

Fear of Attacks Reduces Quality of Life for Canadian HAE Patients



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Conflicts of Interest

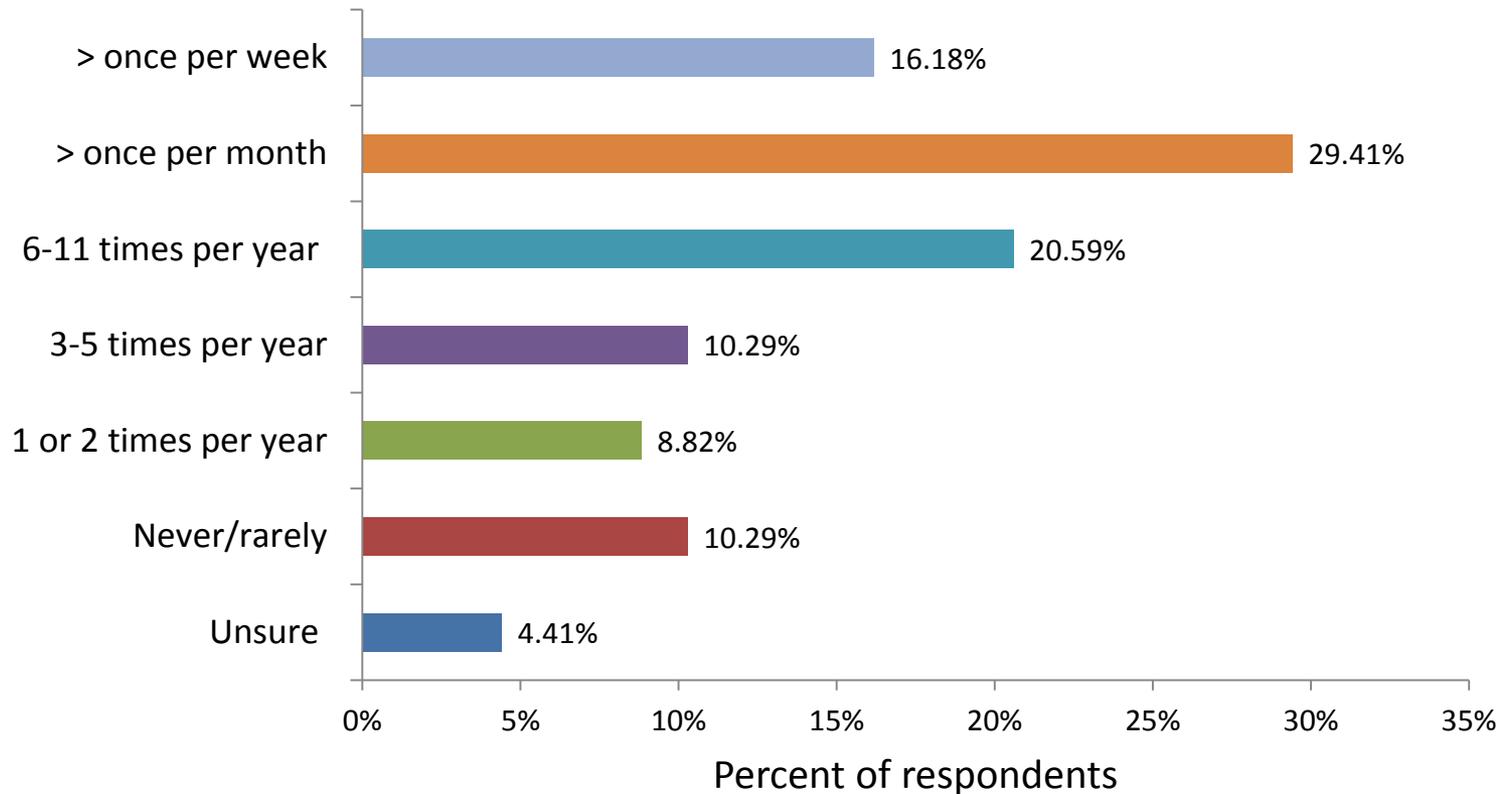
- HAE Canada receives yearly sponsorship funds from CSL Behring and Takeda



