

HEREDITARY ANGIOEDEMA: IMPACT OF THE BURDEN OF DISEASE IN SPAIN

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Background and importance

Hereditary angioedema (HAE) is a rare disease with a negative impact on patients' quality of life. Understanding the patient pathway would contribute to reducing the burden of the disease.

In Spain **no similar published studies** have been identified. This kind of studies makes a great contribution to increase the **knowledge and visibility** of the disease.

Aim and objectives



Understand the patient with HAE pathway by identifying and assessing the elements that comprise the **burden of the disease**.

Method



Descriptive study based on a **bibliographic review** and the expertise of a **multidisciplinary panel** of 18 professionals with knowledge in HAE (Allergology, Immunology, Medical Emergency, Hospital Pharmacy, Nursing) and Patient Associations represented by patients and caregivers. Following an individualized questionnaire, a personal interview was carried out.



The **patient pathway** was elaborated from the analysis of the management of HAE patients. Subsequently, the elements that comprise the **burden of the disease** were identified. Those elements were associated with **the costs** evaluated from the patient's and the healthcare system's perspectives. A **sensitive analysis** was carried out in order to analyze the variability in the cost results due to variations in the estimations made.

Results



It is estimated that a patient takes on average between **5 and 13 years to be diagnosed**. The lack of knowledge about the disease causes delays in the diagnosis, misdiagnosis and referral to other specialists, which entails costs associated with unnecessary medical interventions and lack of homogeneity in the access to an optimal treatment. The estimated **average cost of an undiagnosed patient is € 3.370/year**, including primary care and hospital emergency visits, medical appointments and lost of productivity.



A patient with HAE suffers an average of **5.8 attacks per year**, although there is great variability among patients. New pharmacological treatments for long-term prophylaxis (LTP) has change the management of the disease due to the prevention of the attacks suffered by patients. It has been estimated that **35% of patients take LTP**.



The estimated **average cost of a patient with HAE is €47,825/year**, including pharmacological costs, admissions, medical appointments and procedures and indirect costs (transport and loss of productivity). On average, pharmacological treatment of LTP represents 79% of the total costs; however, it decreases the number of attacks by a mean of 76%.



In terms of **lost productivity**, it is estimated that a patient with HAE losses **2.5 days of work per year**, although this varies depending on the treatment and situation (numbers of attacks, LTP administration, medication available at home, self-administration...). The estimated **average cost of the loss of productivity is €317 per patient per year**. The loss of productivity associated with the loss of educational and professional opportunities and the emotional impact of HAE are important components of the burden of the disease.



The possibility of having the **medication available at home for self-administration** is an important benefit for patients and the healthcare system. It is estimated that promoting the self-administration would decrease €82/year the average cost of a HAE patients.

Conclusions HAE has a high impact on the healthcare system and on the patients' quality of life. Identifying the key elements at each stage of the patient pathway is essential to improve their quality of life while ensuring the sustainability of the healthcare system.

- ❖ **Early diagnosis** avoids unnecessary interventions, improves the management of the patients and decreases the burden of the disease.
- ❖ **LTP** contributes to decrease the number of attacks suffered by a patient, reducing the burden of the disease.
- ❖ The prescription of **LTP** in patients with a high number of attacks and the implementation of **telepharmacy/telemedicine** programs improves the quality of life, reduces visits to health care facilities and decreases sick leaves.

The evidence generated from this study has great value for the management of the disease in Spain.

