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Differing Perspectives of Caregivers and Physicians in France on Key Issues in the Management of Patients With Lennox-Gastaut Syndrome: Results From the REFLET Survey

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Introduction

- Lennox-Gastaut syndrome (LGS) is a rare and severe developmental and epileptic encephalopathy characterised by drug-resistant epilepsy with multiple seizure types, distinctive electroencephalographic patterns, and cognitive and behavioural impairments. It has a major impact on the lives of affected individuals, families, and caregivers[1,2]
- The REFLET survey was designed to gather and compare perspectives of parents/carers and physicians of individuals with LGS on the aspects of care considered important by each group. The specific responses of parents/caregivers have already been communicated[3]

Objective

- The purpose of this analysis was to outline the key aspects of care identified by each group and to emphasise areas of agreement or disagreement

Methods

- Two cross-sectional surveys, completed between 29 February and 12 May 2024, were sent to parents/caregivers and physicians caring for individuals with LGS
- Parents/caregivers were recruited opportunistically through physicians and a patient association. Physicians were recruited via the Scientific Committee and a specialised agency
- The survey complied with the MR-004 methodology (CNIL declaration nº 2232699) and all participants gave informed consent
- Data collected were: demographic and clinical characteristics of patients, their region of residence, the healthcare professionals involved in their follow-up, and the demographics and characteristics of the primary caregiver, eg the type of centres in which they practice, and experience in the management of epilepsy and LGS
- The caregiver's survey explored the primary challenges faced by patients, the aspects of LGS and its management that they felt were adequately addressed by the treating physicians, and the areas they wished physicians would address more effectively
- The physician's survey focused on the different aspects physicians believed they adequately address during their consultation; which of those aspects they felt fall within their direct remit and which they were most concerned by

Results

Demographic description of the survey population

- A total of 53 parents/caregivers responded (42 parents, 11 caregivers), caring for 38 individuals with LGS aged ≤18 years and 15 patients aged >18 years (**Figure 1**)[3]
- Among the 36 physicians who responded, there was a diverse range of specialties, including paediatricians (n=19, 53%), adult neurologists (n=12, 33%), and specialists caring for children and adults (n=5, 14%) (**Figure 2A**)
- These physicians were generally experienced in the management of epilepsy, with more than 11 years of experience among 72% of physicians surveyed (**Figure 2B**)
  - Among these, 25% saw >20 patients with LGS annually (**Figure 2C**)

Comparing physician and parent/caregiver points of view

- Both groups identified the same aspects of importance in the management of patients with LGS; namely, seizure outcomes (duration, frequency, and type), management of adverse events (AEs) related to antiseizure medications, nonseizure outcomes (sleep, behaviour), and quality of life (QoL; autonomy, QoL of parents/caregivers) (**Figure 3** and **Figure 4**)
  - Among physicians, ≥78% believed they managed all these aspects adequately, even though they considered some of them to be outside their remit (**Figure 3**)
- Parents/caregivers acknowledged that the impact of seizures (seizure frequency and duration: 92%) and AEs (83%) were well addressed by physicians (**Figure 5A**)
- Among parents/caregivers, 38% and 62% felt that behavioural issues and parent/caregiver QoL, respectively, were not adequately accounted for by physicians to the extent they desired (**Figure 5B**)

Results (cont.)

Figure 1. Demographic characteristics of patients cared for by the parents/caregivers completing the survey

