Medical Chart Abstraction to Confirm Diagnosis and WHO Functional Class of Pulmonary Arterial Hypertension in Patients Identified via a U.S. Retrospective Claims Database

Background

Pulmonary arterial hypertension (PAH) is a rare disease in which patients experience elevated pulmonary vascular resistance (PVR) and pulmonary arterial pressure that result in remodeling of the pulmonary vasculature and lead to right heart failure and premature death. The prevalence is 1-6 cases per million people in the US. The incidence peaks in the 25-50 years age group. PAH is not known to cause mutations in the Scl6a2. PAH is a chronic disease with limited treatment options, and management needs to be individualized. PAH is a common disease in the United States.

Methods

The study was a retrospective mixed methods study using health plan claims data and medical chart reviews for patients with PAH. A total of 110 patients were randomly selected from payer claims data. The study was conducted from January 1, 2006, to December 31, 2010. All patients were diagnosed with PAH by a specialist or a primary care physician. The study aimed to validate the diagnosis of PAH and WHO functional class using electronic and medical record claims data. The study was approved by an independent institutional review board.

Results

Summary of Findings

Thirty-nine percent (N=43) of requested charts were obtained and abstracted. The most frequent reason for non-attainment was "Unable to locate provider or patient." The majority (98%) of patients had a PAH diagnosis documented on the chart. WHO Functional Class was not consistently documented in the charts obtained. Less than 10% had a documented functional class assignment on chart. Clinical testing, signs, and symptoms, were not consistently documented to support WHO Functional Class assignment.

Conclusions

The most frequently used diagnostic algorithm incorrectly identified patients with PAH in a mixed methods study. A multi-provider approach to obtaining medical data for PAH research is needed to provide complete diagnostic and assessment data for the patient. Effective chart abstraction strategies should include verification of provider and patient information. Other sources of severity information may prove useful in future research, i.e., specialty pharmacy records, prior authorization forms, and medication use databases.

References