

INTRODUCTION & OBJECTIVE

Introduction: In response to the COVID-19 pandemic, many United States Hemophilia Treatment Centers (US HTC), like other health care facilities, implemented modified operations starting March 2020. Nationally, changes included the broad incorporation of tele-health services, decreased in-person clinic visits, and large numbers of HTC staff moving to a work-from-home model. Little is known about the patient experience with care received at HTCs from March-December 2020 while modified operations were in place.

Objective: To explore patient-reported impact of COVID-19 on care received from US HTCs.

METHODS

In March 2021, US HTCs launched the third national Patient Satisfaction Survey (PSS) and included new questions to assess COVID-associated barriers to care as well as the use of tele-health during 2020.

The nationally uniform two-page survey was mailed to eligible patients or self-administered online, at clinic or at home, in either English or Spanish. Survey content and format mirrored both previous PSS administrations¹ and other national surveys to enhance comparability and scientific robustness.²⁻³ Regional HTC Administrators oversaw survey implementation in their respective regions, and HTCs independently managed distribution.

Questions included self-reported demographics and satisfaction with individual HTC team members, three services (care coordination, 340B Pharmacy, and adolescent transition support), five care processes (respect, care timeliness and duration, ease of understanding information, shared decision making), and overall HTC care. The survey concluded with an open-ended question seeking additional comments and suggestions.

Eligible patients included individuals with a genetic bleeding disorder and HTC contact in 2020, approximately 28,500 persons. Participation was voluntary. Starting March 2021, the 143 HTCs in the US HTC Network sent one survey to each eligible individual. Parents, caregivers or guardians completed surveys for patients under the age of 18. 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. *Hemophilia*, 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/CG/index.html>

