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THE ECONOMIC BURDEN OF AMYOTROPHIC LATERAL SCLEROSIS IN FRANCE: AN OBSERVATIONAL STUDY OF OUT-OF-POCKET EXPENSES AND THE IMPACT ON CAREGIVERS

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CONTEXT

- Amyotrophic lateral sclerosis (ALS) is a **neurodegenerative disease** with a prevalence of 4 to 6 per 100,000 people. Due to the progressive degeneration of the two neurons of the voluntary motor pathway, it causes paralysis of the limbs and the labial, glossal, pharyngeal, and laryngeal muscles in varying degrees, but with **constant worsening**. The natural progression of the disease leads to death [1].
- Care for ALS patients is multidisciplinary and provided by **rare disease centers specialised in ALS**. These centers coordinate multidisciplinary consultations, alternating with care and follow-up at the patient's place of residence, in direct connection with local healthcare professionals, whether in private practice or in hospital settings.
- The economic burden is not limited to direct medical costs, but also includes expenses related to **caregivers** and the adaptations implemented to facilitate patients' daily lives, which are often insufficiently considered in public health policies.

OBJECTIVES

- To characterise and assess the **out-of-pocket expenses** associated with ALS for families affected by the disease
- To estimate the **cost of caregiving** and its **impact** on carers' daily lives.
- To evaluate the financial impact in terms of **household income loss** and the resulting consequences on **foregone care**.

METHODS

A descriptive multicentre survey was conducted among patients with ALS, with or without the presence of their caregiver, between September 2023 and February 2024. Data were collected through **telephone interviews** (average duration: 40 minutes).

The recruitment of voluntary patients was carried out across the **22 ALS care centres belonging to the FilSLAN network** (information letter provided by a healthcare professional from the centre).

To ensure the **representativeness of the sample**, each centre was asked to distribute the survey to five patients with different characteristics: one ambulant patient, one patient using a wheelchair, one ventilated patient, and two patients under the age of 65.

Patients were asked about:

- Their **socio-economic and medical caracteristics**
- **Expenditures** (healthcare, medical equipment, home adaptations, professional caregivers) remaining at their own expense after reimbursement by the National Health Insurance, complementary insurance, private insurance and/or social benefits, defining the **out-of-pocket expenses (OOP).**
- The **financial impact** of the disease (employment activity, loss of income)
- The **use of caregivers** (professionnal or informal)
- **Forgone healthcare**

RESULTS

- **Fifty (50) patients** from 15 centres participated in the survey, with a **mean age of 61.5 years** (median 65 years). The sample consisted of **64% men**. More than half (54%) of the telephone interviews were conducted with a family caregiver, with or without the patient present.
- The **mean time since diagnosis was 2 years and 5 months**, with an average **diagnostic delay of 1 year and 4 months**.
- The main OOP cost category was home adaptations: 50% of patients reported such expenses, with an average annual out-of-pocket cost of €3,074. The second most significant category was vehicle adaptations (€2,774), followed by the use of professional caregivers (€1,279).
- A **longer time since diagnosis** (p = 0.002) and the **use of professional caregivers** (p = 0.0005) were both significantly associated with higher out-of-pocket costs.

→ In 96% of cases, the caregiver was the patient's spouse, but children (23%) and parents (14%) were also involved. Sixty-four percent (64%) of spousal caregivers had to modify their professional activity because of the disease.
→ The annual cost would have increased by €59,840 if the same care had been delivered by professional caregivers.
→ **20% of respondents reported having forgone certain healthcare services**, equipment, or treatments related to the disease for financial reasons, and 10% reported having done so because no professional accepted to provide the required care.
→ **Among caregivers (N = 27), 22% reported having forgone their own healthcare due to their caregiving responsibilities**. The main reasons were lack of time and the impossibility of leaving the patient alone at home. Furthermore, 82% stated that they had given up leisure activities because of their caregiving role.

