Poster #P068

Lennox-Gastaut Syndrome. Situation analysis and Family Journey

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INTRODUCTION

Lennox-Gastaut syndrome (LGS) is a severe and rare form of **developmental and epileptic encephalopathy** that usually develops in childhood.[1,2].

It is characterised by multiple types of **epileptic seizures, electroencephalogram** (EEG) abnormalities and **neurodevelopmental delay**[1,2].

It is associated with **cognitive and behavioral problems**, difficult to control crises and **progressive deterioration** throughout the patient's life[3].

It can be **secondary**, with **identifiable cause** (75%), **or idiopathic or cryptogenic**, without cause (25%)[3].

OBJECTIVE

To outline the **Family Journey of both paediatric and adult** LGS patients and their families.

METHODOLOGY

Establishment of a multidisciplinary group with representation from healthcare professionals (paediatric neurologists, adult neurologists, neuropsychologists, and nurses) and patient associations.

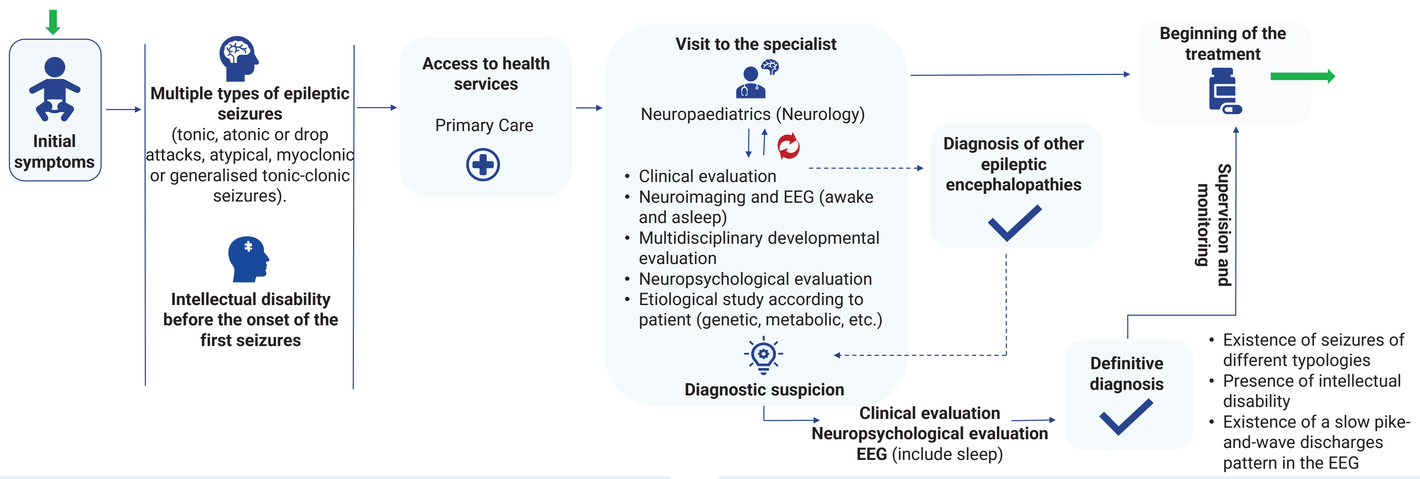
Interviews and work session with the multidisciplinary group.

Consensus on the LGS Family Journey.

FAMILY JOURNEY OF PAEDIATRIC PATIENTS WITH LENNOX-GASTAUT SYNDROME

1

- **Diagnostic delay** due to **variability of symptoms** and confusion with other childhood epilepsies.
- **Progression from other encephalopathies** and need for **constant vigilance.**
- **Diagnostic and early detection limitations** due to lack of EEG with sleep recording and long waiting lists.
- **Early diagnosis** necessary for early treatment and specific and individualised care.



