Understanding the cost of hereditary angioedema in England

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Introduction

Hereditary angioedema (HAE) is a rare, but potentially life-threatening, genetic disease which leads to serious swellings in the face, throat, limbs and abdomen (see Figure 1).

- HAE attacks are unpredictable, attack frequency ranges from rarely to once every 3 days. Patients can experience swelling in multiple locations at one time.
- HAE affects 1 in every 50,000 people in Europe, there are likely to be 1,000-1,500 people affected in the UK.1,2,4 A number of studies have shown that HAE patients are often misdiagnosed because the symptoms are similar to more common conditions.3,4
- Patients delay treatment to their general practitioner (GP) or acute attacks of HAE can require the patient to attend hospital.3 Treatment guidelines recommend rapid treatment to minimise symptoms and/or attacks involving the face, throat or abdomen.3
- Misdiagnosed patients may undergo unnecessary procedures or receive inappropriate treatment.1 The risk of death has been shown to be 3-9 fold higher for misdiagnosed or untreated HAE attacks.3
- Poor awareness, delayed diagnosis and inappropriate treatment contribute to the burden of HAE on patients and the National Health Service (NHS). This study aimed to understand the healthcare costs relating to HAE in the UK.

Methods

The study collected HAE healthcare cost data in England relating to:

1. Primary care – i.e. drug prescriptions by family doctors (GPs) and any interactions between HAE patients and clinical staff in the family doctors clinic (collected via the Health Improvement Network [THIN] database).

2. Secondary care – i.e. patient hospital admissions, outpatient appointments and A&E attendances relating to HAE (collected via Hospital Episode Statistics [HES] database). All data relating to treatment of HAE from 2011-2012 were collected. An overview of the study methodology is presented in Figure 3.
- In addition to this data collection, research with physicians and approximately 100 patients is to be conducted across five hospitals in England and Scotland. This research will focus on the burden of HAE from a patient’s perspective.

Patient identification

In England each entry into the healthcare databases is assigned a code according to the illness being treated. This allowed identification of all visits to the doctor relating to HAE. The codes used for the two databases are listed in Table 1.

Patient characteristics using the IHS and THIN databases

<table>
<thead>
<tr>
<th>Diagnosis code</th>
<th>Description</th>
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<tbody>
<tr>
<td>IHS</td>
<td>International classification of disease (ICD-10) code D89.2 (laboratory in complement system), C2 (serum inhibitor deficiency) was used</td>
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<tr>
<td>THIN</td>
<td>£376,000 HAE code</td>
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Using coding systems to quantify rare diseases such as HAE brings about two potential problems:
- There is potential for coding to be inaccurate or inconsistent due to limited experience of healthcare professionals in coding rare conditions.
- A small number of coding inaccuracies can affect the overall reported prevalence of a rare disease.
- Therefore additional inclusion/exclusion criteria were applied (under guidance from HAE expert clinicians) to ensure that only patients highly likely to be HAE patients were included. These criteria were based on treatments and procedures likely to be associated, or not associated, with HAE care.
- Patients and controls under the age of 18 years and those who had died in hospital were excluded from the analysis.
- Control group
to allow for a comparative calculation of disease costs, each HAE patient identified within the databases was matched to a non-HAE patient (the control according to year of birth and gender (and electoral ward for hospital admissions data).

Cost calculation

- Hospital admissions, prescriptions and interactions with clinical staff recorded from January 1st 2011 to December 31st 2012 were included in the analysis.

Primary care

- The cost of any drugs prescribed was calculated by the unit price of the drug taken from sources such as the Monthly Index of Medical Specialities (MIMS) 2012 multiplied by the quantity prescribed.
- The national cost of primary care was calculated by multiplying the cost per patient by the number of patients identified through the secondary care database (HES). The HES database is run using the national Diagnostic Procedure Cost Groups (DPCG) and associated tariff codes.
- All hospital admissions are associated with a tariff, based on an assigned Healthcare Resource Group (HRG). This tariff is inclusive of all costs associated with the hospital admission. However HRG tariffs do not include HAE-specific medication costs (e.g. C1-INH and icatibant).
- Final results were converted to annual costs.

Primary care

- The annual total cost of hospital visits for HAE patients (n=1,383) in England was £2,388,573 compared to £500,179 in the control sample (p<0.01) (Figure 4).

Secondary care

- A total of 1,383 patients in England visited hospital for HAE over the past 8 years. The average age of patients was 47.3 years and the majority of patients were female (66%).
- Of the HAE patients identified 69% had visited hospital in 2011 and 2012 compared to only 21% of the control sample.
- On an annual basis HAE patients visited hospital significantly more often and spent significantly more days in hospital, compared with similar patients without HAE (see Table 2).

Conclusions

- Therefore, the additional cost of care for HAE patients was £2,308,807 or £1,669 per patient.

References

7. These data have previously been presented at the UK Primary Immuno-deficiency Network (UK PIN) conference (3-7th December 2013, 456B) and in part at the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) conference (2-6th November 2013, PSY21).