptoms such as dyspnea, dysphonia, and dysarthria are crucial in oral communicative performance of the patient [15]. In neuromuscular involvements, the pattern of muscle implies in changes in vocal quality, resonance, breathing, phonoarticulatory precision, speech rate, and prosody and pneumophonoarticulatory coordination. Thus, the speech intelligibility decreases as the disease progresses. At this stage, the patient uses resources such as syntactic reduction and the use of routine vocabulary as well as graphical support in order to ensure the message transmission and better understanding of the speaker [16,17].

In general we may say that according to the knowledge of the progression of ALS, diagnosis and early treatment are still the most widely used tools for the advancement of therapy. Care must be made on an individual basis and always taking into consideration the symptoms and / or interaction with the health team, caregivers and family members of patients. Furthermore, physical therapy proves to be essential for the reduction of pain and conditions such as loss of power or function, and thus assists in promoting quality of life of patients while minimizing the deficiencies presented at each stage of evolution of the disease. It is important to stress the need for further studies with groups of patients undergoing treatment for longer periods of time, so that we will get more improvements regarding the therapeutic use and application of new methods of treatment [18,19].

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