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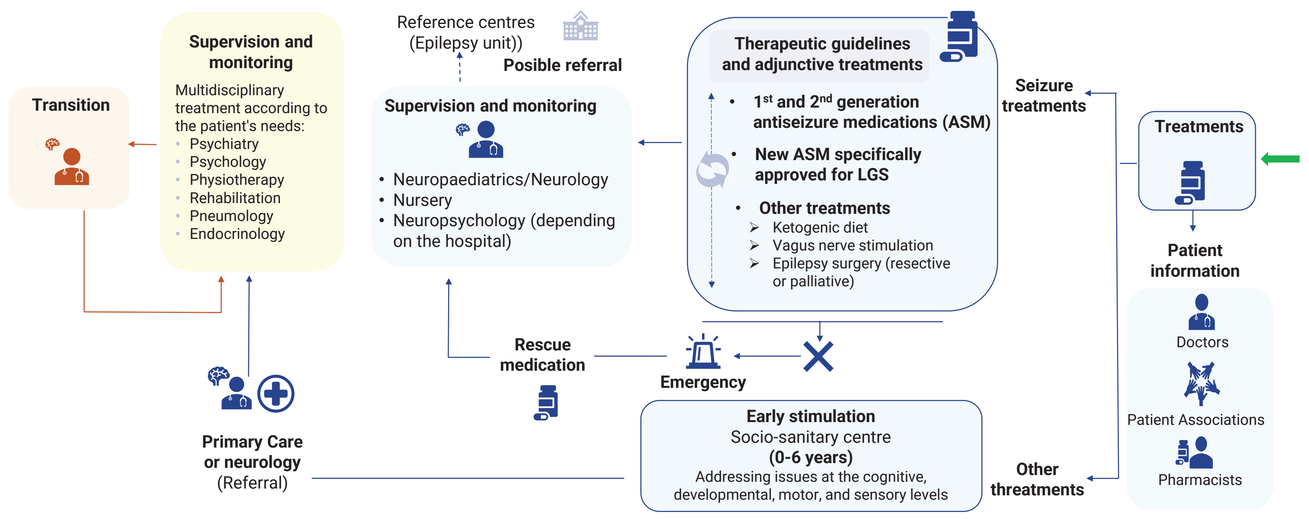
- **Individualised treatment, tailored to patient assessment,** crucial due to treatment resistance.
- **Therapeutic innovation** essential to meet the needs of patients who do not respond to current treatments.
- **Access to specialised and innovative treatments** limited by bureaucracy.

Initial symptoms and entry to healthcare services | **Diagnotic process**

4

- **Education of family members** by neuropaediatricians, nurses and social workers to manage uncertainties and resolve doubts.
- **Multidisciplinary collaboration and team coordination** to manage complications, comorbidities and polymedication through specific protocols.
- **Child-adult transition** organised through **coordinated programs** between paediatric and adult care.



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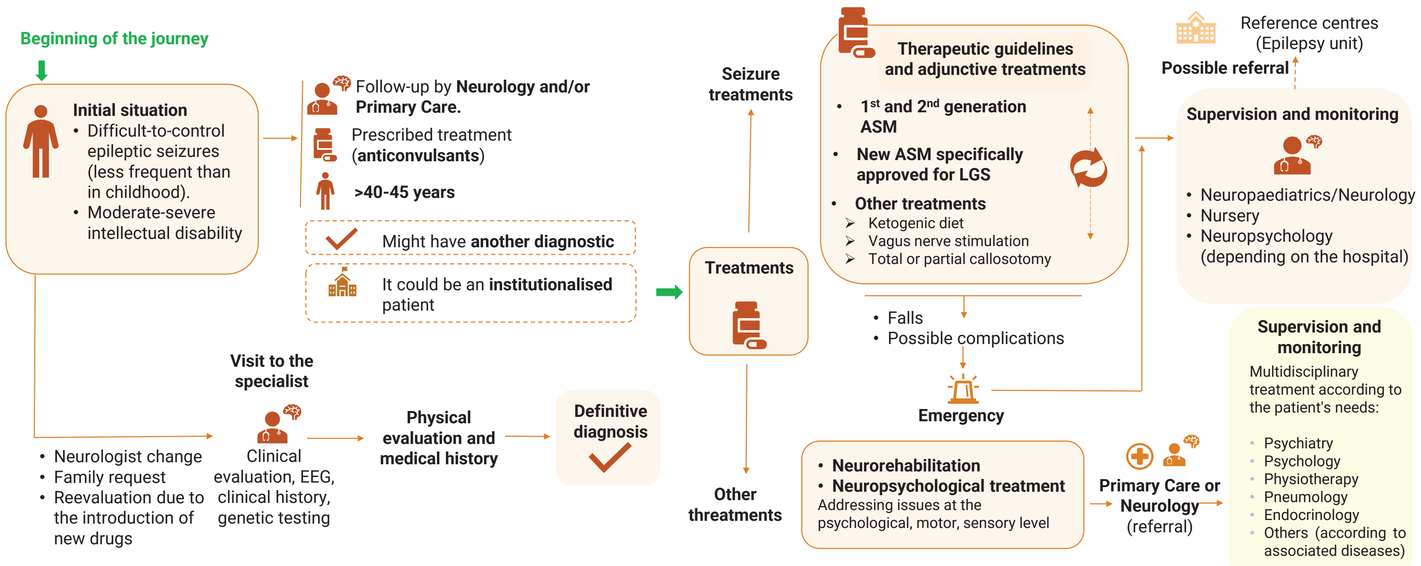
- **Non-pharmacological treatments** available in limited centres.
- **Inequitable access to early care** and long waiting lists.
- **Insufficient public post-early care services** (neurorehabilitation and neuropsychology) and high financial burden on families.
- **Patient associations crucial** in supporting families.
- **Challenging partnership** due to the variability of the disease.

