



Patient Satisfaction with US Hemophilia Treatment Centers in 2020 – Examining Video Visits and COVID-19

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INTRODUCTION & OBJECTIVE

Introduction: Patient satisfaction is an important healthcare outcome and influences treatment adherence and reimbursement. However, satisfaction is typically assessed using local surveys, thwarting uniform analyses across institutions and trends over time. Our aim is to characterize satisfaction throughout the 144 centers that comprise the United States Hemophilia Treatment Center Network (USHTCN), including satisfaction during the COVID-19 pandemic.

Objective: To explore patient-reported satisfaction with care received at US Hemophilia Treatment Centers (HTC) with a focus on those participants reporting a tele-health visit at an HTC in 2020.

METHODS

The USHTCN conducted a nationally uniform HTC Patient Satisfaction Survey (PSS) in 2015, 2018 and 2021 assessing care received in the prior year. HTCs disseminated the two-page survey for self-administration online, in clinic or at home, in either English or Spanish. Questions aligned with federal priorities and other national surveys to enhance comparability and scientific robustness.¹⁻⁴ Regional leaders oversaw survey implementation and HTCs independently managed distribution.

The survey included self-reported demographic information and satisfaction with overall HTC care, team members, services and care processes. Questions also assessed how frequently language, insurance and COVID were barriers to HTC care. A question assessing tele-health visit frequency in 2020 was added.

Eligible participants included individuals with a genetic bleeding disorder and who had HTC contact in 2020, approximately 28,500 persons. Participation was voluntary and responses were anonymous. Parents, caregivers or guardians completed surveys for patients under the age of 18. These surveys were collected March – August 2021. Data were entered and analyzed centrally at the data coordinating center, and aggregated at national, regional and HTC levels.

¹Riske, Shearer, and Baker. Patient satisfaction with US Hemophilia Treatment Center Care, Teams and Services: The First National Survey. *Haemophilia*, 26: 991–998.
²National Survey of Children's Health. <http://childhealthdata.org/learn/NSCH>
³National Survey of Children with Special Health Care Needs <http://www.childhealthdata.org/learn/NS-CSHCN>
⁴CAHPS Clinician and Group Surveys <https://cahps.ahrq.gov/Surveys-Guidance/CGIndex.html>

Figure 1: Satisfaction with HTC Care, HTC Teams and HTC Processes and Services for overall and tele-health patients 2020

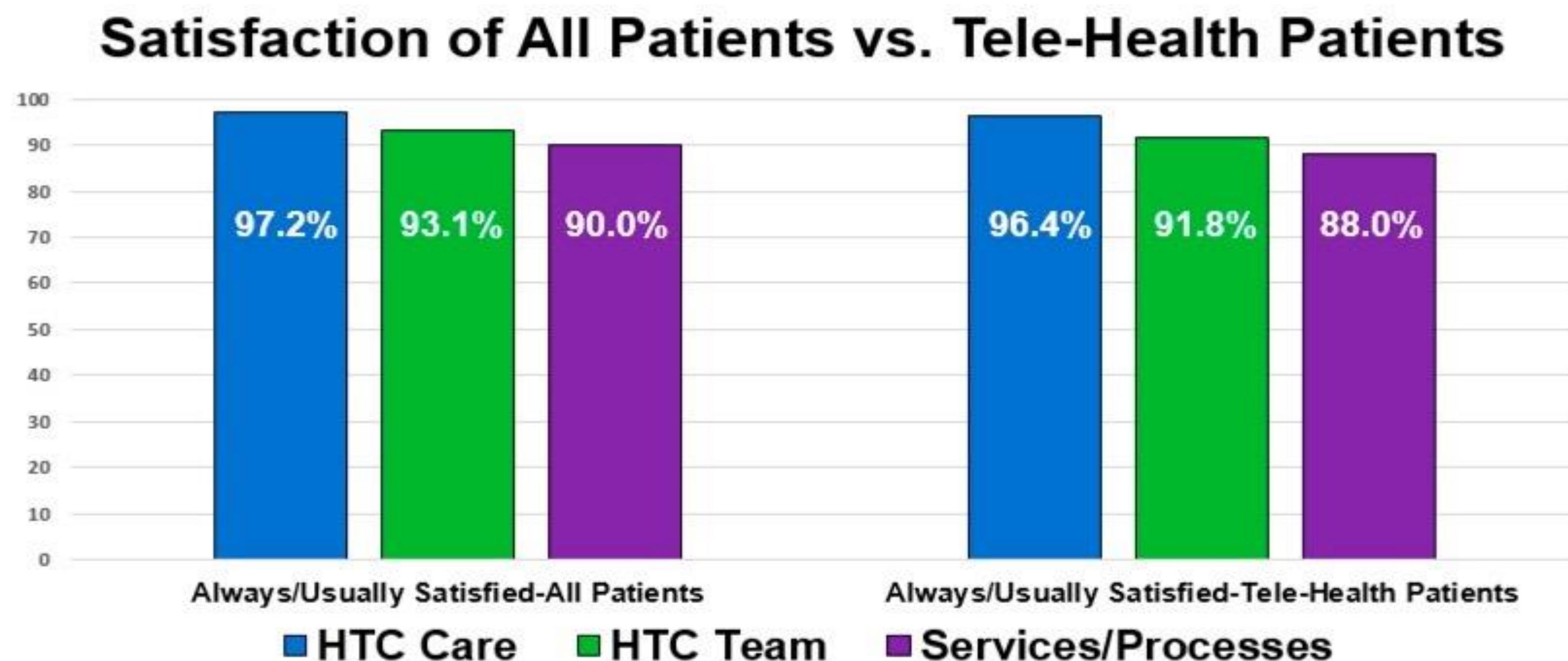


Figure 2: Reported Insurance, COVID-19, or Language Barriers

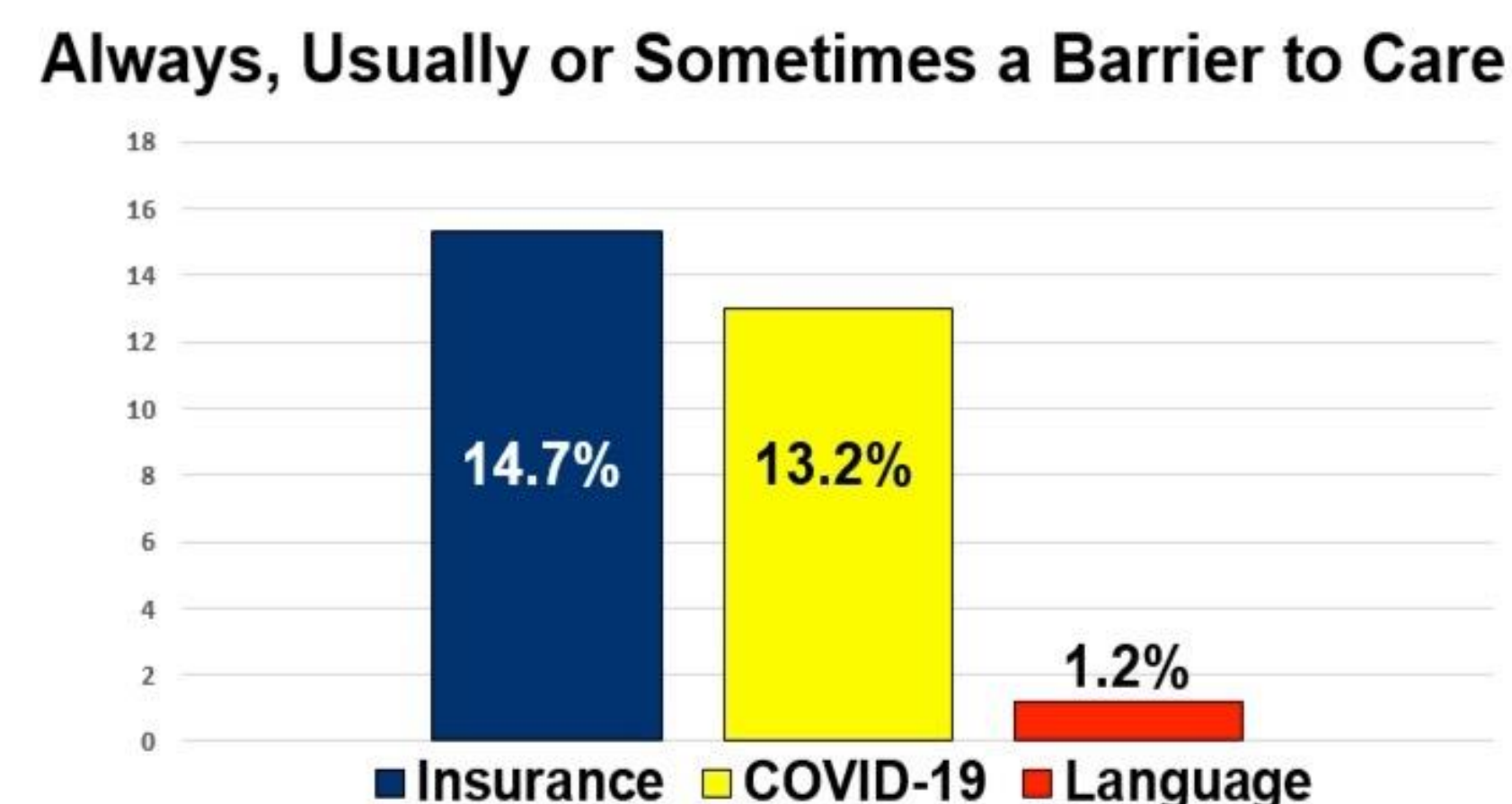


Figure 3: Impact of COVID-19 on Patient Satisfaction

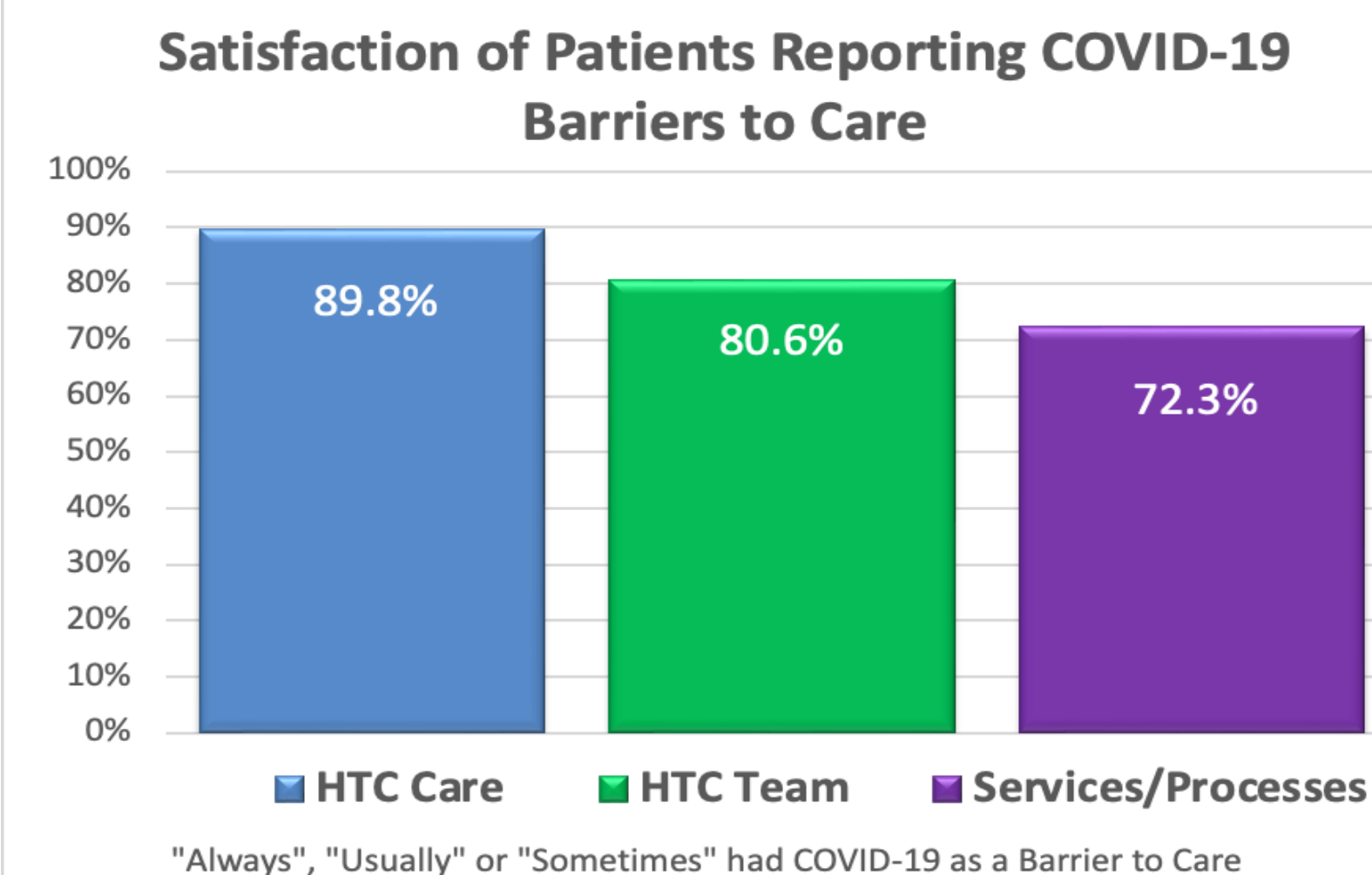


Figure 4: Demographics of Survey Participants (n=5308)

Race	Gender	Bleeding Disorder
White	Male	Hemophilia
Black or African Amer.	Female	von Willebrand Disease
Asian	Other	Other or Unknown
Native HI or Pac. Islander		
Amer. Indian or AK Native		
Ethnicity	Age Group	Disease Severity
Multi	0-11 years	Severe Hemophilia or vWD Type 3
Other	12-17 years	Moderate Hemophilia or vWD Type 2
	18-31 years	Mild Hemophilia or vWD Type 1
Hispanic/Latino	35+ years	Other or Unknown
Not Hispanic/Latino		

RESULTS

5308 respondents from 133 of 144 HTCs (92%) participated.