Introduction and Methods

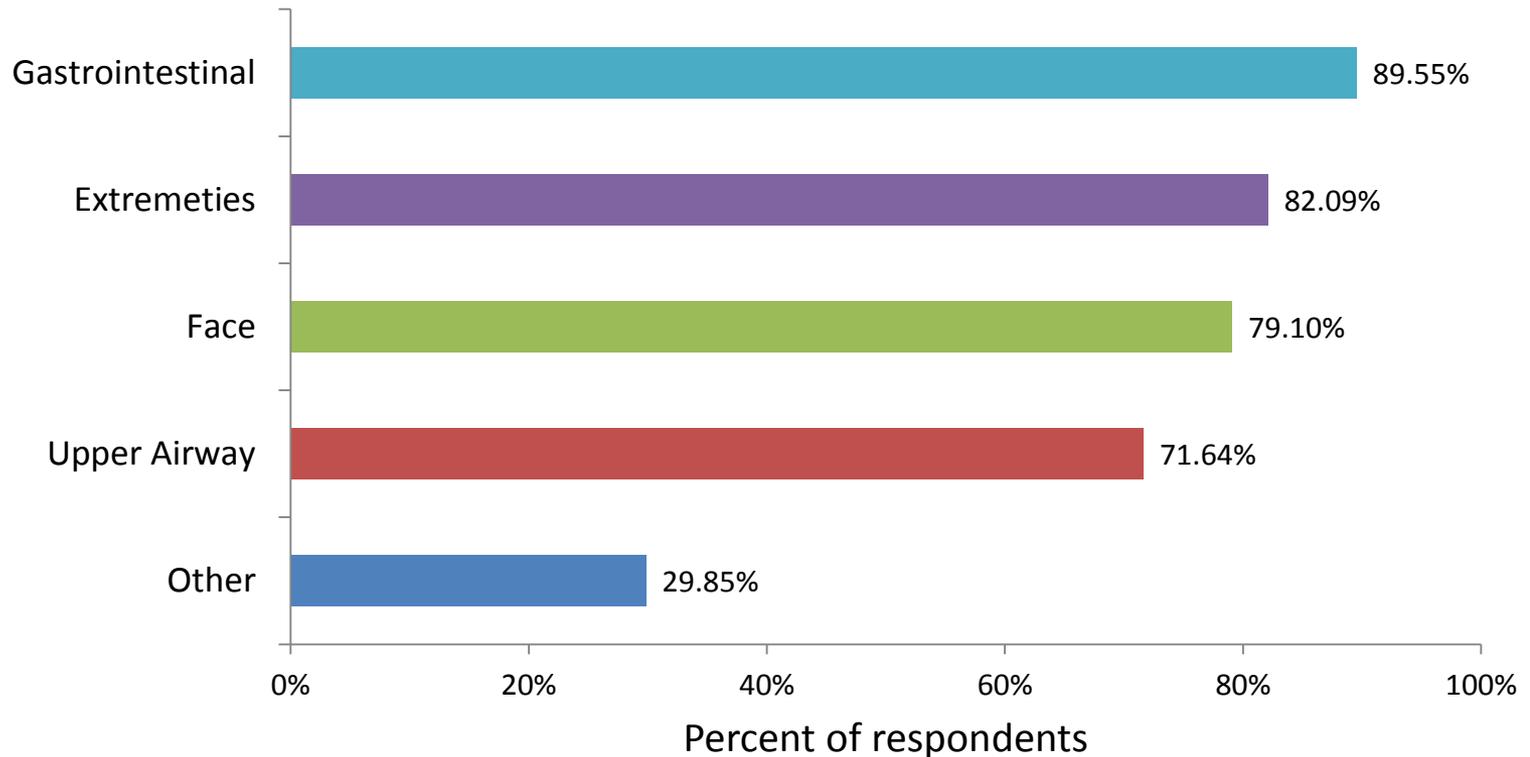
- Hereditary angioedema (HAE) is a rare inherited disorder characterized by recurring swelling attacks often without a trigger.
- In 2019, HAE Canada conducted 2 on-line surveys to assess challenges faced by HAE patients and caregivers and to gain insight into their experience with the newest prophylactic therapies:
 - subcutaneous C1 esterase inhibitor
 - subcutaneous kallikrein inhibitor, lanadelumab
- Responses to 6 of the survey questions are reported here.

