Hereditary Angioedema: A Comprehensive Integrated Medical and Pharmacy Claims Analysis of Utilization and Costs Among 15 Million Commercially Insured Members

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Background

Hereditary angioedema (HAE) is a rare autosomal dominant disease affecting about 1 in 50,000 people in the United States. 

HAE attacks are caused by the accumulation of bradykinin, a vasoactive peptide, and can last from minutes to days with edema symptoms varying from mild swelling to gastrointestinal distress and life-threatening airway edema requiring hospitalization. 

HAE attacks can be self-limiting and often respond to oral therapies, however many patients will need to use prophylactic treatments. 

Current guidelines developed by the World Medical Organization (AMCP) in collaboration with the Primary Care Society and Acanthamoeba (AHA) recommended that low dose prophylaxis has been considered in patients with rare complications who have severe disease activity, frequency of attacks, and failure to maintain control with the appropriate on-demand treatment. 

Acute and prophylactic HAE specialty drugs are administered through both the medical and pharmacy benefits. 

In 2016, the cost of HAE specialty drugs across Prime’s commercial business was $6–9 per member per month (PMPM). 

A new HAE prophylaxis treatment, Haegarda®, was approved in June 2017 and has been gaining market share due to its availability, ease of administration and clinical effectiveness. 

Methods

Integrate medical and pharmacy claims data from an average of 15 million commercially insured members per month were queried from July 1, 2015 to June 30, 2017 (analytic period). 

Members were identified by the presence of a diagnosis on medical or pharmacy claims. 

HAE specialty drugs, defined as Berinert®, Cinryze®, Kalbitor®, Firazyr®, and Ruconest® were identified using the Medical and Medicaid Procedure Code (HCPCS) or Generic Product Identifier (GPI) codes. 

A member’s earliest HAE claim date of service in the first half of 2016 on the medical or pharmacy benefit was considered their index date. 

Members were required to be continuously enrolled prior to and during the 12-month follow up period. 

Member characteristics, health care utilization and expenditures were evaluated over the 12-months following their index date (point period) and described based on HAE expenditures, $395,507 over 12 months. 

New starts were defined as members with no HAE claims in the pre-period (six months prior to index date). 

Members were classified as having one or more different HAE specialty drugs in the pre-period. 

Members with HAE specialty pharmacy claims only, HAE medical claims only and members with both HAE pharmacy and medical claims were identified. 

Emergency room (ER) visits, hospitalizations and office visits were identified by revenue codes in the pre-period. 

All medical and pharmacy claims allowed amounts (plan paid plus member paid) were summed to calculate total cost of care in the point period. 

The proportion of coverage from different HAE specialty drugs users was calculated on the pre-period. 

If a member’s HAE specialty drugs claim in the post-period was accounted for using Cinryze for prophylaxis, all HAE specialty drugs were assigned to the Cinryze specialty drug. 

For Cinryze medical claims, all claims were assigned a 30-day supply. 

For Kalbitor, Firazyr, Berinert and Ruconest, claims in the post-period were assigned a 30-day supply for PDC calculations. 

The visual representation of the 10 members with the highest HAE specialty drug expenditures over 12 months is presented. There is one box for each HAE drug claim and the size of the box is in proportion to the median total cost of care of all 15 million commercially insured members. 

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Results

The 10 members with the highest HAE specialty drug expenditures over 12 months had an average age of 43.5 years old, with a range of 0 to 75 years old, and 21.3% of these were females. 

100% had claims for two or more different HAE drugs. 

78% had HAE specialty drug claims on the medical and pharmacy benefits. 

42% were new starts. 

24% were new starts. 

HAE specialty drug expenditures were $7,972,622 over 12 months. 

The average total cost of care across all HAE members was $409,925 per member over 12 months. 

HAE drugs were 30% of the total cost of care for HAE members, or $83,349 per member over 12 months. 

Among members with at least 1 hospitalization in the first half of 2016, the total HAE specialty drug expenditures were $64,887 per member over 12 months, the average total cost of care was $37,615 and the median total cost of care was $32,500. 

Limitations

Pharmacy and medical claims have the potential to be miscoded and exclude submissions of members’ actual drug use and diagnoses. 

The data used in this study was limited to a commercial population and results are not generalizable to Medicare or Medicaid populations. 

Medical claims do not include lab supply information. For this analysis, all claims were assigned a 30-day supply. 

Further research is needed to develop a more accurate metric to calculate the true cost of care for members. 

Conclusions

Individuals utilizing HAE drugs were extremely rare at 0.1 per 1 million in the commercial population, and are even rarer in the Medicaid population. 

HAE specialty drugs accounted for the majority (85%) of the total cost of care for these members. 

In order to ensure the medical costs of HAE continues to rise, at least 20 HAE specialty drugs had an HAE drug claim in both the medical and pharmacy benefits and 40% of the HAE specialty drug expenditures were through the medical benefit. 

While the introduction of Haegarda in July 2015, for severe HAE prophylaxis, and more agents in the pipeline, it is important for outcomes to evaluate HAE management programs and strategies. 

With the cost of HAE, high rate of new starts (24%), and high cost of HAE (averaging >$50,000 annually), insurers may want to consider applying pharmacist care management to all HAE members starting with their first HAE drug claim.

References