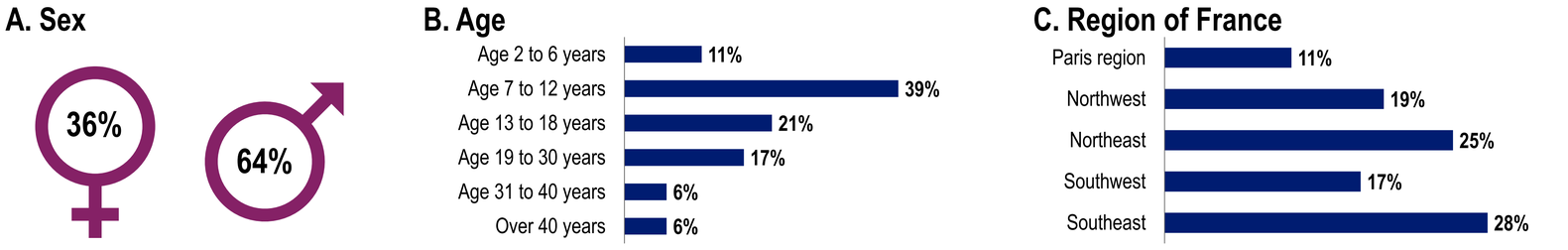


Figure 2. Physician specialty and experience

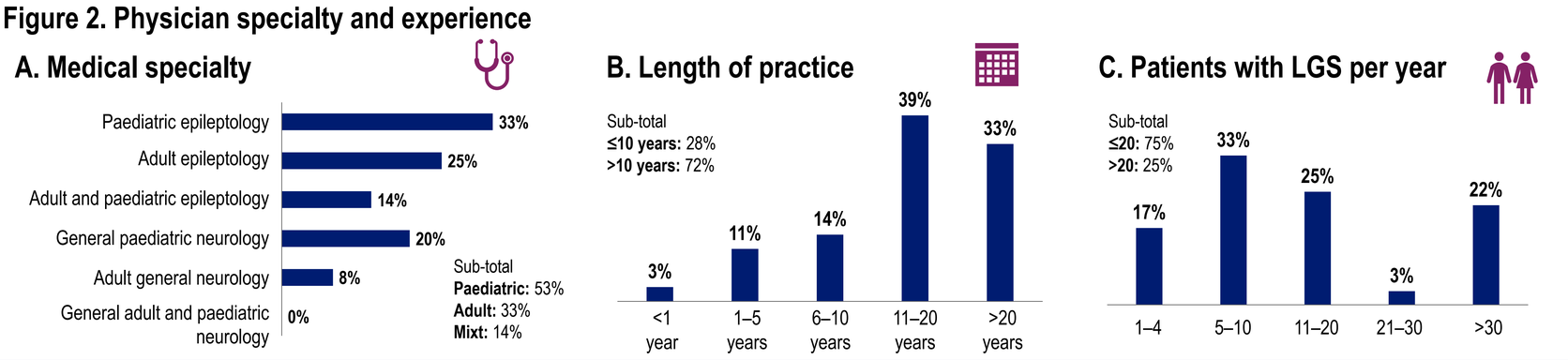


Figure 3. Physician perspectives on their areas of responsibility

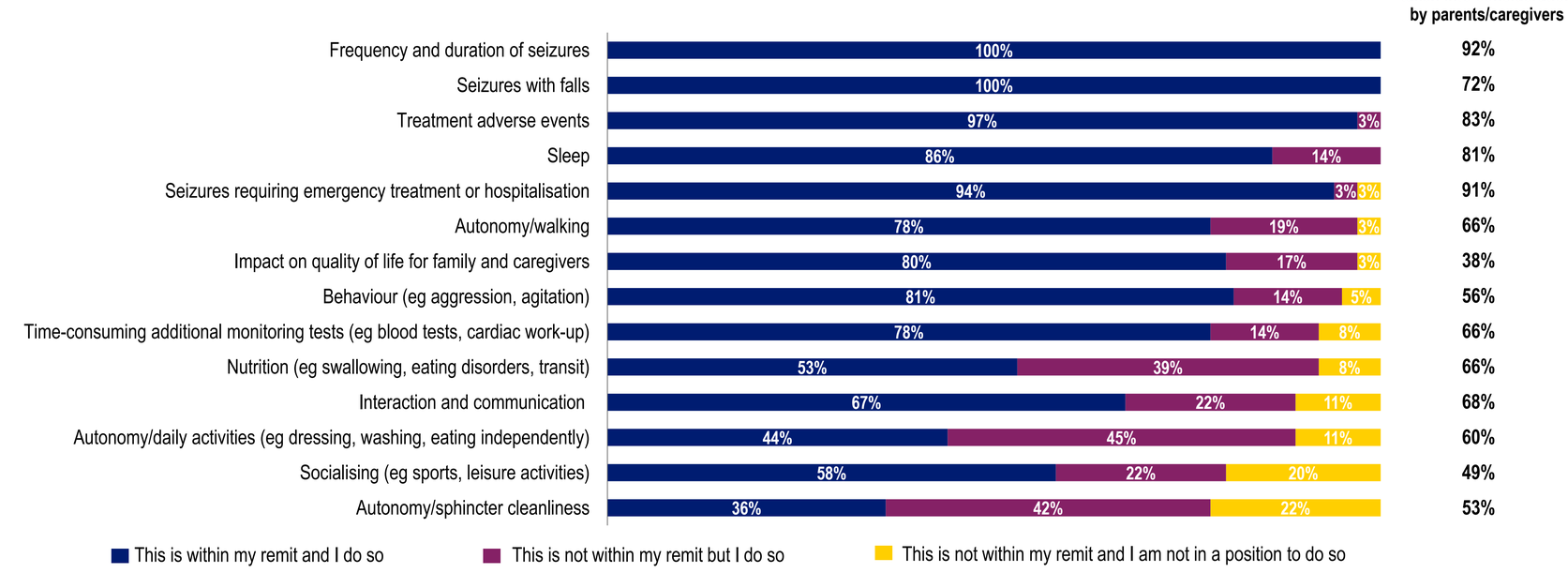


Figure 4. Important aspects of disease management that parents/caregivers would like physicians to account for during their next consultation