Frequency of HAE attacks



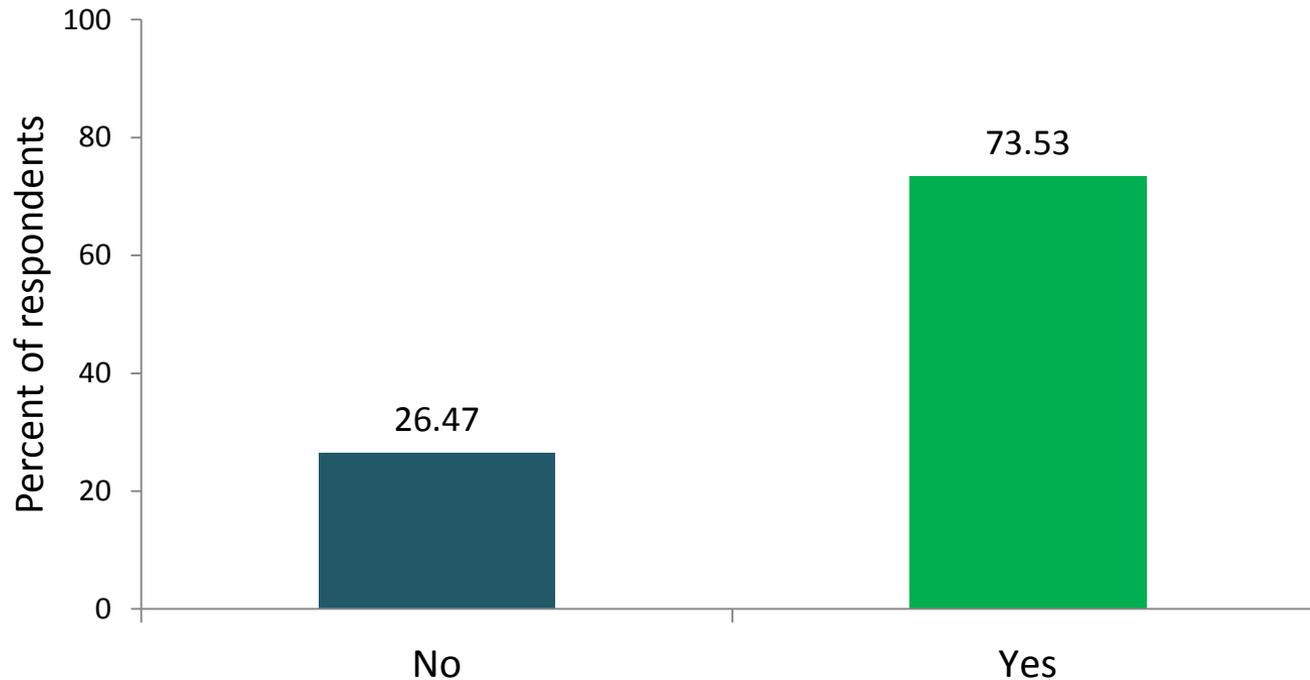
68 individuals with HAE responded to the question “How frequently do you (or the person you care for) experience attacks”.