Impact of Tele-health on Satisfaction (Fig. 1): Respondents reported being 'always' or 'usually' (A/U) satisfied with overall HTC care (97.2%), team members (93.1%) and care processes/services (90.0%), respectively. 1875 (35.3%) respondents reported at least one tele-health visit in 2020. Among 'tele-health' respondents, overall satisfaction with HTC care, team members, and care processes/services at A/U levels was 96.4%, 91.8% and 88.0% respectively.

Barriers: Insurance, Language, and COVID-19 (Fig. 2): 779 (14.7%) reported insurance barriers, 701 (13.2%) reported COVID-19 barriers, and 66 (1.2%) reported language barriers to obtaining needed HTC services 'always,' 'usually,' or 'sometimes' (A/U/S).

Impact of COVID-19 on Satisfaction (Fig. 3): For the 701 (13.2%) persons reporting COVID-related barriers to care, overall satisfaction with HTC care, team members, and care processes/services at A/U levels was 89.8%, 80.6% and 72.3%.

CONCLUSIONS

Patient-reported satisfaction with USHTCN overall care, teams, services and processes was consistently high in 2020. Use of video visits did not substantively reduce satisfaction with HTC care, services or process. However, among patients reporting at least one tele-health visit and COVID barriers to care, satisfaction was somewhat reduced. Future analyses will further examine HTC patient satisfaction and the presence of additional barriers among those with video visits and those reporting COVID as a barrier to help HTCs improve care quality.

A National Patient Satisfaction Survey administered across the US HTC Network remains feasible, is supported by HTCs nationally, and provides valuable information from patients and families.

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