

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

Jane Hsieh¹, Jacquie Badiou², Rozita Borici-Mazi³, Teresa Caballero⁴, Amin Kanani⁵, Gina Lacuesta⁶, Christine McCusker⁷, Susan Wasserman⁸, Stephen Betschel⁹

Affiliation:

1. Toronto, Ontario, Canada
2. HAE Canada, Ottawa, Ontario, Canada
3. Queen's University, Kingston, Ontario, Canada
4. Hospital Universitario La Paz, Madrid, Spain
5. University of British Columbia, Vancouver, British Columbia, Canada
6. Dalhousie University, Halifax, Nova Scotia, Canada
7. McGill University Health Centre, Montreal, Quebec, Canada
8. McMaster University, Hamilton, Ontario, Canada
9. University of Toronto, Toronto, Ontario, Canada



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Jane Hsieh, Jacquie Badiou, Rozita Borici-Mazi, Teresa Caballero, Amin Kanani, Gina Lacuesta, Christine McCusker, Susan Wasserman, Stephen Betschel

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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

1. Prior N, Remor E, Pérez-Fernández E, et al. Psychometric Field Study of Hereditary Angioedema Quality of Life Questionnaire for Adults: HAE-QoL. *J Allergy Clin Immunol Pract.* 2016;4(3):464-473.e464.



Questions?

- jane.hsieh@alum.utoronto.ca

