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INITIATIVES TO IMPROVE THE MANAGEMENT OF PATIENTS WITH HEREDITARY ANGIOEDEMA BY HOSPITAL PHARMACY

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Background and importance

<u>Hereditary angioedema (HAE)</u> is a rare, hereditary disease with a negative impact on the quality of life of patients. The increase in the knowledge of HAE and the appearance of new treatments in recent years have contributed to modifying the course of this disease. In this scenario, hospital pharmacists have acquired a more significant role.

Aim and objectives



Identify and promote initiatives to improve the management of patients with HAE by Hospital Pharmacy and evaluate the

importance of care coordination for a multidisciplinary approach to patients with HAE.

Method

Initiatives to improve the care of patients with HAE were **identified**, evaluated and prioritized by a multidisciplinary panel of experts (a group of hospital pharmacists, one allergist and one nurse/HAE patient).

- The initiatives were grouped into seven key areas of activity: evaluation and selection of medicines; dispensation and telepharmacy; pharmacokinetic monitoring and telemedicine; care coordination; patient health education; research, education and training.



Subsequently, the initiatives were prioritized based on their impact on improving patient care and on the feasibility of their implementation (scale of 1-5).

As it is a rare disease, a prior training session about the pathology and its clinical approach was carried out to ensure a common konwledge base. This session was carried out by an allergist member of GEAB.

Results

Twenty-eight initiatives were identified and grouped in seven work areas. After the prioritization of the initiatives, the experts identified five

priority initiatives for Hospital Pharmacy: Evaluation and selection of medicines:

1. Incorporate the patient's perspective and opinion in HAE treatment decisionmaking processes using PROs (Patient Reported Outcomes) and PREMs (Patient

Reported Experience Measures).

2. Participate in **multidisciplinary meetings** for the evaluation and selection of drugs for HAE.

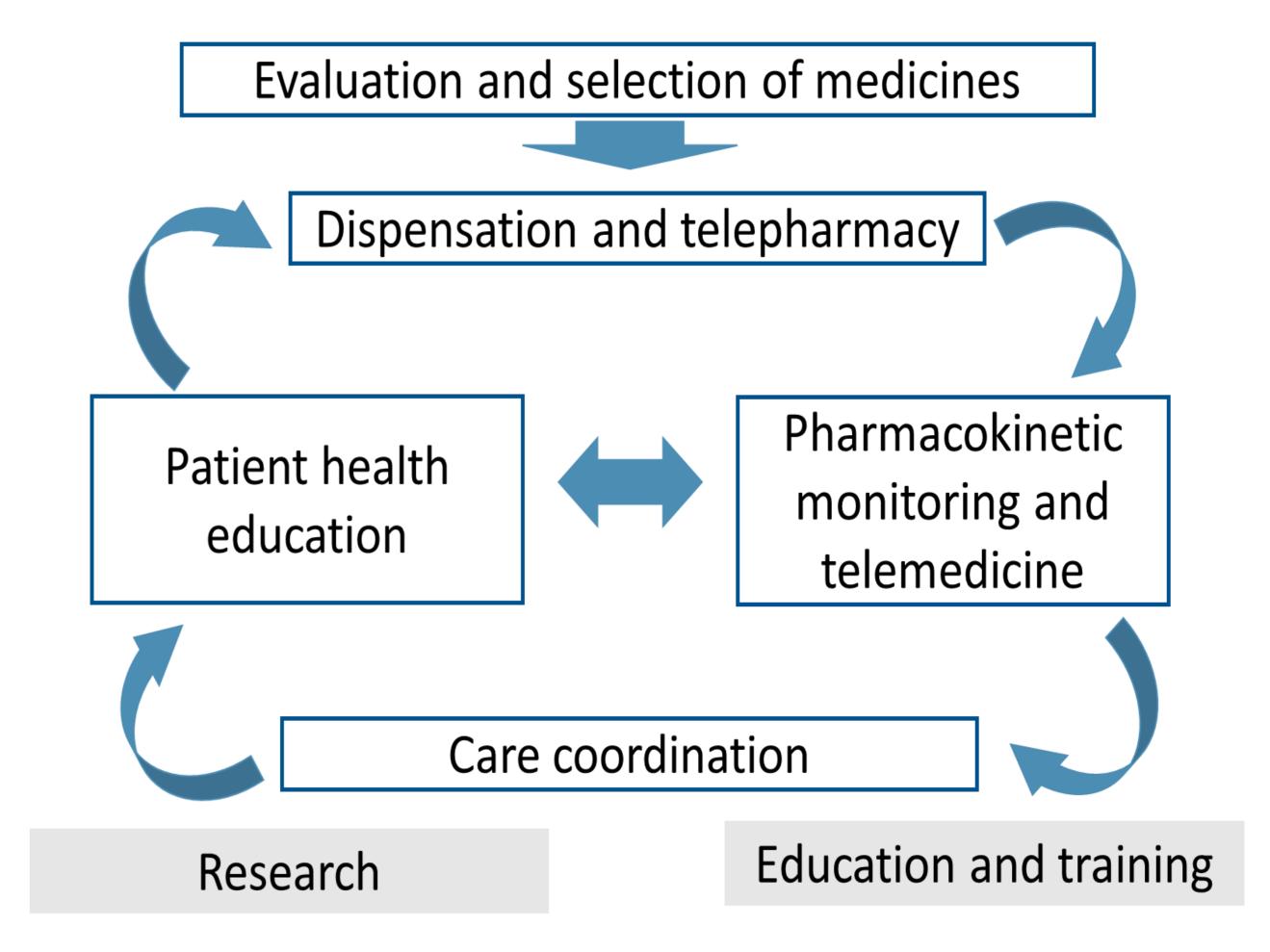
Care coordination:

3. Develop a **guideline of recommendations** for the coordination of the healthcare professionals responsible for the management of patients with HAE.

Pharmacokinetic monitoring and telemedicine

4. Develop **consensus protocols** in order to carry periodic **monitorization and evaluation** of patients with HAE and to evaluate the results obtained from the

Figure: Key areas of activity in the management of HAE patients.



In colaboration with CSL Behring

administration of long-term prophylaxis (LTP).

Patient health education:

5. Promote the use of telepharmacy tools for patient education and information as

a complement to face-to-face care.

Conclusions: Five priority initiatives are proposed for the management of patients with HAE, highlighting the importance of **care coordination** to improve the multidisciplinary approach of these patients. From this study, specific actions have been identified that could improve the approach to patients with HEA by hospital pharmacists. Thus, these professionals will be able to promote potentially implementable initiatives that could have a real impact on patients' lives. This kind of studies contribute to increase the visibility of rare diseases, especially HEA.

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