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Women and girls with hemophilia: Gender-based differences in comprehensive care

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Women's Research

Abstract

Women and girls with hemophilia: Gender-based differences in comprehensive care Objective: The majority of studies of hemophilia have focused on males, leaving a gap in our knowledge of patient characteristics and care provided to females with hemophilia. This study aimed to systematically investigate whether gender-based differences in care exist and to describe the level of care females with hemophilia receive. This study utilized retrospective data analyses to investigate the effect of gender on comprehensive care in the US Hemophilia Treatment Center (HTC) Network, including enrollment as patients and participation in comprehensive care visits. Method: This is a retrospective cross-sectional study utilizing the American Thrombosis and Hemostasis Network's (ATHN) dataset. The sample included patients enrolled in ATHN during a two-year period from April 2016 to April 2018. Inclusion criteria were factor VIII (FVIII) or factor IX (FIX) deficiency (defined as FVIII or FIX level < 50%) of all ages and severities. Descriptive statistics were performed for the entire sample, but direct comparisons were limited to patients with mild hemophilia due to the low number of females with moderate or severe hemophilia. Results: Females made up 7% of the overall sample, 19% of mild FVIII deficient patients, and 24% of mild FIX deficient patients. Females with mild hemophilia had higher factor levels than males with mild hemophilia ($P < 0.001$), older age at diagnosis ($P < 0.001$), and a shorter duration of enrollment in the ATHN database ($P < 0.001$). Females were less likely to have a comprehensive care visit ($P < 0.001$), and more likely to have an unknown treatment type ($P < 0.001$) or an unknown factor type ($P < 0.001$). Males were significantly more likely to have a comprehensive care visit even when controlling for factor level, inhibitor status, HIV status, hepatitis status, and ATHN enrollment duration (OR: 1.53; CI: 1.29-1.85; $P < 0.001$). Conclusions: The proportion of patients at all HTC's who are female is significantly lower than expected based on estimated population prevalence of 0.3 to 1 female with FVIII or FIX < 40% for every male with hemophilia (Hermans and Kulkarni, Haemophilia, April 2018). This study provides evidence that the care of females with hemophilia differs from that of males with hemophilia. Determining the precise way in which gender impacts care warrants further discussion and investigation. These differences may reflect variability of practices of care team members, of patient self-perceptions and behaviors, of surveillance practices, or even differences in the rate at which data is being entered into the ATHN dataset for female patients. However, it is clear that at some level of the patient care paradigm gender is making an impact. The authors acknowledge The American Thrombosis and Hemostasis Network, ATHN-affiliated US HTC's, and their 38,000+ patients who have contributed their demographic, clinical, and genetic information to the ATHN dataset.