Emergency room visits by patients with HAE based on data from the Canadian 2020 national survey

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Introduction: Hereditary angioedema (HAE) is a genetic disorder resulting in low or dysfunctional C1 inhibitor (C1-INH): Type 1/2 HAE and/or dysregulation of bradykinin production: HAE with normal C1INH (HAEnC1-INH). HAE is characterized by recurring, painful swelling occurring in any part of the body. Laryngeal swelling can be fatal and abdominal swelling is very painful. Consequently, HAE patients often require emergency room (ER) visits.

Methods: In 2020, an online survey was sent to all members of HAE Canada. Survey results were collated, sorted by self-reported Type 1/2 HAE and HAEnC1-INH, and expressed as percent of respondents.

Results: 106 (76% female) patients with Type 1/2 HAE and 45 with HAEnC1-INH (84% female) responded to the survey. In the prior year, most did not attend the ER for treatment of an angioedema attack (Type 1/2 HAE: 73%; HAEnC1-INH: 69%;). For those who did, throat and facial swelling (39% vs 25%) and problems breathing (25% vs 11%) were more frequent for patients with HAEnC1-1INH compared to Type1/2 CI-INH.

Prior to treatment access, 40% of Type 1/2 and 51% of HAEnC1-INH patients had >6 ER visits in the prior year and (77.5% Type 1/2; 79.31% HAEnC1-INH) had at least 1 visit, respectively. After access to treatment, 10% of Type 1/2 and 15% of HAEnC1-INH patients had >6 visits to the ER in the prior year while 44.59% vs 57.69% had at least 1 visit.

Discussion: These results suggest that providing treatment to patients that can be taken at home reduces ER visits and possibly health care costs.