Study Identifies Key Barriers and Promoters in Translating Hereditary Angioedema Research to Clinical Care

New study identifies key barriers to translating HAE research to care, citing insurance hurdles, testing access, and knowledge gaps as major obstacles.

WEST HARTFORD, CT, UNITED STATES, October 14, 2025 /EINPresswire.com/ -- A study of allergy/immunology clinicians has identified factors that may enhance or impede the translation of research findings to clinical care for patients with hereditary angioedema (HAE). The study was conducted by CMEology, a leader in continuing medical education and innovator in outcomes research. The peer-reviewed article is available in PLOS One: Barriers and promoters to adapting research findings to clinical care in hereditary angioedema in the United States: A qualitative study.

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> *William R. Lumry, MD*

Patients with HAE experience recurrent attacks of swelling that affect the upper airway, internal organs, or extremities, causing pain and reducing quality of life [1,2]. Upper airway HAE attacks can be life-threatening. HAE is a rare disease that is challenging for clinicians to diagnose and manage properly. To better understand these challenges, CMEology initiated a qualitative study employing hybrid deductive and inductive analysis of semi-structured interviews with allergy/immunology clinicians practicing in the United States.

"Allergy/immunology clinicians in this study identified a range of important factors that impact HAE research translation into real-world patient care in their practices" according to William R. Lumry, MD, Clinical Professor of Internal Medicine, Allergy and Immunology Division, at the University of Texas Southwestern Medical School, Dallas, TX, and Medical Director of the AARA Research Center in Dallas.

"Qualitative research in HAE has previously focused primarily on the experiences of patients with HAE, rather than allergy/immunology clinicians," said Dr. Lumry. "However, efforts to improve care delivery and quality of life for patients with HAE must also take clinician perspectives into account."

The study found that the most significant barrier to translating research to clinical care is navigating the insurance prior authorization process for HAE medications, including those used for long-term attack prevention. Clinicians reported that insurer requirements often delay or restrict patient access to therapies despite established clinical guidelines, placing a heavy administrative burden on healthcare providers. Difficulties in obtaining reliable laboratory testing for accurate diagnosis also impede timely and effective care.

Clinicians pointed to limited time and resources to stay updated on developments specific to HAE and highlighted knowledge gaps among primary care providers that contribute to misdiagnosis or delayed diagnosis. Hesitancy in adopting newer therapies and the increasing complexity of treatment options also hinder research translation. Patient-related barriers include limited understanding of HAE and challenges with treatment adherence and follow-up.

Despite these challenges, several factors were identified as promoters of research translation. These include the availability of medication samples allowing a trial of new therapies pending insurance approval, drug administration routes tailored to patient preference, and use of shared decision-making. Improved clinician knowledge, facilitated through online peer forums and continuing medical education, was also seen as important.

The findings of this study emphasize the need to address institutional and practice barriers and enhance clinician and patient education on HAE. Overcoming these obstacles may improve clinical care and outcomes for people living with HAE.

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About HAE

HAE affects approximately 1 in 50,000 people [1]. The disorder typically develops during childhood and persists through adulthood. Episodes of swelling involving the mucous membranes or skin are recurrent and often unpredictable. Upper airway tissue swelling can be fatal. HAE attacks are emotionally taxing and negatively affect quality of life [2]. Pharmacologic management of HAE focuses on the acute treatment and long-term prevention of attacks [3]. The use of medications for long-term prevention reduces the frequency and severity of attacks and is associated with improvements in health-related quality of life [4,5]. Optimizing preventive therapies and quality of life have become a primary goal of HAE care [3]. Treatment options for HAE have expanded in recent years, making health care provider and patient education increasingly important.

About CMEology

Founded in 2011, CMEology develops high-impact continuing education activities that have reached millions of healthcare providers and patients. CMEology collaborates with leading institutions to design patient-centered programs that emphasize evidence-based care, support the National Quality Strategy, and deliver measurable improvements in clinical practice. CMEology's activities inspire and empower learners, using rigorous assessment and outcomes analysis to demonstrate real-world impact. For more information, please visit https://www.cmeology.org.

References

[1] Busse PJ, Christiansen SC. Hereditary Angioedema. N Engl J Med. 2020;382(12):1136–48.
[2] Bork K, Anderson JT, Caballero T, et al. Assessment and management of disease burden and quality of life in patients with hereditary angioedema: a consensus report. Allergy Asthma Clin Immunol. 2021;17(1):40.
[3] Busse PJ, Christiansen SC, Riedl MA, et al. US HAEA Medical Advisory Board 2020 Guidelines for the Management of Hereditary Angioedema. J Allergy Clin Immunol Pract. 2021;9(1):132–150.e3.
[4] Lumry W, Craig T, Anderson J, et al. Patient outcomes associated with subcutaneous C1INH prophylaxis for hereditary angioedema: a retrospective analysis. Allergy Asthma Clin Immunol. 2023;19(1):105.
[5] Lumry WR, Maurer M, Weller K, et al. Long-term lanadelumab treatment improves health-related quality of life in patients with hereditary angioedema. Ann Allergy Asthma Immunol. 2023;131(1):101-8.e3.

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