Site of HAE attacks



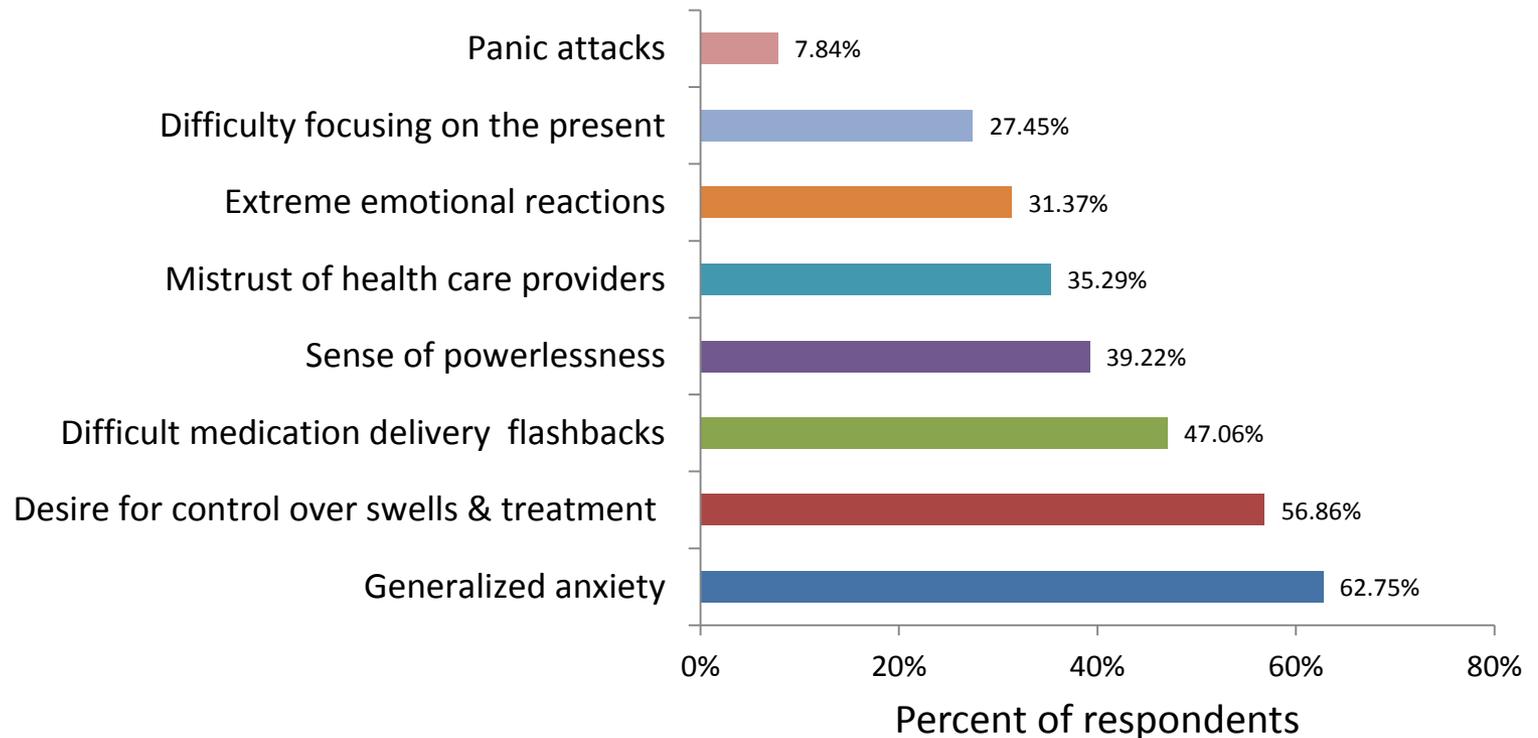
67 individuals with HAE responded to the question “on what part of the body have you experienced attacks?” They could check all that applied. In the other category, 17/20 responded genital area/groin, 3/20 back/buttocks, and 1 each breast, sinuses, joints.

Respondents fear unpredictable, debilitating attacks



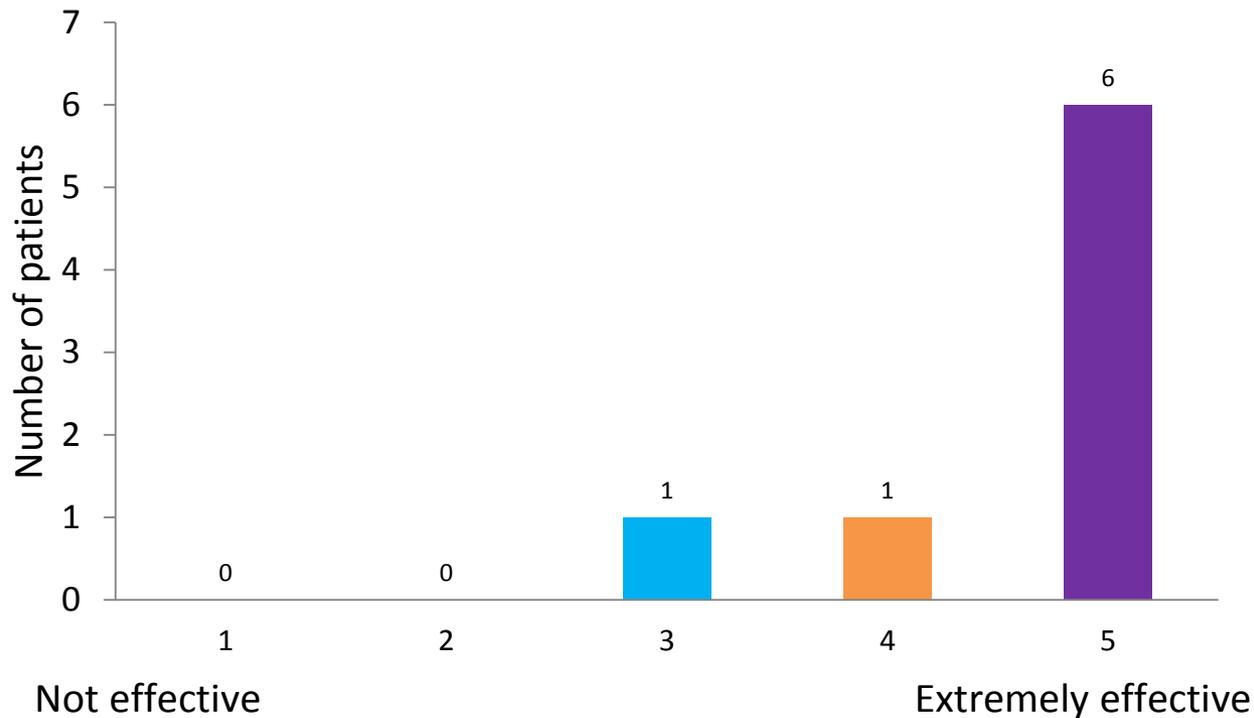
The majority (50/68) of respondents indicated that they had regular fear of unpredictable debilitating HAE attacks. Fear was rated mild by 15, moderate by 31 and severe by 4.

