

Real world data of Canadians living with Hereditary Angioedema (HAE): Attributes of new medications.



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Objective

- To assess challenges HAE patients and their caregivers face and to gain insight into their experience and expectation with therapies used to treat hereditary angioedema

Conclusions

- The data collected indicates that newer, more effective and more convenient treatments for are wanted by Canadian HAE patients.
- The newest approved treatment, lanadelumab, which is given by subcutaneous injection every 2 weeks fulfils some of these requirements according to a limited number of patients.
- It is important that Canadian HAE patients have access to multiple treatments to address the unpredictable nature of this disease.

Introduction

- Hereditary angioedema (HAE) is a chronic spontaneous life-threatening disease. Until recently, treatment options for HAE have been limited and required infusion. New treatment options would be beneficial to this population.

Methods

- In 2019, HAE Canada conducted an online survey of patients and caregivers to assess the challenges patients and caregivers face as a result of hereditary angioedema and to gain insight into their experience and expectation with therapies used to treat hereditary angioedema.
- Responses to 6 of the survey questions were analyzed and are reported here.

Results

- Of 73 respondents to the questions, 68 were living with HAE and 6 were providing care to a patient with HAE.

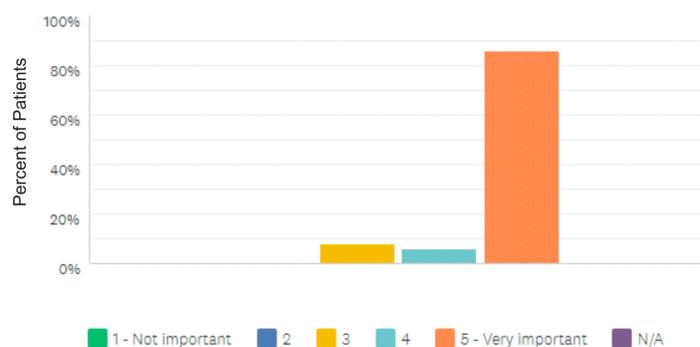


Figure 1 Most (43/50) respondents indicated that access to new treatments was extremely important to them.

	Level of importance				
	1 Not important	2	3	4	5 Extremely important
A more convenient dosing interval/less frequent dosing	9.52%	2.38%	9.52%	14.29%	64.3%
Improved management/reduction in attacks of edema (swelling)	0.00%	0.00%	4.76%	9.52%	85.71
Easier mode of delivery as a subcutaneous option (vs. IV)	2.38%	2.38%	2.38%	14.29%	76.19
Option to administer prophylactically before known triggers (eg. traveling, dental procedures).	2.44%	0.00%	2.44%	12.20%	80.49

Table 1 These attributes of a new medication were considered extremely important by a majority of surveyed patients.

Results (continued)

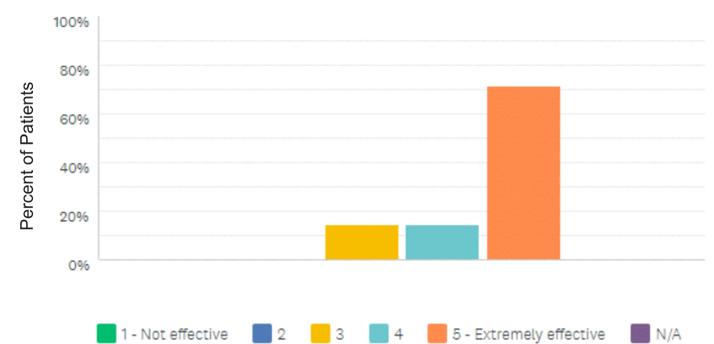


Figure 2 Eight participants (13%) had received treatment with lanadelumab through participation in a clinical trial (5), compassionate access (1) or private insurance (1). Five participants rated it extremely effective in preventing HAE attacks.

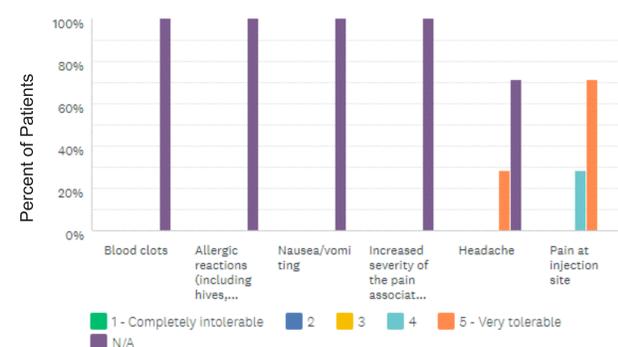


Figure 3 Reported adverse events were headache (2/8) and pain at injection site (7/8) scored as tolerable to very tolerable.

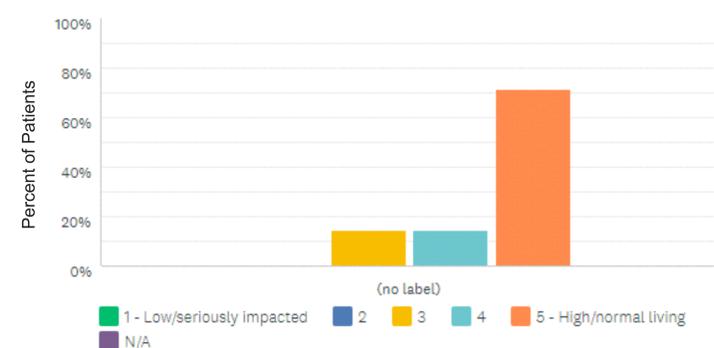


Figure 4 The majority of participants (5/8) indicated that their quality of life while taking lanadelumab was comparable to normal living.