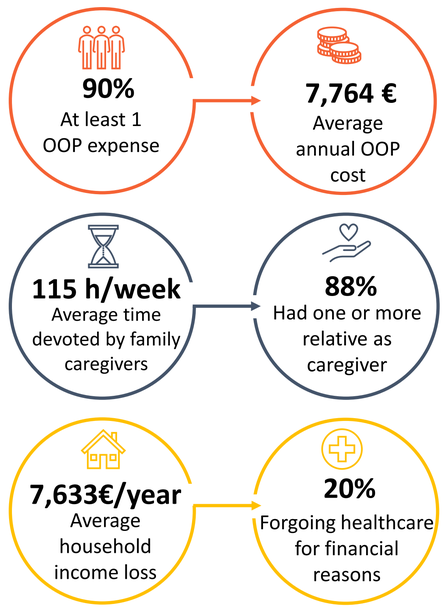

Tableau 1 : Socio-demographic and clinical characteristics of patients (N=50)

Place of residence	
Living with a partner/spouse	36 (72%)
Living alone	4 (8%)
Beneficiary from any **financial support** (AAH or APA) for handicap*	18 (36%)
Employment status at date of interview of patients (N=24 at the time of the interview)	
Working	3 (13%)
Invalidity	13 (54%)
Sick leave	8 (33%)
Region of disease onset	
Limb onset	36 (72%)
Other	14 (28%)
Nutritional supplementation	11 (22%)
Noninvasive ventilation	27 (54%)

* Allocation aux Adultes Handicapés (AAH), Allocation Personnalisée d'Autonomie (APA)

Figure 1 : Involvement of informal and professional caregivers

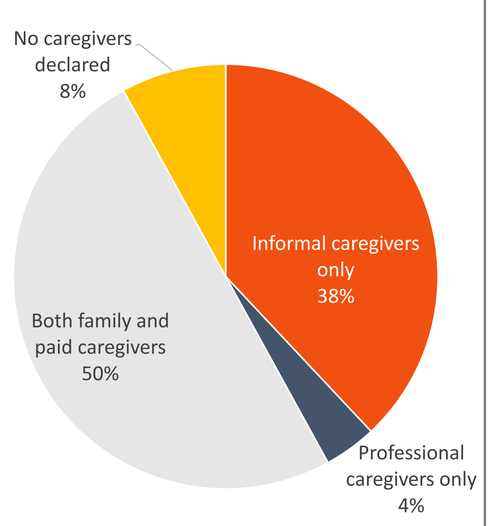

Tableau 2 : Out-of-pocket expenses of ALS patients (N=50)

	N (%) patients with at least one item of cost declared in each category	Mean annual cost (standard deviation)
Home modification	25 (50%)	3 074 € (8,295)
Technical aids		
Mobility[1]	24 (48%)	330 € (689)
Comfort[2]	19 (38%)	95 € (356)
Personal vehicle[3]	20 (40%)	2 774 € (5,239)
Professional caregivers	27 (54%)	1 279 € (3,351)
Communication devices	6 (12%)	56 € (192)
Partially or non-reimbursed ALS-related current expenditures[4]	15 (30%)	112 € (268)
Partially or non-reimbursed ALS-related visits to healthcare professionals	33 (66%)	44 € (66)
Total	**45 (90%)**	**7 764 € (9,940)**

[1] Manual and electric wheelchair, walking aids, transfer disc etc
[2] Devices used at home, mattress, etc
[3] Change, modification of home access, etc
[4] Drugs, hygiene, etc

DISCUSSION

This **first French study** on the economic burden of ALS for patients and their families shows that numerous expenses remain at the families' expense, despite a comprehensive and relatively generous social protection system. A complementary study, based on the national reimbursement database (French National Health Data System, or SNDS), was conducted in parallel and allowed for the estimation of the medical care costs associated with the disease.

These results are consistent with those of a Canadian study published in 2014 [2], which reported an annual out-of-pocket cost of a similar magnitude, identifying major expense categories such as home adaptations, mobility-related costs, and informal care – findings that are in line with our results.

Several limitations can be highlighted for this type of survey: a selection bias towards more educated or less severely affected patients (given the length and complexity of the questionnaire), recall bias, and a possible underestimation of additional financial support such as the AAH and the APA.

CONCLUSION

Despite the full coverage of ALS by the French healthcare system and the associated financial support, the disease represents not only a human burden but also a significant economic burden for patients and their families.

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