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Short Communication

Meeting Patient Needs in Hereditary Angioedema Care

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Abstract

Hereditary angioedema (HAE) is a rare, chronic disease that causes recurrent episodes of severe swelling in the face, airways, limbs, and intestinal tract. Recent advances have provided HAE patients with more treatment options. My research and the work of others have investigated patient preferences and perspectives on available HAE prophylactic treatments. Increasing numbers of patients are taking prophylactic medication for HAE (primarily injectable) and most are satisfied with their current treatments. Nonetheless, as alternative treatments become available, their preferences may shift, with many patients expressing a desire for alternative routes of administration. Healthcare providers should have an ongoing, open dialogue with their patients regarding which HAE treatments are best for their needs.

Keywords: Angioedema, heriditary; Patient preference; Prophylaxis; Administration, oral; Decision making

INTRODUCTION

Hereditary angioedema (HAE) is a rare disease estimated to affect 1 in 50,000 people [1]. Patients with HAE suffer from recurring episodes of severe angioedema in the face, airways, limbs, and intestinal tract [2], impacting quality of life and potentially causing extreme pain and death by asphyxiation [3]. HAE patients typically are deficient in, or have a dysfunctional, C1 inhibitor protease. C1 inhibitor usually inhibits spontaneous swelling triggered by the complement system, protease factor XII, plasma kallikrein, and, ultimately, leakage of fluid from blood vessels into surrounding tissue caused by bradykinin [4]. Treatments for HAE seek to restore/replace C1 inhibitor function or interrupt the pro-inflammatory molecules that lead to swelling.

WHAT IS THE CURRENT HAE TREATMENT ENVIRONMENT?

On-demand treatments (taken at the onset of HAE attacks) include C1 inhibitor concentrates, ecallantide (a kallikrein inhibitor) or icatibant (a bradykinin receptor-antagonist) [5]. Early treatment of an attack is associated with shorter attack duration and better treatment response [6-8].

Prophylactic treatments that help prevent or lessen the severity of HAE attacks include plasma derived C1 inhibitors, lanadelumab-flyo (kallikrein inhibitor), and berotralstat (kallikrein inhibitor). Androgens are also used but are not recommended as a first-line prophylactic treatment for HAE due to possible adverse anabolic side effects [5]. Lanadelumab-flyo, approved in 2018, offers the convenience of bi-weekly subcutaneous injections, whereas C1 inhibitors require more frequent (twice weekly) subcutaneous injections or IV infusions. The December 2020 approval of berotralstat, an oral once-daily treatment, continues a theme of increasingly convenient HAE medication development to better meet patients' needs.

PATIENT PREFERENCE FOR HAE TREATMENTS

Two surveys were conducted in 2018 and 2019 to understand patient perspectives and preferences regarding HAE prophylactic treatments. Previously, I presented data from the 2019 survey with 100 HAE patients [9]. Research with a cohort of 75 HAE patients conducted in 2018 was published by Geba et al. [10]. Both surveys produced similar results and I will summarize some of the key findings here. Most patients reported taking at least one prophylactic medication for HAE attacks (64% in 2018 and 85% in 2019) [11]. An average of 65% of patients were extremely satisfied with their prophylactic medication [9]. Nonetheless, 52% of patients taking HAE prophylaxis agreed that prophylactic treatment for HAE is burdensome and 98% would prefer an oral treatment if one were available [10]. Almost all of these (96%) patients agreed that oral HAE prophylaxis would fit their lives better and most (67%) agreed that convenience would be their primary reason for trying oral HAE prophylaxis [10]. Amongst those not treating their HAE prophylactically, nearly all (96%) said they would feel encouraged to do so if a more convenient option were available [10]. Route of

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administration may be of greater concern to these patients as about two-thirds (67%) feel preventative treatment is burdensome, 63% want to avoid needles, and all (100%) indicated an oral medication for HAE would fit their life better than an injectable medication [10].

Patients are generally happy with their prophylactic HAE treatments but express interest in less burdensome routes of administration [12]. HCPs need to keep abreast of treatment alternatives for HAE including improved efficacy, mode of delivery, and ease of use. Greater convenience holds the possibility of greater adherence and, therefore, better outcomes for patients.

CONCLUSION

HCPs must see the needs of their patients with HAE as dynamic and continually evolving. As a patient's life circumstances change, so too may their treatment regimen preferences. Chronic care must evolve and adapt over a patient's lifetime and with the changing availability of treatments.

As a healthcare provider, there is often a desire to understand the profile of a patient who is best suited for a particular treatment, but in the case of HAE prophylaxis, there is a variety of treatment options that are ideal for any patient with HAE who is a candidate for prophylactic therapy. With administration route and frequency being the primary differentiators of the current generation of HAE prophylaxis, the role of informed/shared decision-making is even more crucial. By regularly engaging patients to assess where they are in their lifelong journey with HAE, providers can work with patients to help them make informed choices and choose treatments that most closely align with their patient's needs.

CONFLICT OF INTEREST

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