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Patients Report High Satisfaction with US Hemophilia Treatment Centers: National Trends 2014 and 2017

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Abstract

Background: US Hemophilia Treatment Center (HTC) care reduces mortality and hospitalizations, and guidelines recommend this care model. Yet national data that uniformly and longitudinally monitors patient experience with HTC care is limited. **Objective:** To assess patient satisfaction with HTC services and clinicians over time. **Methods:** The US HTC Network conducted the first ever nationally uniform patient satisfaction surveys on care received in 2014 and 2017. A Regional workgroup devised, piloted, and finalized an electronic, two-page survey for self-administration at clinic, or at home, in English or Spanish. Content was based on national instruments to enhance comparability and scientific robustness. Questions assessed demographics; satisfaction with HTC team members and services; insurance and language barriers. Respondents were anonymous but identified their HTC. Participation was voluntary. Patients with HTC contact in 2014 and 2017 were eligible. Data were collected for 4 months in 2015 and 6 in 2018; on average 130 HTCs (94%) from all US regions participated. Parents completed surveys for children under age 18. Data were entered, analyzed and aggregated at national, regional and HTC levels at a central site. **Results:** 5006 and 4767 persons participated, respectively, in 2015 and 2018. In both years, over 1400 (30%) respondents were female, nearly 80% were White, and 10% Hispanic. On average, 3038 had Factor 8 or 9, 1280 Von Willebrand, 186 other factor deficiencies and 369 other bleeding disorders. Respondents reported being 'always' or 'usually' (A/U) satisfied with HTC staff and services from 90% - 97% of the time in both 2014 and 2017. In both years, >4400 gave these highest A/U ratings for HTC Hematologists and Nurses; 3300 for Social Workers; >2600 for Physical Therapists; 1400 for Genetic Counselors, and >1100 for Psychologists. In both years, 96% were A/U satisfied overall with HTC services. Over 95% gave the A/U satisfaction ratings both years for these services: getting needed care and information, being treated respectfully, spending sufficient time with staff, and involved in shared decision making. 82% and 91% of respondents, respectively, gave the A/U satisfaction ratings for care coordination with primary care providers and other specialists. Over 90% of >700 youth age 12-17 gave HTC teen transition services the A/U satisfaction ratings both years. 96% of >2760 respondents reported A/U satisfaction with their HTC Pharmacy (340B) Factor Program in 2017. Insurance and language barriers to HTC care posed problems A/U for 27% and 15%, respectively both years. **Conclusions:** Patients consistently report high levels of satisfaction with HTCs, documenting HTC value over time. Patient satisfaction influences treatment adherence, can influence reimbursement, and is increasingly required by payers. A national uniform survey is feasible to conduct using a regional structure to implement, is well received by patients, and provides critical information to stakeholders.