



CHALLENGES IN MANAGEMENT OF PATIENTS WITH AMYOTROPHIC LATERAL SCLEROSIS

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Introduction: Amyotrophic lateral sclerosis (ALS) represents one of the most unfavorable progressive forms of motor system neurodegeneration, with the involvement of upper and lower motor neurons. Dysphagia and dysarthria together with the atrophy and fasciculations are common features in patients with ALS resulting from the degeneration of lower motor neurons in the brain stem and spinal cord. These symptoms have a significant impact on quality of life and overall life expectancy of the affected individuals. Most recent evidence highlights the survival of patients up to a decade, whereas the life expectancy given the presence of progressive respiratory failure ranges between 2 to 4 years after disease onset. Given the significant functional, behavioral and motor decline, it appears of vital importance to manage these patients by adapting a multidisciplinary holistic approach in order to address the underlying needs of the affected individuals and their families. There is strong evidence, which support the initiation of palliative care services at the early stages of the disease.

Methods: This report is based on the case of a 52-year-old female patient with ALS who has been treated as an inpatient at the National Scientific Center for Oncology and Transplantology, Astana, Kazakhstan. We are focusing on the challenges that arise whilst managing a patient with progressive motor neuron disease and supporting our recommendations with the recent evidence obtained from a search of the PUBMED, Cochrane database, American Academy of Neurology and peer-reviewed journal articles.

Results: The results of this study, which combined systematic literature review and case-based discussion, have shown to clearly support the idea to implement multidisciplinary approach for successful management of patients with ALS. Multidisciplinary team would ideally include neurologists, respiratory nurse specialists, psychologist, and district general nurses, speech therapists, GPs, social care workers, palliative care consultants and pharmacists. These specialists will help with symptom control and provide psychological and social support of the affected individuals, thus helping to achieve the goal of personalized, patient-centered care.

Conclusion: Based on the literature data and the results of our observation, there is no doubt that a multidisciplinary approach is required to manage patients with ALS. It is necessary to estimate the number of patients suffering from ALS in Kazakhstan, their quality of life and nutritional needs and to ensure their access to comprehensive palliative care services.