Fear of attacks leads to negative feelings



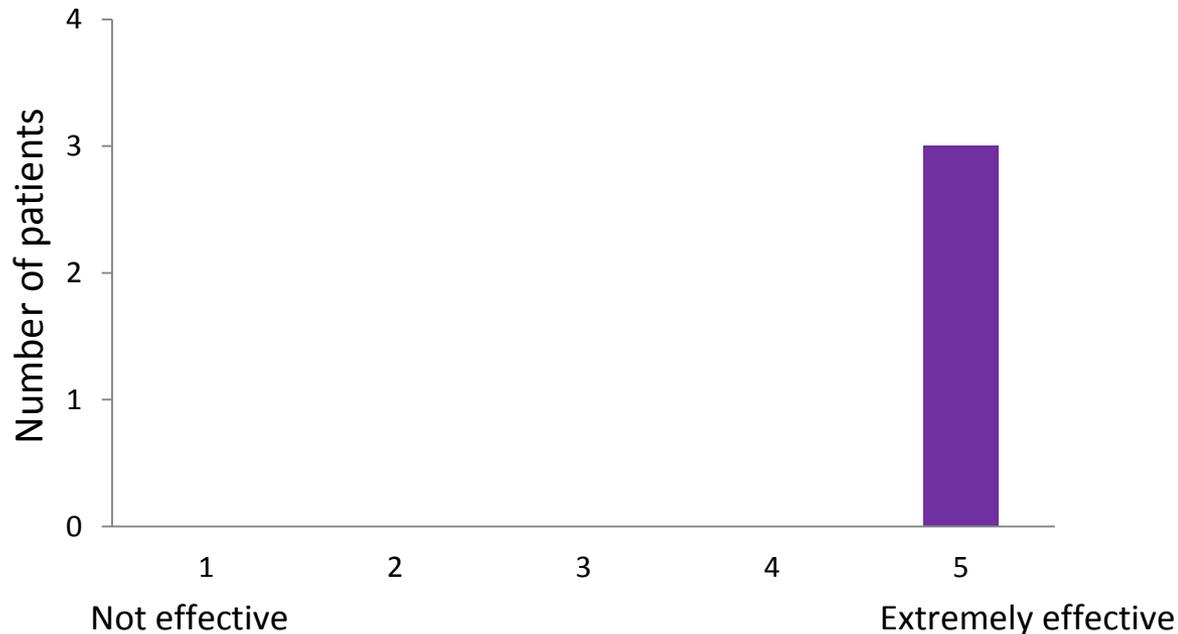
Responses of HAE patients to the question “Does your fear of attacks lead to any of the following symptoms/behaviours/ feelings?”

Experience with lanadelumab



Lanadelumab was considered extremely effective by 6/8 subjects who used it. The reported side effects were pain at injection site (6/8) and headache (2/8) which were considered tolerable to very tolerable.

Experience with subcutaneous C1-INH



Three Canadian patients had been treated with subQ C1-INH. All 3 rated it as extremely effective at preventing HAE attacks. Reported adverse events [headache (1/3) and injection site reaction (2/3)] were considered tolerable to very tolerable.

Conclusion

- Unpredictable painful or life-threatening HAE attacks are feared by HAE patients and lead to generalized anxiety.
- The newest medications subcutaneous C1-INH and lanadelumab are effective in reducing attacks.
- Positive results by survey respondents describe the impact of new drug therapies on reducing the fear and improving quality of life of Canadian HAE patients.

