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Medical resource utilization and quality of life of HAE patients based on data from the 2020 national survey

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Background:
Hereditary angioedema (HAE) is a rare genetic disease characterized by unpredictable, recurrent episodes of angioedema leading to swelling of limbs, face, larynx and the gastrointestinal tract. Episodes are painful and can be fatal. Most patients have deficient or dysfunctional C1 inhibitor (HAE C1INH), but a significant percentage have other mutations causing similar episodes of angioedema (HAEnC1INH).

Methods:
Because randomized controlled trials may not fully reflect HAE patients' burden of illness, HAE Canada has conducted multiple surveys to obtain data which would otherwise be unavailable. Data obtained includes demographics, number and severity of attacks, treatment utilization and satisfaction, quality of life (QoL), burden of illness, health care utilization and economic costs to the patient.

Results:
Results from our 2020 survey show that despite 88% of HAE patients using HAE medication, a significant proportion still have >12 attacks/year (HAE C1INH: 27%, HAEnC1INH: 50%) and unscheduled visits to the ER (HAE C1INH: 45%, HAEnC1INH: 54%), missed work (HAE C1INH: 53%, HAEnC1INH: 61%) and have high levels of anxiety (HAE C1INH: 61%, HAEnC1INH: 67%). Medications are evolving but due to heterogeneity of treatment effects, more treatment options are needed for attack prevention, acute attack management as well as more convenient treatment modalities (e.g., oral or subcutaneous versus intravenous). Better treatments and better access to treatment may offset costs to the health care system and improve patient QoL.

Conclusions:
Our data has been used to raise awareness of HAE and to advocate for access to treatment. However, there are still unmet needs and further research is needed to better manage all forms of angioedema. A registry to collect real-world data would be highly beneficial.

References: