

Abstract Title : Healthcare resource utilization in people with hemophilia treated within vs. outside u.S. hemophilia treatment center network clinics: An interim analysis of the CHES US study

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Abstract Body

Introduction

People with hemophilia (PwH) in the United States (US) may receive comprehensive care through the Hemophilia Treatment Center Network (USHTCN). Little is known about the care of PwH treated in non-USHTCN clinics. Characterizing the outcomes, general burden of disease and healthcare resource utilization (HCRU) in PwH treated in non-USHTCN clinics is key to improving health outcomes in PwH.

This preliminary analysis aimed to update clinical characteristics of HCRU for PwH treated at USHTCN and non-USHTCN clinics and identify the elements potentially driving inconsistencies across both settings.

Methods

Cost of Hemophilia: A Socio-Economic Survey United States (CHES US) is a 12-month retrospective, longitudinal burden-of-illness study which collects, since 2022, demographic, clinical, HCRU data as abstracted from medical records by health care providers (HCPs); and humanistic and socio-economic information from adult (≥ 18 years) male PwH A or B of any severity via a voluntary self-complete form.

Study methodology allowed inclusion of USHTCN and non-USHTCN clinics. This interim analysis used updated data to compare clinical and HCRU outcomes in PwH treated in both settings. Information on demographics, clinical characteristics, comorbidities, bleeding and joint outcomes and hemophilia-related HCRU were collected from medical records. Joint health was assessed using target joint (TJ) and problem joint (PJ) protocols; chronic joint pain and/or limited range of movement due to compromised joint integrity [i.e., chronic synovitis and/or hemophilic arthropathy], with or without persistent bleeding metrics. Continuous variables are presented as mean (SD) and categorical variables as n (%). Chi-square tests and Mann-Whitney U tests were used to compare categorical and continuous variables, respectively.

Results

At interim database lock (June 2025), 814 PwH (non-USHTCN n=749, 91.6%; USHTCN n=68, 8.4%) met inclusion criteria. The USHTCN cohort was composed by a significantly higher proportion of severe PwH compared to the non-USHTCN cohort (n=39, 57.4% vs. n=285, 38.2%; $p<0.01$). While mean age was similar (non-USHTCN: 33.4 [13.2] years; USHTCN: 34.6 [13.0] years; $p=0.3$), a larger percentage of non-USHTCN PwH were uninsured/underinsured (n=103, 13.8% vs. n=3, 4.4%; $p<0.05$). Full time employment was reported in 63.2% (n=43) of USHTCN and 54.2% (n=404) of non-USHTCN PwH ($p=0.150$).

USHTCN PwH had a more complex coinfection profile, with higher prevalence of Hepatitis C (n=10, 14.7% vs. n=3, 0.4%) and HIV (n=5, 7.4% vs. n=5, 0.7%) (both $p<0.001$). Across the USHTCN and non-USHTCN cohorts, both anxiety and depression were reported (as abstracted from medical records) for 5.9% (n=4) vs. 13.3% (n=99) (both $p=0.08$). Higher prevalence of anemia (n=85, 11.4% vs. n=2, 2.9%; $p<0.05$) and fatigue (n=99, 13.3% vs. n=4, 5.9%; $p<0.01$) were reported in the non-USHTCN cohort.

Similar mean annual bleed rates (1.3 [2.4] vs. 1.3 [1.5]; $p=0.48$) and chronic joint damage profiles (1.1 [1.3] vs. 1.5 [1.7] PJs; $p=0.07$) were observed. Mean number of TJs was significantly higher in the non-USHTCN cohort (0.9 [1.3] vs. 0.3 [0.9] TJs; $p<0.001$).

A significantly larger proportion of non-USHTCN PwH had ≥ 1 bleed-related hospital visit (n=143, 19.2% vs. 2, 2.9%; $p=0.001$) in the 12 months prior. While the non-USHTCN group had longer all-type hospitalizations (including ward and intensive care unit) (2.6 [10.1] vs. 0.1 [0.8]; $p<0.001$), no significant differences were observed in mean number of hospital visits (1.7 [2.0] vs. 0.8 [0.4]; $p=0.09$) and emergency room visits (0.2 [0.6] vs. 0.1 [0.3]; $p=0.09$).

The number of outpatient visits (not including hematology consultations) was 0.3 (0.6) vs. 0.5 (0.6) for non-USHTCN and USHTCN PwH ($p=0.25$), respectively. History of surgical procedures was reported in 20.1% (n=150) of non-USHTCN and 13.1% (n=9) of USHTCN PwH ($p=0.171$); mean surgery-related hospital days were reported as 1.0 (6.2) and 0.1 (0.4) ($p=0.28$), respectively.

Conclusions

These findings highlight differences between care settings for PwH in the US, suggesting that while managing a more clinically complex population, the USHTCN model is associated with lower HCRU. The findings suggest that the proactive, interdisciplinary approach of the USHTCN is efficient and effective in preventing acute and long-term complications of PwH, while reducing the burden on the broader healthcare system and improving health related outcomes of this population.

Keywords: Clinical Research, Real-World Evidence, Bleeding and Clotting, Study Population, Hemophilia, Clinical Practice (Health Services And Quality), Diseases, Human, Research, Health Economics, Adult

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