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Review Article

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The Experience of Als Patients in Treatment with Riluzole in Europe

Erind Thartori[1*] and Xhulia Marina[2]

[1]*Chief Nursing Officer/ Mother Teresa University Hospital, Tirana, Albania*
[2]*General Nurse at American Hospital, Tirana, Albania*

[*]**Corresponding author**
Erind Thartori, Chief Nursing Officer/ Mother Teresa University Hospital, Tirana, Albania.

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Introduction
Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive and fatal neurodegenerative disease that affects the nerve cells in the brain and spinal cord that control voluntary muscle movement. Riluzole is a basic drug in the standard therapies approved for patients with Amyotrophic Lateral Sclerosis. Riluzole is a 50 mg tablet and the usual dosage for these patients is 100 mg every 24 hours, divided into two doses of 50 mg per day. Its mechanism of action affects the inhibition of glutamate release in synapses, reducing excitotoxic damage to motor neurons. This drug does not cure patients with ALS, but it prolongs life by an average of 3 months to several years, slowing the deterioration of the patient.

Objectives
Some of the objectives of this work are to assess the suitability of patients with this treatment and the body's response to this preparation. The impact of Riluzole on the quality of life, as well as the analysis of side effects. Also, the assessment of adherence and persistence to riluzole.

Methodology
This material is based on comparative studies based on European registries and the experiences of patients with ALS in different European countries, according to the stages of the disease. Information has been collected from many European countries and their experience in treatment with riluzole has been analyzed.

Conclusion
Riluzole remains an important but not the only component in the management of ALS. An integrated nursing approach based on evidence and multidisciplinary coordination is crucial to improve the experience, compliance and quality of life of patients across Europe. Policy-making should be oriented towards equity of access, networks of specialist care and patient empowerment at every stage of treatment.

Recommendations
Standardization of clinical practices at the European level, strengthening the role of the nurse in therapy management, integration of PROs (Patient Reported Outcomes), psychosocial and educational support.

ALS (Amyotrophic Lateral Sclerosis)

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive and fatal neurodegenerative disease that affects the nerve cells in the brain and spinal cord that control voluntary muscle movements [1]. Over time, these nerve cells (motor neurons) become damaged and die, leading to muscle weakness, atrophy, and, ultimately, paralysis. ALS affects motor neurons, which are responsible for sending signals from the brain and spinal cord to the muscles to perform movements. When these neurons are damaged, they can no longer send messages to the muscles, leading to:

Muscle weakness: Often starts in one part of the body, such as an arm or leg, and then spreads.

- Muscle atrophy: Loss of muscle mass.
- Muscle cramps and tremors: Especially in the hands, feet, and tongue.
- Difficulty walking and performing daily activities.
- Problems with speech (dysarthria) and swallowing (dysphagia): This can lead to weight loss and malnutrition.
- Difficulty breathing: Over time, the respiratory muscles weaken, requiring mechanical assistance for breathing.

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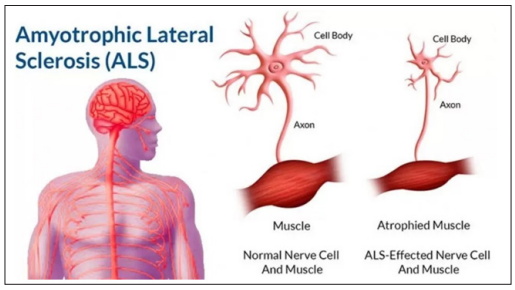
It is important to note that, in most cases, ALS does not affect mental ability, senses (such as sight, hearing, smell, taste), or bladder and bowel functions. However, a small number of people may develop memory problems or behavioral changes.



The Importance of Riluzole Treatment

Riluzole is a basic drug in the standard therapies approved for patients with Amyotrophic Lateral Sclerosis [2]. Riluzole is a 50 mg tablet and the usual dosage for these patients is 100 mg in 24 hours, divided into two doses of 50 mg per day.

Its mechanism of action affects the inhibition of glutamate release in synapses, reducing excitotoxic damage to motor neurons. This drug does not cure patients with ALS, but it prolongs life by an average of 3 months to several years, slowing down the patient's deterioration. It is most effective if started at the moment of diagnosis. During the treatment of patients with riluzole, controls with liver function tests (ALT, AST, GGT) should be maintained, in the first year every three months and then every 6 months. Riluzole therapy can also cause neutropenia, severe fatigue, nausea, weight loss or vertigo [3].

Among the most common side effects are loss of appetite, fatigue, increased liver enzymes and in rare cases hepatitis and neutropenia. It is very important that the patient is systematically monitored for these signs. For the prescription of this medication, certain criteria must be respected, as this preparation was not found in Albania. The patient must be diagnosed with ALS according to the EL Escorial or Gold Coast criteria. Age younger than 75 years (there are some European countries that do not limit it based on age).

There should be no severe hepatic impairment before treatment and patients should be in good condition to take tablets. In most European countries riluzole is the standard first-line drug for ALS. It is often used in combination with other therapies such as: Edaravone (Germany, France).

Pharmaceutical Forms of Riluzole

Tablet (most commonly used) with a standard dose of 50 mg, administered as 1 tablet, twice a day (100 mg in 24 hours). It is the most commonly used form throughout Europe. In advanced stages, patients have difficulty taking it as they experience difficulty swallowing (dysphagia).

Liquid form Riluzole 5mg/ml (Oral solution 50mg/10 ml). It is suitable for patients with difficulty swallowing. The dose is equivalent to 50 mg. On the market we find it under different trade names such as Tiglutik (in the USA and some EU countries) and Rilutek (in other EU countries) [4]. The advantages of the liquid form are that it allows easier administration via oral syringe or via PEG (Nasogastric tube/gastrostomy). It also increases the comfort of patients with advanced stages of the disease. This form of the preparation is also increasing in France, Germany, Italy and the United Kingdom in patients with dysphagia [5].

