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## BACKGROUND & OBJECTIVE

**Background:** Hemophilia Treatment Center (HTC) care using a team approach reduces mortality (Soucie 2000),<sup>1</sup> hospitalizations, and costs (Soucie 2001)<sup>2</sup> for patients with severe disorder, and satisfaction with care is increasingly recognized as an important quality metric (Reid 2010).<sup>3</sup> While people with mild hemophilia obtain services at an HTC, there has been little information reported on the satisfaction with overall HTC care, individual team members' services and care processes of this particular cohort.

**Objective:** To characterize satisfaction with HTC services among US HTC patients with mild hemophilia compared to those with severe hemophilia.

<sup>1</sup>Soucie et al. *Blood* 2000. <sup>2</sup>Soucie et al *Haemophilia* 2001. <sup>3</sup>Reid et al *Health Affairs* 2010

## METHODS

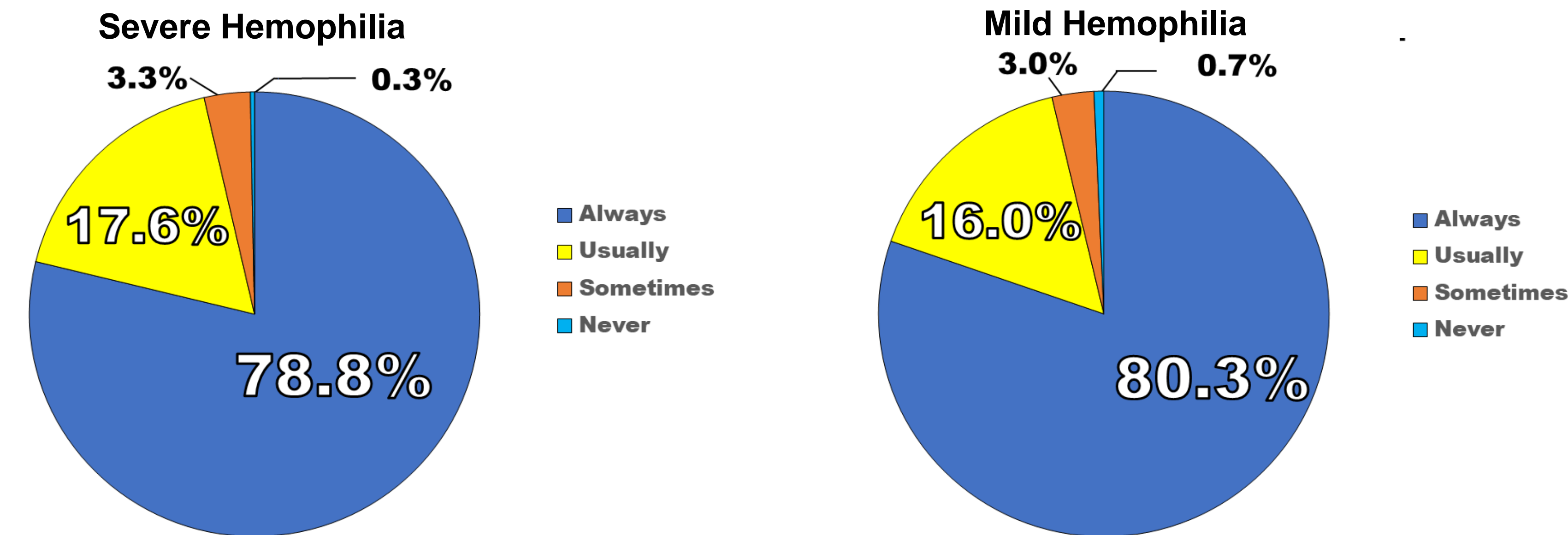
The US HTC Network (USHTCN) conducted the second nationally uniform patient satisfaction survey in 2018 for care received in 2017. A cross-regional workgroup devised, piloted, and finalized an electronic, two-page survey for self-administration at clinic, or at home, in English or Spanish. Content was based on national instruments to enhance comparability and scientific robustness.<sup>1-3</sup>

Questions assessed demographics; satisfaction with HTC team members and services; insurance and language barriers. Open-ended questions sought qualitative data. Respondents were anonymous but identified their HTC. Participation was voluntary. No reminders were sent. Patients with HTC contact in 2017 were eligible. One survey was completed per household. Data were collected for 6 months in 2018; 128 (92%) from all US regions participated. Parents completed surveys for children under age 18.