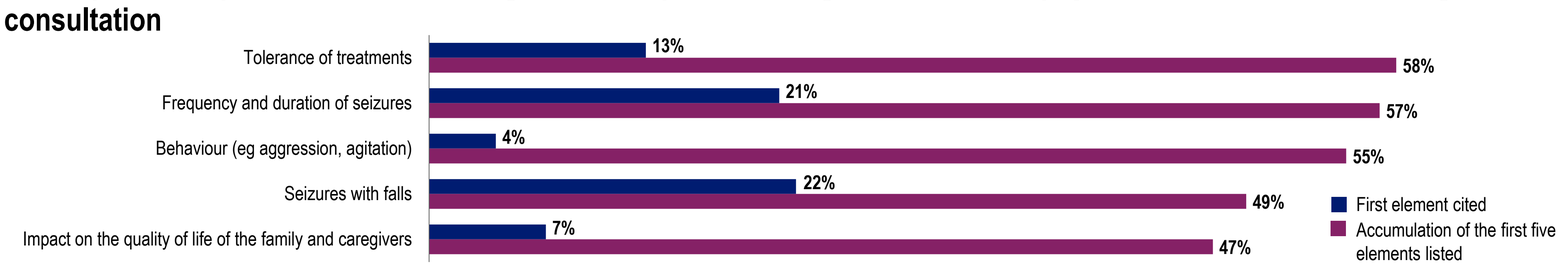
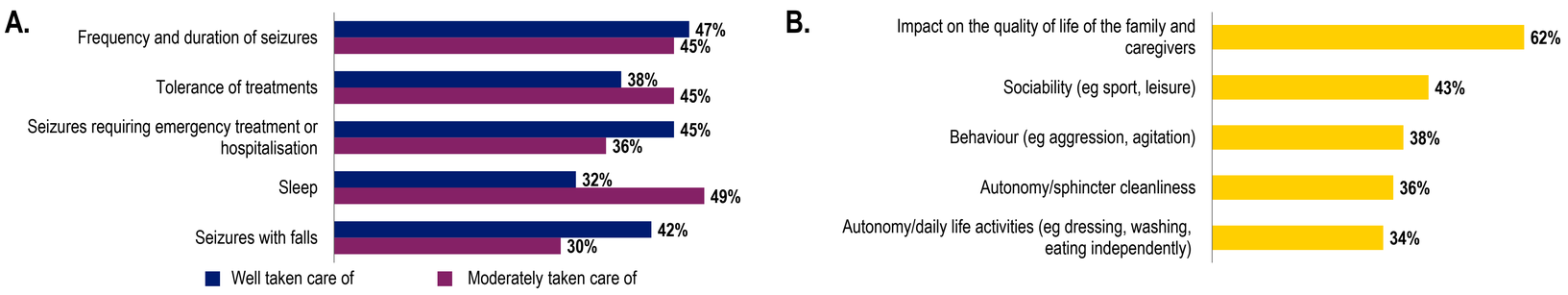


Figure 5. Aspects perceived by the parents/caregivers as being A) well or moderately accounted for by physicians, or B) not sufficiently accounted for by physicians in the current management of the disease



Conclusions

- These findings provide insights into the similarities and differences between the perceptions of parents/caregivers and physicians regarding the management of key aspects of LGS. However, given the small sample size, the results presented here may not be generalisable and should be viewed as exploratory
- While parents/caregivers felt that physicians adequately addressed seizure management, they also perceived that nonseizure aspects of the disease, such as impact of behaviour and QoL of the patients and caregivers, received less attention from physicians
- This contrasted with physicians' perspectives, as the majority considered they address aspects of care evaluated in this survey, whether these fell within their area of responsibility or not
- These findings suggested that parents/caregivers perceived opportunities for physicians to adopt a broader multidisciplinary approach with greater focus on nonseizure outcomes and QoL, as well as seizure outcomes and AEs

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References: 1. Strzelczyk A, et al. *Orphanet J of Rare Dis.* 2023;18:42. **2.** Specchio N, et al. *Epilepsia.* 2022;63:1398–1442. **3.** Kuchenbuch M, et al. 26èmes Journées Françaises de l'Epilepsie 2024, Poster P-51.

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This study has been declared to the CNIL as compliant with MR04 (declaration number 2232699). Informed consent was obtained from participants prior to taking part in the survey.

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