Orodispersible film "Emylif": It is a new form in Europe (Germany, UK), available as a film that dissolves on the tongue, without the need for water. It offers a solution for patients with difficulty swallowing and reduces the risk of aspiration.

Oral film form "Exservan": In the USA, an oral film of riluzole has been developed and is the target of regulatory review by the FDA for easy-to-swallow forms.

Experience of ALS Patients Taking Riluzole Tablets

Positive experience refers to: Ease of use, as most patients experience it as a simple therapy by taking one tablet twice a day.

Sense of hope: Although the effect of riluzole is not curative, patients often express that the fact that there is a treatment dedicated to ALS gives them a sense of control and security.

Trust in the doctor Neurologist: Patients tend to follow the doctor's advice precisely, as part of a multidisciplinary team and treatment.

Among the reported difficulties are side effects in the gastrointestinal system, such as nausea, loss of appetite, epigastric pain and often these signs are reasons for its discontinuation. Excessive fatigue that significantly affects daily activity. Liver damage and the need for additional and periodic examinations make the patient worried. Cost and accessibility of this medication since in some European countries this preparation is covered by the state, while others (patients who do not have insurance) have high financial costs to obtain it.

Experiences at Different Stages of the Disease

In the early stages, patients are more motivated, tolerate the side effects of riluzole better and are more regular in taking them.

While in the advanced stages, patients have even greater problems and concerns, such as difficulty swallowing, which significantly affects taking the tablets. Some patients at this stage crush the tablets or use them in liquid form if they find them. Often, due to the serious condition of the patients, they find it impossible to take these tablets.

Data on Patient Experience in European Countries

In Italy (Emiglia-Romagna) 84% of young ALS patients started treatment with Riluzole. A small proportion of them discontinued due to hepatic or gastrointestinal side effects. In a population-based registry in the Emilia Romagna region (2009-2014), 84.1% of young ALS patients received Riluzole. This indicates a high rate of taking the drug after diagnosis [6].

A real-world pharmacoepidemiological study found that in some regions (Latium, Umbria, Tuscany) more than half of ALS patients were users of Riluzole and there were significant differences between regions. In Latium there were more non-users, while in Tuscany there was a higher percentage of users.

In Portugal: 75% of patients completed treatment within 15 days of diagnosis, 60% discontinued within the first year due to side effects or perceived lack of effect. A retrospective study at the Central Hospital of Lisbon (2006-2016) estimated a prevalence of 8 per 100,000 inhabitants receiving Riluzole. Of the 77 patients receiving riluzole, 75% started treatment within 15 days of diagnosis but 60% received treatment for less than 12 months [7].

In Sweden: Patient experience was related to the actual prevalence of the disease; regular use was an indicator of strong support from the health system. A study from Sweden in 2003 estimated that the percentage of riluzole users is quite high and this clearly shows the prevalence of this disease in the population. The percentage of sales of riluzole (expressed in daily doses per 100,000 inhabitants) was 3.8 and this correlated well with the prevalence of ALS of 5.4 per 100,000 inhabitants. The researchers suggested that sales statistics can serve as an indicator of the prevalence of ALS in the population.

Conclusions

This paper shows that riluzole remains the basic pharmacological standard with a moderate clinical benefit and a well-known safety profile. However, the patient experience is uneven across European countries due to differences in access, reimbursement, available formulations, laboratory follow-up and socio-economic support. Patients value the shared decision-making approach, clear explanation of realistic expectations and active monitoring of side effects, which directly affect compliance with treatment and quality of life. Riluzole remains a component but not the only one in the management of ALS.

An integrated nursing approach, based on evidence, PRO, and multidisciplinary coordination is crucial to improve the experience, consistency, and quality of life of patients across Europe. Policymaking should be oriented towards equity in access to specialized care networks and patient empowerment at every stage of treatment.

Recommendations

Based on the analysis of the experience of patients with ALS and treatment with riluzole in Europe, the following measures are recommended

Standardization of clinical practices: Development of unified guidelines for monitoring riluzole (laboratory analyses, dose interruption/reduction protocols).

Ensuring equal access to all formulations (tablet and oral suspension) to facilitate drug intake in patients with dysphagia. Strengthening the role of the nurse in therapy management: Specific training for nurses on side effects, pharmacological interactions and patient education.

Involving nurses in clinical decision-making and as the main point of contact for the patient and family. Integration of PROs (Patient Reported Outcomes): Systematic use of instruments such as ALSAQ-40/5 to measure the experience and quality of life of patients in clinical follow-up.

Use of telemonitoring and digital platforms for the continuous collection of patient feedback.

Psychosocial and educational support: Provision of multidisciplinary services (nutrition, speech therapy, psychology, physiotherapy) integrated with pharmacological treatment.

Structured education for patients and families on realistic expectations from riluzole, methods of administration and the importance of monitoring.

Health policy and equal access: Reducing inequalities between European countries through uniform reimbursement and ensuring equal access to therapy.

Establishment of national and international registries to collect real-world data on effectiveness and patient experience.

Further research: Comparative studies on patient experience with riluzole in different European countries.

Investigation of combined strategies (riluzole+ edearavone+ multidisciplinary care) on quality of life and survival.

Cost-effectiveness analyses that take into account the patient and family perspective.

These recommendations aim not only to optimize riluzole therapy, but also to increase the quality of life and patient experience with ALS across Europe.

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