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Type I/II HAE: Treatment and attack frequency improvements between 2017 and 2020 based on data from the Canadian national patient surveys

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Introduction:
Types I and II hereditary angioedema (HAE) comprise a rare genetic disorder which results in low levels of C1 inhibitor (C1-INH) or its function and unpredictable attacks of angioedema. Over the last several years, newer treatments with easier delivery have been approved for prophylactic treatment of these patients. We explored the use and impact of these newer treatments.

Methods:
Online surveys were sent to Canadian HAE patients in 2017 and 2020 to better understand their treatment and health burden. We extracted the responses of patients who reported having Type I or II HAE to evaluate treatment use and attack frequency. Data was analyzed as the percent of responses to a given question.

Results:
There were 56 respondents who self-identified as Type I/II in 2017 (75% female, 46±16 years of age) and 106 in 2020 (76% female, 54±16 years of age).

In 2017, 28 of 56 used prophylaxis with 24/28 (86%) taking IV C1-INH and 4/28 (14%) oral medications (androgen or tranexamic acid). In 2020, 71 of 106 used prophylaxis: C1-INH, IV: 27/98 (28%) and subcutaneous: 31/98 (32%); lanadelumab: 10/98 (10%); and oral medication (androgen) 2/98 (2%). Consequently, the percent of patients without attacks increased from 7.8% in 2017 to 22% in 2020 and those who reported having no attacks for which they would have gone for treatment were it available rose from 6.7% to 61%. In 2020, treatment costs were borne either by a government plan (80%), private insurance (11%), a clinical trial (7.6%) or the patient (1.1%), (n=92). This information was not obtained in 2017. Visits to the hospital, emergency room and clinic were unchanged.

Conclusion:
The addition of newer prophylactic treatments which can be administered at home subcutaneously has benefited HAE patients by reducing attacks and attacks requiring treatment between 2017 and 2020