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Female Patients with Hemophilia A: A Claims-Linked Chart Review

Afonja, Olubunmi; Farej, Ryan; Batt, Katharine; Martin, Carolyn; Aubert, Ronald; Carlyle, Maureen; White, John; Sidonio, Robert

Submission Group

Women's Research

Abstract

Objective: Hemophilia A is a male-predominant disorder because of its inheritance pattern, yet many females have Factor VIII deficiency with bleeding events requiring similar treatment.[1] However, data about female patients remains scarce due to the rarity of diagnoses. Healthcare claims yield sufficient research sample size, yet lack important clinical data. This study was performed to characterize female patients with HA or HA-related symptoms using a claims identification approach, validated with medical chart abstraction. Methods: Administrative claims dated 01 January 2012—31 July 2016 were accessed for patients with commercial and Medicare Advantage with Part D insurance and 18 months' continuous health plan coverage from the Optum Research Database. To maximize selection of patients with potential HA, expansive inclusion criteria were implemented. These included stated diagnosis or treatments commonly used for HA (i.e., Factor VIII, desmopressin), and/or bleeding event diagnoses (i.e., heavy menstrual bleeding, dental extraction, post-partum bleeding) combined with treatment for bleeding disorders. Patients with hemophilia B or qualitative platelet disorder diagnoses were excluded. A sample of patients was selected for medical chart abstraction for information on bleeding history, traditional HA therapies, and other treatments for bleeding (i.e., hysterectomy, transfusions, surgical cauterization, or iron supplementation).Summary: From >1 million female patients meeting broad HA or bleeding-event criteria, 323 had evidence of Factor VIII or desmopressin use. The abstraction sample included 150 patients; 86 providers participated. Upon review, 56 patients had no evidence of a bleeding disorder (unanticipated desmopressin use) and were excluded. The remaining 30 had evidence of a bleeding disorder, Factor VIII concentrate use, and/or Von Willebrand disease. Upon medical chart review by clinician experts, 8 patients were identified as having probable or possible HA. Their mean age was 60 ± 17 years, and most were Medicare-insured, with broad distribution across the US. The mean Charlson comorbidity score was 2.50 ± 2.56; the most prevalent comorbidities were coagulation/hemorrhagic, fluid/electrolyte, and non-traumatic joint disorders. Conclusions: Because HA diagnoses among females are rare, bleeding events or treatments coded for reimbursement rarely reflect the most accurate diagnosis. The broad inclusion criteria used for initial claims identification in this study unintentionally selected patients with desmopressin use unrelated to bleeding (e.g., diabetes insipidus) suggesting identification of female HA patients with severe symptoms is difficult even with broad criteria in a large data source. Accurate use of diagnostic codes to characterize female patients will be key to successful treatment and future claims-based research for this population. Disclosures: This study was funded by Bayer. [1] Byams VR, Kouides PA, Kulkarni R, et al.; Haemophilia Treatment Centres Network Investigators. Surveillance of female patients with inherited bleeding disorders

in United States Haemophilia Treatment Centres. Haemophilia. 2011 Jul;17 Suppl 1:6-13.