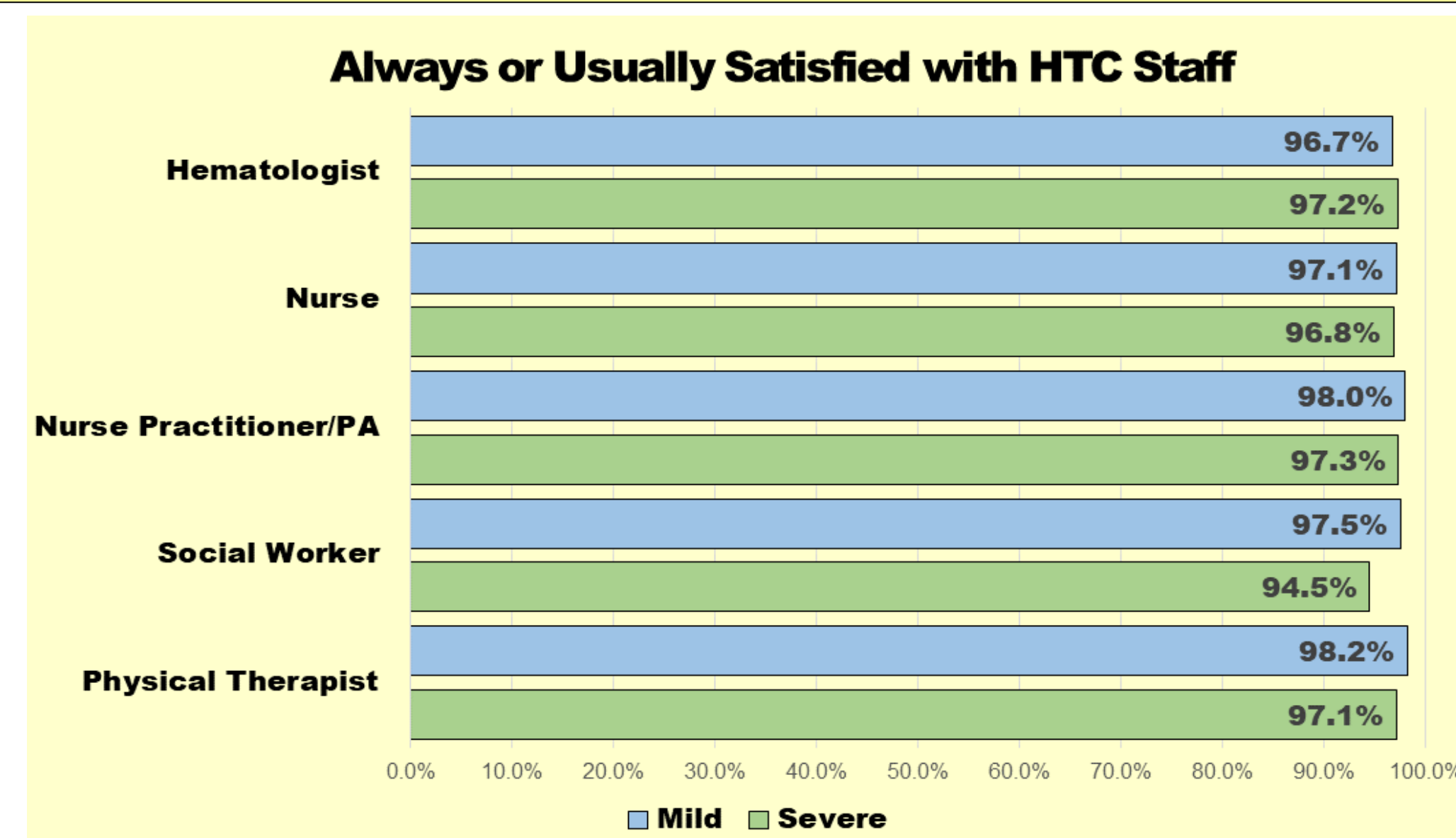
Data were entered, analyzed and aggregated at national, regional and HTC levels at a central site. Regional HTC Core Centers oversaw regional survey administration.

