

Initiatives to improve the management of patients with hereditary angioedema by hospital pharmacy

Supplementary material

Table 1S. HAE experts participating in the study.

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Table 2S. Initiatives identified by the panel of experts.

Category	Initiative	Impact	Resources feasibility	Decision-making feasibility	Mean feasibility
1. EVALUATION AND SELECTION OF MEDICATIONS	1.1 Establish and implement assessment procedures for HAE treatments	4,25	4,50	3,67	4,08
	1.2 Collaboratively establish the most effective, safe, and suitable therapeutic strategies based on each patient's characteristics, comparing various available HAE therapeutic alternatives in the market	4,00	4,50	3,92	4,21
	1.3 Participating in multidisciplinary meetings to evaluate and select medicines for HAE	4,83	3,75	3,75	3,75
	1.4 Incorporating patient's perspective in the evaluation and decision-making processes related to HAE treatments, using patient-reported outcomes (PROs) and patient-reported experience measures (PREMs)	4,92	2,92	3,63	3,27
2. DISPENSING IN HOSPITAL PHARMACY AND TELEPHARMACY	2.1 Identify and develop strategies aimed at humanizing the dispensing of HAE treatment in the hospital pharmacy service and home medication delivery (e.g., adapting schedules and dispensing methods to patients' needs, establishing more accessible communication channels), ensuring that the patient has sufficient stock to address a crisis	4,75	3,58	3,67	3,63
	2.2 Promote informed home medication delivery programs (telepharmacy), selecting patients for whom this service is suitable	4,33	4,17	3,17	3,67
	2.3 Establish systems to ensure that the patient has sufficient treatment stock at home for a potential outbreak, manage available resources, acquire new drugs, or plan exceptional situations (surgeries, accidents, etc.), ensuring that the patient always has medication at home	4,58	4,25	4,42	4,33
	2.4 Develop appointment reminder systems for patients to pick up medication for long-term prophylaxis of HAE (e.g., through mobile devices)	4,08	2,75	4,25	3,50
	2.5 Provide administration instructions for treatments in non-specialized healthcare centers	4,08	3,17	3,67	3,42

3. PHARMACOTHERAPEUTIC MONITORING AND TELEPHARMACY	3.1	Developing protocols for periodic health monitoring and evaluation of patients with HAE, including assessments of their health status and outcomes following administration of long-term prophylaxis	5,00	3,25	4,42	3,83
	3.2	Participate in the multidisciplinary team in reviewing and developing protocols for the pharmacotherapeutic monitoring of HAE patients	4,42	3,33	3,67	3,50
	3.3	Define and establish channels that improve communication between the hospital pharmacist and patients, facilitating proper patient monitoring and pharmacotherapeutic follow-up (e.g., use of mobile applications, in-person and/or telemedical consultations)	4,67	3,33	3,17	3,25
	3.4	Adapt teleconsultation technologies in each center to enhance non-presential communication with the patient	4,67	4,17	4,25	4,21
4. COORDINATION WITH THE CARE TEAM	4.1	Preparation of guidelines with recommendations for coordinating the multidisciplinary team responsible for managing patients with HAE, defining and establishing channels of communication to ensure harmonization in decision-making process and prevent duplication of information for the patient	5,00	4,50	4,50	4,50
	4.2	Have a designated pharmacist knowledgeable about the pathology and promote visibility initiatives for the pharmacist's role within the hospital as part of the multidisciplinary team responsible for managing HAE patients	5,00	3,75	4,50	4,13
	4.3	Define integrated care processes for HAE between emergency teams and primary care	5,00	3,25	4,00	3,63
	4.4	Establish and share a working protocol on short-term prophylaxis, defining situations in which it should be carried out and the medication to be administered	5,00	5,00	5,00	5,00
5. PATIENT INFORMATION AND EDUCATION	5.1	Have a reference pharmacist for the pathology and promote initiatives that reinforce the visibility of the hospital pharmacist to patients	5,00	5,00	5,00	5,00
	5.2	Promote initiatives in collaboration with Patient Associations to make known the role of the hospital pharmacist in managing HAE patients	5,00	4,50	4,50	4,50
	5.3	Promoting the use of telepharmacy tools for patient health education and training as a complement to in-person appointments	5,00	4,50	4,50	4,50

	5.4	Develop a guide of recommendations for HAE treatments on the storage and transportation conditions of medication	4,50	4,50	4,50	4,50
	5.5	Conduct informative/training sessions with patients and other healthcare professionals on the management of HAE and medication	5,00	5,00	5,00	5,00
	5.6	Provide information/training (oral/written) to patients on safety issues, enabling them to acquire skills to detect adverse effects, tolerance, and safety, as well as training them to ensure adherence	5,00	5,00	5,00	5,00
6. RESEARCH	6.1	Promote research in real clinical practice, leveraging existing initiatives and available resources (e.g., patient and hospital medication treatment registries in Catalonia)	5,00	2,75	3,25	3,00
7. TRAINING AND EDUCATION	7.1	Promote training activities/stays for professionals in centers with greater expertise in managing HAE patients	3,75	3,50	3,50	3,50
	7.2	Promote consulting models by centers with more experience in managing HAE patients, to support less-experienced centers in patient and medication management as well as economic aspects	3,75	3,50	3,50	3,50
	7.3	From the Spanish Society of Hospital Pharmacy (SEFH), promote training programs among hospital pharmacists in the management of HAE patients	5,00	4,50	4,50	4,50
	7.4	Promote training programs among healthcare professionals in patient training and communication techniques.	5,00	4,50	4,50	4,50

HAE: Hereditary Angioedema; SEFH: Spanish Society of Hospital Pharmacy