Follow-up and supervision (<18 years) | **Initial treatment and control**

FAMILY JOURNEY OF ADULT PATIENTS WITH LENNOX-GASTAUT SYNDROME

1

- **Lack of training and health conciousness** in adult pathology to improve diagnosis and management of uncontrolled cases.
- **Re-evaluation of patients** with uncontrolled seizures or significant deterioration to adjust disease management.
- **Adequate EEG evaluation** given the variability of patterns in adults
- **Complete clinical evaluation and detailed medical history examination** to ensure correct diagnosis.



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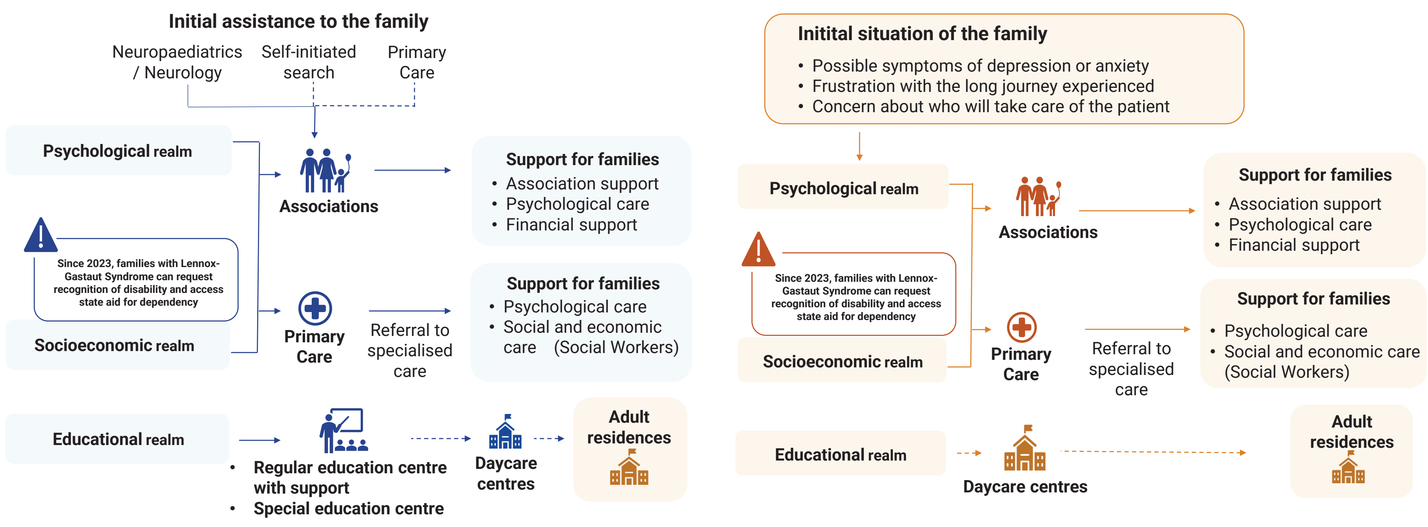
- **Individualised treatment** is essential due to the severity and associated neurological disability.
- **Access to therapeutic innovations** in adults despite limitations in hospital dispensation.
- Lack of access to **neurorehabilitation, neuropsychology and physiotherapy** in the public system and high economic burden for families.
- **Multidisciplinary collaboration** in the absence of specific clinical guidelines and reinforcement of the role of specialised nurses.

Initial situation and diagnostic process | **Initial treatment, follow-up and supervision**

PSYCHOSOCIAL NEEDS

- Difficulty in accessing **psychosocial care** in the public health system due to lack of resources and long waiting lists.
- Lack of knowledge and bureaucratic difficulties in obtaining **public financial aid.**
- Lack of access to **support and specialised resources** in the regular educational environment.
- Limitation in the administration of **treatment in educational centres** and **lack of awareness** of epilepsy.
- Need to facilitate access to **support materials** such as helmets and wheelchairs through the public health system.



- Limited access to **psychosocial care and specialised centres and services** in the public health system due to lack of resources and long waiting lists.
- Lack of knowledge and bureaucratic difficulties in accessing **public financial aid.**
- Problems with **referral protocols** and long waits to access **residences and day care centres.**
- Lack of **resources for families and caregivers**, especially for full-time care.
- Need to facilitate access to **support materials** such as helmets and wheelchairs through the public health system.

CONCLUSIONS

- LGS has **varied symptomatology**, complicating diagnosis. **Early diagnosis** is essential for i**ndividualised care and personalised treatments** with pharmacological and non-pharmacological options.
- It affects **cognitive, motor and adaptive development**, with an emotional and economic impact on families and caregivers**. Psychological resources and neurorehabilitation programs** are necessary.
- A **comprehensive approach** with specialised medical care and **psychosocial support** is vital. It is crucial to promote **research** and raise awareness of early diagnosis and **access to appropriate treatments**.

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