<sup>1</sup><http://childhealthdata.org/learn/NSCH> <sup>2</sup><http://www.childhealthdata.org/learn/NS-CSHCN>  
<sup>3</sup><https://cahps.ahrq.gov/Surveys-Guidance/CG/index.html>

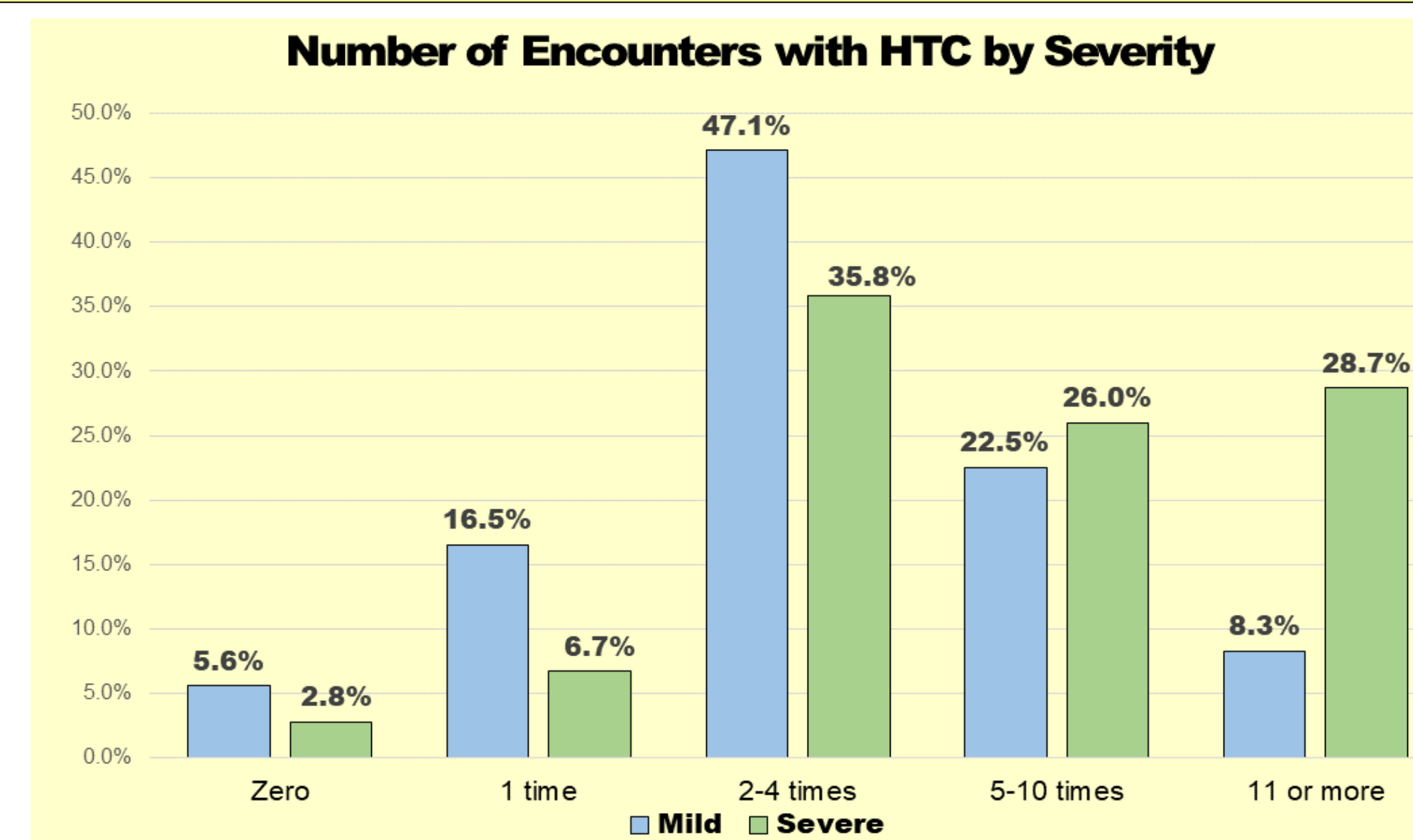
**Figure 1: Overall Patient Satisfaction with Care Received at HTC in 2017**



