Fear of Attacks Reduces Quality of Life for Canadian HAE Patients

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Background: Hereditary angioedema is a rare inherited disorder characterized by recurrent episodes of severe swelling in different parts of the body often with no known trigger.

Methods: In 2019, HAE Canada conducted 2 online surveys to assess challenges faced by HAE patients and caregivers and to gain insight into experience with the newest prophylactic therapies: subcutaneous C1 esterase inhibitor, and lanadelumab a subcutaneous monoclonal antibody plasma kallikrein inhibitor.

Results: The first survey had 73 respondents: 68 (92%) individuals with HAE, and 6 (8%) caregivers. Attacks were experienced more than once a month by 29.4% (20/68) and more than once a week by 16.2% (11/68). They occurred in the GI tract in 89.6% of patients (60/67), as facial swelling in 79.1% (53/67) and in the upper airway in 71.6% (48/67). 74% (50/68) of respondents indicated they feared unpredictable, debilitating attacks which led to generalized anxiety in 63.3% (31/49) and a desire for control of swelling and treatment plans in 59.2% (29/49).

Eight participants (13%) had been treated with lanadelumab, mainly through participation in a clinical trial. Five considered it extremely effective in preventing attacks. Reported adverse events [headache (2/8) and injection site pain (7/8)] were tolerable to very tolerable.

The second survey, intended to obtain information about the C1 inhibitor, had 19 respondents, 3 of whom had received the treatment. It was “extremely effective” for all 3 respondents and significantly reduced attacks for 2 of them. Reported adverse events [headache (1/3) and injection site reaction (2/3)] were tolerable to very tolerable.

Conclusion: Unpredictable painful or life-threatening HAE attacks are feared by HAE patients and lead to generalized anxiety. The newest medications are effective in reducing attacks. Positive results by survey respondents describe the impact of new drug therapies on reducing the fear and improving quality of life of Canadian HAE patients.

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