

Hereditary angioedema in Canada: Changes in medication use and untreated attacks between the 2017 and 2020 surveys

Jacque Badiou¹, Michelle Cooper¹, Daphne Dumbrille¹, Robert Bick², Maggie Dao³, Suzanne M. Kelly³, , Gina Lacuesta⁵, Paul Keith⁶, Amin Kanani⁷, Martine Paquette¹, William H. Yang⁴

¹Hereditary Angioedema Canada; ²Health Policy Consultant, Markham, ON, ³Red Maple Trials Inc., Ottawa, ON; ⁴Ottawa Allergy Research Corporation, Ottawa, ON, ⁵Dalhousie University, Halifax, NS, ⁶MacMaster University, Hamilton, ON, ⁷University of British Columbia, Vancouver, BC

Introduction: HAE is a genetic disease leading to intermittent attacks of angioedema of the face, the extremities, genitalia and the abdomen. Access to treatment may be impacted by the mode of delivery. Many approved medications are delivered intravenously. Newer approved medications are delivered subcutaneously. The oral medications used to treat HAE (androgen and tranexamic acid) are older, not approved for HAE (androgen), have unwanted side effects and are less effective. Newer, effective oral medications are desired by patients with HAE.

Methods: Using data from the HAE Canada patient surveys performed in 2017 and 2020, we analyzed and compared responses to questions on the type of medications used to treat HAE and number of attacks not treated because of access to medication.

Results: IV medication use was similar in 2017 (on-demand: 58.8%, prophylaxis 41.3%) and 2020 (on-demand: 41.3%, short-term (44.0%), long-term (32.5%) prophylaxis). Similarly, there was little change in oral medication use. In 2017: 3.8% for on-demand and prophylaxis; in 2020: 2.5%, on demand, 9.2% short-term and 3.4% long-term prophylaxis. By contrast, subcutaneous medication use has increased from in 2017: 10.0% on-demand, 1.25% prophylaxis to, in 2020, 60.4% on-demand, 28.1% short-term and 38.4% long-term prophylaxis. Percentages may exceed 100% because of multiple categories for use. In 2017, the number of attacks not treated because of medication access was zero for 4.35% of patients while in 2020 it was zero for 59.7%.

Conclusion: The use of newer, self-administered HAE treatments has significantly increased between 2017 and 2020. In parallel, the percent of patients with attacks not treated because of lack of access to medication has decreased significantly. Medications taken at home which are non-invasive and accessible (subcutaneous or oral) are desired by HAE patients and will likely have a significant impact on their quality of life.

Word count: 294