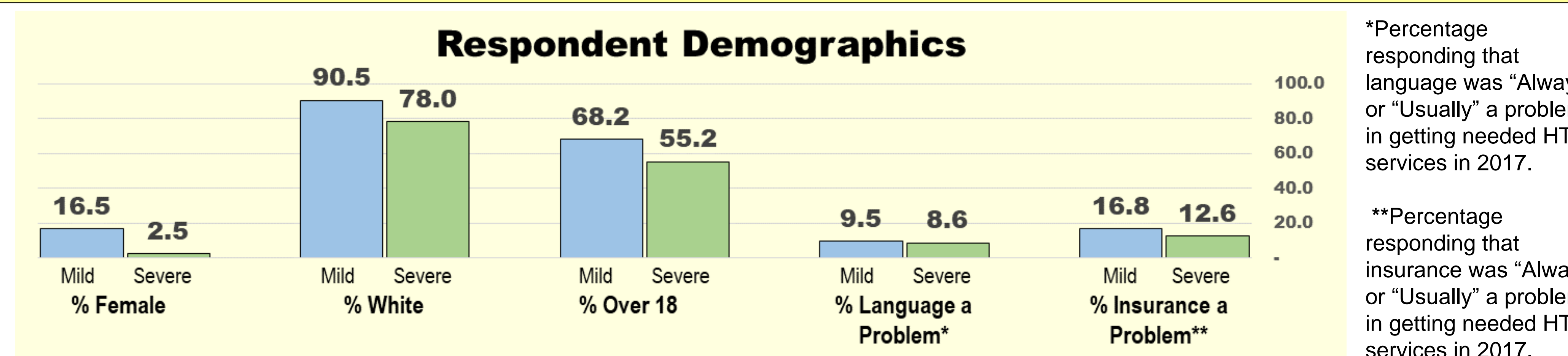
**Figure 2: Satisfaction with Core HTC Team Members in 2017**



**Figure 3: Number of HTC Encounters in 2017**



**Figure 4: Respondent Demographics Mild vs. Severe Hemophilia in 2017**



## RESULTS

**Respondent Demographics (Fig. 4):** A total of 835 persons with mild (MLD) and 1439 with severe (SEV) hemophilia participated (total=2274) in PSS 2017. MLD were more likely to be female (16.5% MLD versus 2.50% SEV), White (90.5% MLD versus 78% SEV), and older (68.2% over age 18 MLD versus 55.2% SEV).

**Overall Satisfaction (Fig. 1):** Overall satisfaction with HTC care team at the "always" or "usually" levels was nearly identical regardless of severity: 96.4% (SEV) and 96.3% (MLD).

**Patient Satisfaction with HTC Clinical Staff (Fig. 2):** Patients with mild and severe hemophilia consistently reported high levels of satisfaction -- at the "always" or "usually" levels -- with each of the HTC staff professional disciplines. This ranged from 94.5% to 98.2%

**Patient Encounters with HTC (Fig. 3):** Severe hemophilia patients were three times more likely than mild patients to have over 10 HTC encounters in 2017, specifically 28.7% SEV versus 8.3% MLD.

**HTC Care Processes:** Ease of getting care, being able to reach HTC team when needed, spending sufficient time with staff, being treated respectfully, and being involved in shared decision making were all rated as 'always' or 'usually' satisfied by over 95% of respondents, regardless of severity level.

**Barriers to HTC Care (Fig. 4):** Language 'always' or 'usually' posing problems with obtaining needed HTC care was slightly higher for persons with mild hemophilia (9.5% MLD versus 8.6% SEV). Individuals with mild hemophilia were more likely to report 'always' or 'usually' having problems with insurance coverage, than individuals with severe hemophilia: 16.8% MLD verses 12.6% SEV.

## CONCLUSIONS

A sample of 835 US Hemophilia Treatment Center patients with mild hemophilia consistently report high levels of satisfaction with overall HTC care, with individual HTC team members, and HTC services and processes at levels similar to satisfaction reported by 1439 of their severely affected counterparts in 2017. While about 25% of all HTC patients have 'mild' hemophilia, the similarity of respondent experience *regardless of disease severity* suggests that HTCs are consistent in their approach. These data, from patients who obtain care at 128 (92%) of HTCs, add to the national evidence base about how specific HTC patient populations value HTC care. A nationally uniform survey is feasible to conduct using the USHTCN's regional structure to implement, is well received by patients with differing severities, and furthers understanding of HTC value.

## ACKNOWLEDGEMENTS

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