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Bleeding types and treatments in patients with von Willebrand disease before and after diagnosis

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Abstract

Objective: Von Willebrand disease (VWD) is the most common inherited bleeding disorder, however, initial diagnosis and subsequent management of patients after diagnosis remains a challenge. The aim of this study was to characterize the specialists who are treating patients before and after diagnosis of VWD. We also identified the most common bleeding types and the treatments given to these patients. **Methods:** This retrospective study analysed data from a US medical claims insurance database (IQVIA PharMetrics Plus Database) for patients who had made insurance claims for VWD (International Classification of Diseases, ninth edition [ICD-9] code: 286.4). The claims were made from January 01, 2006 to June 30, 2015. Patients with ≥ 2 medical claims for VWD and who were continuously enrolled for a 2-year period before and after their 1st VWD claim were included in this study. Descriptive statistics were used to summarize patient demographic and clinical characteristics, which included bleed types, treating physician specialty, and type of VWD treatment, in both the pre- and post-diagnosis periods. **Summary:** A total of 3,756 patients were included: 73% were female, and the median age at VWD diagnosis was 34 years old (age range 2–82 years). Pre-diagnosis, the top 3 treating physician specialties were hospitalists (22%), primary care physicians (14%) and obstetrician-gynecologists (13%). Post-diagnosis, the top 3 treating physician specialties were hospitalists (14%), primary care physicians (8%) and obstetrician-gynecologists (10%). Only 6% of patients saw a specialist hematologist before VWD diagnosis for a bleeding event and this decreased to 3% after diagnosis. The number of claims made by patients for bleeding events decreased from 45% pre-diagnosis to 34% post-diagnosis. In females, heavy menses were the most common bleed type, representing 29% of pre-diagnosis claims and 21% of post-diagnosis claims. In males, epistaxis was the most common bleed type, representing 13% of pre-diagnosis claims and 8% of all post-diagnosis claims. Overall, insurance claims for medical treatments associated with VWD increased from 19% pre-diagnosis to 27% post-diagnosis. The most prescribed treatments in women were oral contraceptives, desmopressin (DDAVP) and aminocaproic acid (ACA) (pre-diagnosis: 18%, 5% and 2%, respectively; post-diagnosis: 20%, 11% and 5%, respectively). In men, the most prescribed treatments were DDAVP, ACA and von Willebrand factor (VWF) concentrates (pre-diagnosis: 5%, 4% and 2%, respectively; post-diagnosis: 9%, 6% and 4%, respectively). **Conclusions:** These data show an overall reduction in the frequency of bleeding event insurance claims after VWD diagnosis. This was coupled with an increase in treatment insurance claims for DDAVP, ACA and VWF after diagnosis. These results highlight the importance of diagnosis of VWD and treatment optimization in these patients. Also, only a minority of patients received care from a hematologist, which may impact treatment and care.