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

Satisfaction of All Patients vs. Tele-Health Patients

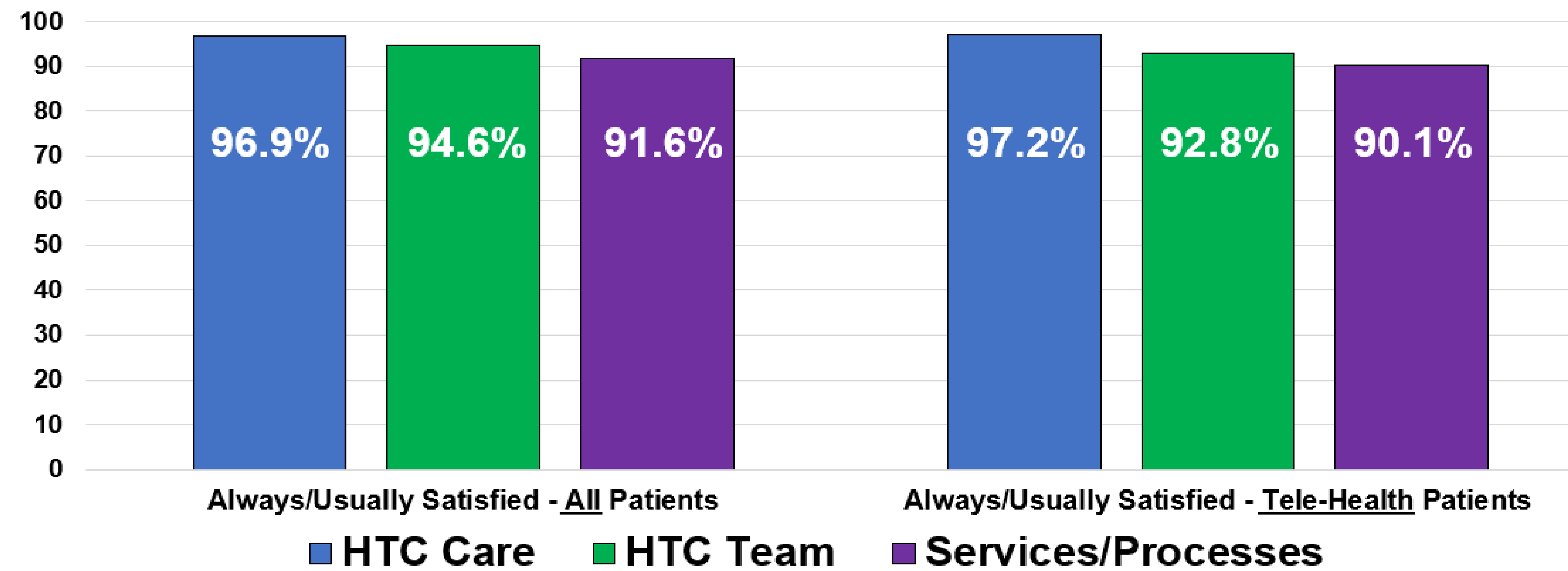


Figure 2: Reported Insurance, COVID-19, or Language Barriers

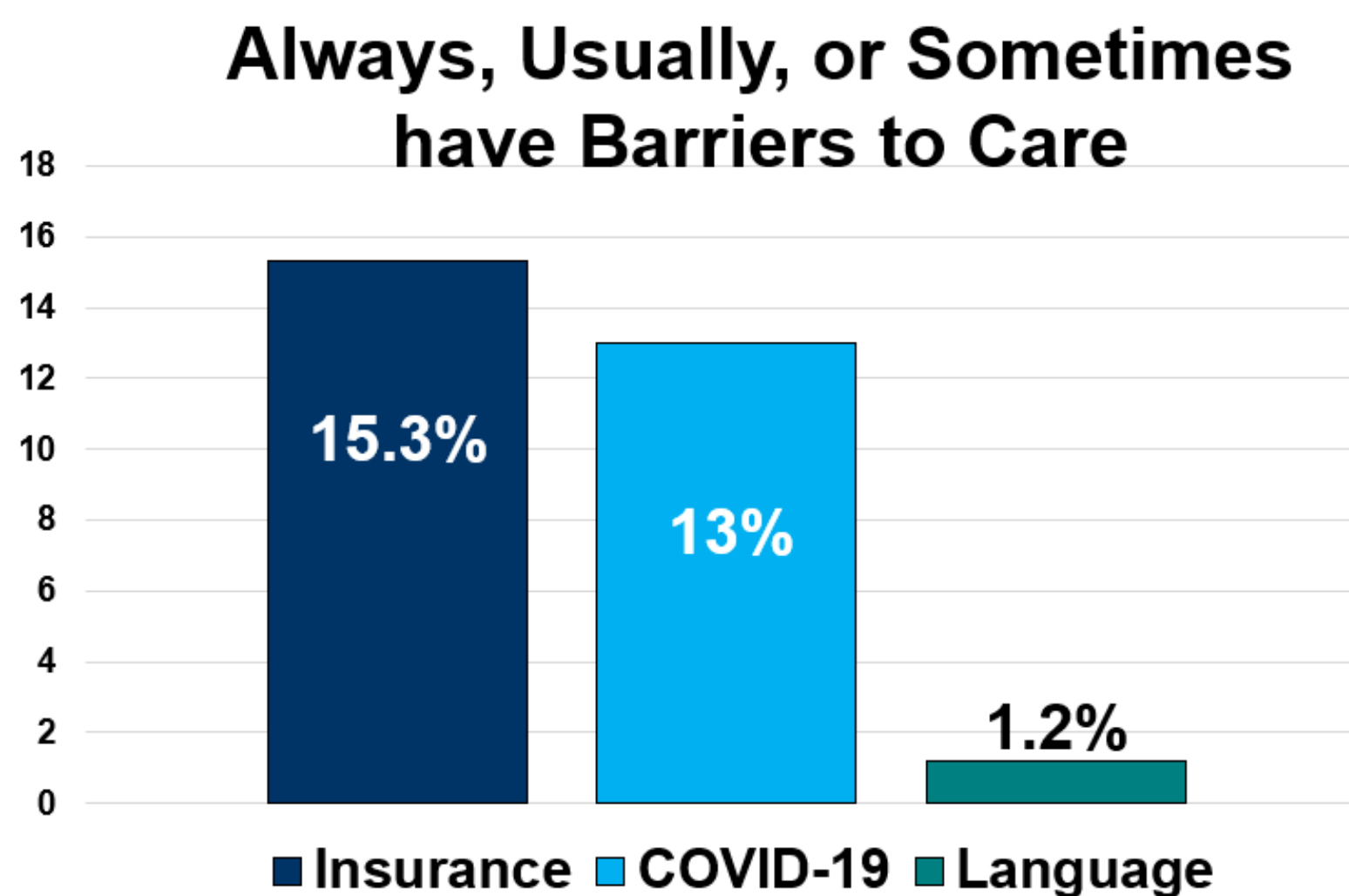


Figure 3: Impact of COVID-19 on Patient Satisfaction

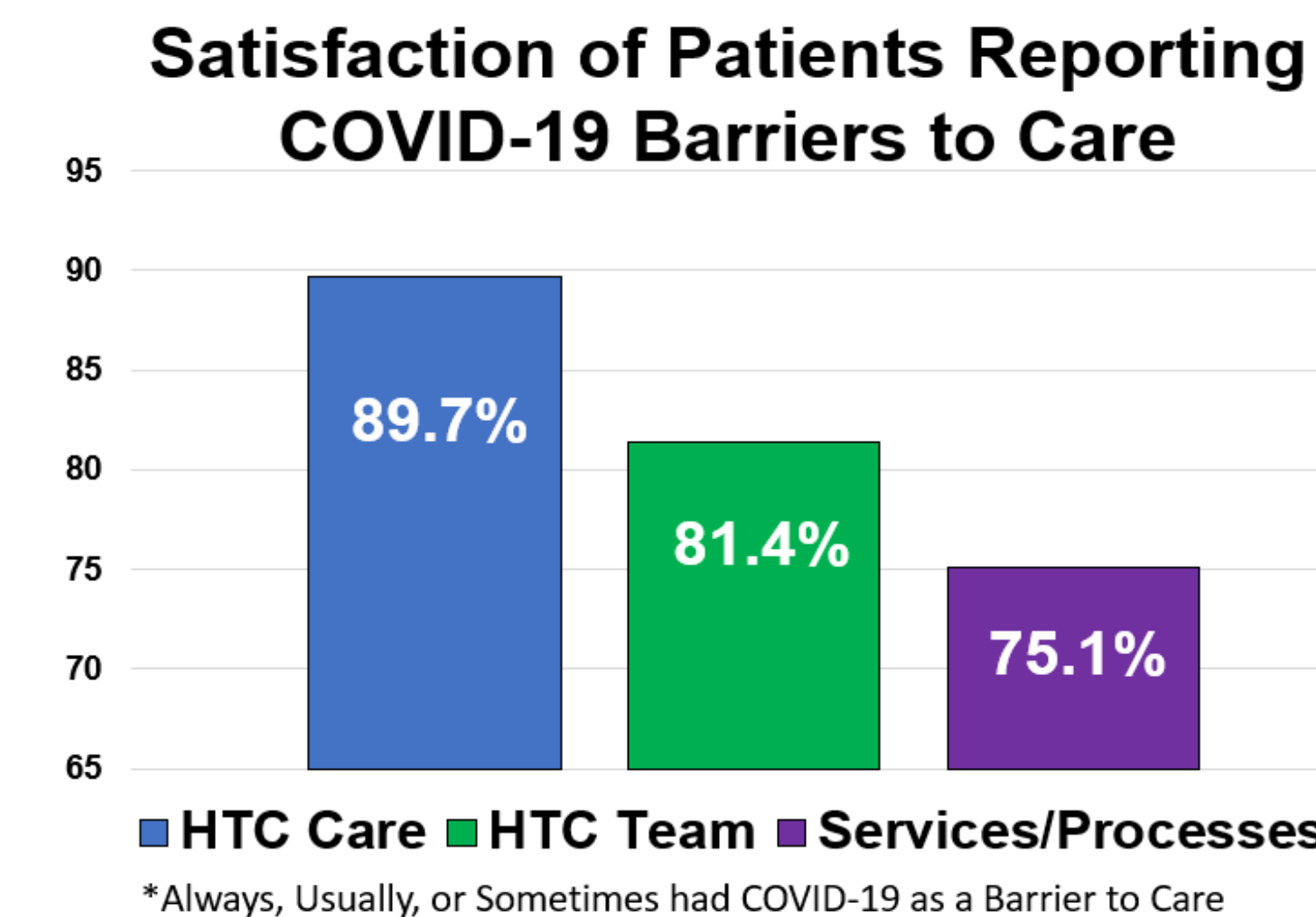


Table 1: Demographics of Survey Participants

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		
Multi		
Other		
Ethnicity	Age Group	Disease Severity
Hispanic/Latino	0-11 years	Severe Hemophilia or vWD Type 3
Not Hispanic/Latino	12-17 years	Moderate Hemophilia or vWD Type 2
	18-31 years	Mild Hemophilia or vWD Type 1
	35+ years	Other or Unknown

RESULTS

Demographics of Survey Participants (Table 1): Preliminary analyses were conducted on 2062 surveys received by 4.20.2021 from patients obtaining care at 86 (60.1%) of 143 HTCs. Children and teens comprised 29.6%, females 31.7%, non-whites 18.7%, and hemophilia 61.0% of respondents.

Satisfaction with HTC Care, Team, Processes /Services (Fig. 1): Overall, respondents reported being 'always' or 'usually' (A/U) satisfied with overall HTC care (96.9%), team members (94.6%) and care processes/services (91.6%), respectively.

Impact of Tele-health on Satisfaction (Fig. 1): 794 (38.5%) respondents reported at least one tele-health visit in 2020. Among these 794 respondents, overall satisfaction with HTC care, team members, and care processes/services at A/U levels was 97.2%, 92.8% and 90.1% respectively.

Barriers: Insurance, Language, and COVID-19 (Fig. 2): 316 (15.3%) reported that insurance, 269 (13.0%) reported COVID-19, and 24 (1.2%) reported that language were 'always,' 'usually,' or 'sometimes' (A/U/S) barriers to obtaining needed HTC care.

Impact of COVID-19 on Satisfaction (Fig. 3): For the 269 persons reporting COVID-related barriers, their overall satisfaction with HTC care, team members, and care processes/services at A/U levels was 89.7%, 81.4% and 75.1% respectively.

CONCLUSIONS

Preliminary evidence indicates that patient-reported satisfaction with US HTCs nationwide remained high compared to earlier surveys, despite the presence of COVID-associated modified operations, including the broad implementation of tele-health services in lieu of in-person clinic visits. COVID-related barriers to HTC services were associated with decreased satisfaction rates. However, use of tele-health visits was not associated with a reduction in patient satisfaction.

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.

ACKNOWLEDGEMENTS

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