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HAE with normal C1 esterase inhibitor (HAEnC1INH): Treatment and attack frequency changes from 2017 to 2020 based on data from the Canadian national patient surveys

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Background:
Hereditary angioedema with normal C1 esterase inhibitor (HAEnC1INH) is a rare genetic disorder which results in unpredictable attacks of angioedema. There are no approved treatments for HAEnC1INH although there are treatments for HAE with low levels or dysfunctional C1INH. We explored the use and impact of these treatments in patients with HAEnC1INH.

Methods:
Online surveys were sent to Canadian HAE patients in 2017 and 2020 to better understand treatment and health burden. We extracted the responses of patients who reported having HAEnC1INH to evaluate treatment use and attack frequency. Data was analyzed as the percent of responses to a given question.

Results:
In 2017, There were 26 respondents (88% female) who self-identified as having HAEnC1INH and 45 (84% female) in 2020. HAE treatments were used by 73% in 2017 and 86% in 2020. C1INH either intravenous (IV) or subcutaneous (SQ) was the most common medication used to treat acute attacks (2017: IV 50%; 2020: IV 30%, SQ 11.4%) and for prophylaxis (2017: IV 27%; 2020: IV 33%, SQ 24%).

The percent of patients with>12 attacks in the prior year decreased from 85% in 2017 to 50% in 2020. The percent who had no attacks that were untreated rose from 0.0% to 58%. Most patients had no hospital and clinic visits (2017: 39%; 2020: 44%). Emergency room and clinic visits were largely unchanged but fewer patients had frequent (>7/per year) doctor visits (2017: 43%; 2020: 11%).

Conclusions:
Patients with HAEnC1INH received treatments approved for HAE with low or dysfunctional C1INH in both 2017 and 2020 and the proportion increased in 2020. There was a parallel decrease in attacks and in untreated attacks.

References: