

Assessment of HAE-specific quality of life and proximity to acute therapy

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Conflicts of Interest Disclosure

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Enterprises, etc. with which there is a COI relationship to be disclosed pertaining to the topic presentation:

- (1) Consultant: BioCryst, CSL Behring, Novartis, Takeda (Shire)**
- (2) Shareholding / profit: None**
- (3) Patent royalties: None**
- (4) Lecturer honoraria: CSL Behring, Green Cross, Ionis, Octapharam, Takeda (Shire), AstraZeneca, Aralez**
- (5) Manuscript fees: None**
- (6) Funds for sponsored/joint research: Canadian Hereditary Angioedema Network (CHAEN), BioCryst, CSL Behring, Novartis, Takeda (Shire)**
- (7) Scholarship endowment: None**
- (8) Affiliation with donated courses: None**
- (9) Gifts or other compensation: Travel grants from the Canadian Organization for Rare Disorders. Funding for travel/meeting attendance from CSL Behring, Novartis, and Shire**



Background

- HAE is a rare, potentially life-threatening condition whereby patients can experience recurrent and unpredictable episodes of angioedema
- Timely access to effective treatment for attacks is expected to improve the care of patients, the patient's perception of control over their disease, and their quality of life.



Purpose:

To examine the quality of life of Canadian HAE patients regarding:

1. the impact of having treatment available at home to treat attacks
2. living close to their HAE specialist
3. living close to a hospital



Methods:

- 90 HAE patients in Canada participated in an anonymous, online clinical and an HAE specific quality of life (HAE-QoL) questionnaire ⁵
- Eligible patients were literate in either English or French, 18 years or older, and had HAE type 1 or 2. Questions in the HAE-QoL covered seven domains:
 1. physical functioning and health
 2. disease related stigma
 3. emotional role and social functioning
 4. concern about offspring
 5. perceived control over illness
 6. mental health
 7. treatment difficulties.
- We calculated QoL score medians and interquartile ranges to describe the sample
- The non parametric Kruskal-Wallis test was used to compare quality of life scores between categories of time to get to hospital, and distance to their HAE specialist



Results:

Time to hospital	Median total QoL scores and interquartile ranges
< 30 minutes	110 (95-122)
>30 minutes, >59 minutes	84.5 (61.5 - 90.5)
N/A, self injecting meds	107 (90-114)

- A Kruskal-Wallis test was conducted to examine the differences in total QoL scores according to time to get to hospital/whether patients self injected medications at home. A significant difference was found between the 3 categories [$H(2) = 15.25, p < 0.05$]
- Patients who were <30 minutes away from the nearest hospital compared to patients who were 30 minutes to 2 hours away from the hospital had higher total HAE-QoL scores and scores on the HAE-QoL domains.
- Those who self-injected treatment for attacks at home also had higher total QoL scores than those who were >30 minutes away from the hospital.
- We did not see any difference in health-related quality of life scores between patients groups that reported living at various distances from their specialist, ranging from <20 km to >500 km.



Conclusions:

This is the first study to use the HAE-QoL questionnaire to assess Canadian patients with HAE. Patients who have timely access to treatment, either by living <30 minutes from the nearest hospital or having treatment at home for acute attacks, have higher total HAE-QoL scores than those who do not have access to self-administered acute treatment or who live farther away from the hospital.



References

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Questions?

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