

Real World Data of Canadian Adults living with Angioedema: Part 4 - Health Economic Burden

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Rationale: Hereditary angioedema (HAE) is a rare inherited disorder characterized by recurrent painful episodes of severe swelling in different parts of the body. The direct health care costs of HAE are significant but are little studied. We sought to understand the health care utilization of patients with HAE in Canada

Methods: In 2017 a comprehensive email survey was sent to all members of HAE Canada to gather information on multiple aspects of HAE. The data from respondents was collected and analysed as the percentage of respondents. Responses to questions on health care use were analysed for this report.

Results: The survey collected data from 113 respondent adults living with HAE. In the prior year, 11/79 (14%) reported <3 attacks while 34/79 (43%) reported ≥12. Routine HAE treatment was mainly performed at home (58/75, 77.3%) but some received treatment in a hospital (12.0%) or clinic (9.3%). In response to questions regarding health care use in the past year, most (43/71, 60.6%) saw a physician 1-3 times for HAE-related problems but 22% had 4-10 and 10% had >10 physician visits. Planned hospital visits were made 1-3 times by 32/69 (46.4%); 7.3% went >10 times and 33.3% not at all. Unplanned ER visits were made: never by 32/71 (45%), 1-6 times by 48%, and >7 times by 7%.

Discussion: These findings suggest that having HAE leads to substantial health care costs which would be higher but for the high proportion of patients who receive treatment at home.

Allowed: 250 words

Actual: 244