

COVID-19 IMPACT ON PATIENT SATISFACTION WITH US HEMOPHILIA TREATMENT CENTERS



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INTRODUCTION

Introduction: The COVID-19 pandemic prompted many US Hemophilia Treatment Centers (HTCs) to modify operations starting March 2020. Many HTCs incorporated telehealth, decreased in-person clinic visits, and numerous staff worked remotely. However, little is known about the patient experience with HTC care received from March-December 2020.

OBJECTIVE

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

METHODS

Methods: In March 2021, US HTCs launched the third nationally uniform Patient Satisfaction Survey (PSS), adding questions regarding telehealth use and COVID-associated barriers to care during 2020.

The two-page survey was mailed to and completed by patients or self-administered online, in English or Spanish. Survey content and format mirrored previous PSS administrations¹ and other national surveys to enhance comparability and scientific robustness.²⁻⁴

Questions assessed self-reported demographics, satisfaction with HTC team members, services, care processes, and overall HTC care. Participation was voluntary.

Approximately 28,500 eligible individuals with a genetic bleeding disorder had HTC contact in 2020. Parents/caregivers/guardians completed surveys for patients age <18.

Data were entered, analyzed and aggregated at national, regional and HTC levels.

REFERENCES

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/CG/index.html>

ACKNOWLEDGEMENTS

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RESULTS

Demographics of Survey Participants (Table 1): Analyses were conducted on the 5308 patients who responded and obtained care from 133 (92.4%) of the 144 US HTCs. Respondents were children and teens (35.9%), female (32.2%), non-white race (19.1%) and hemophilia diagnosis (61.0%).

Satisfaction with HTC Care, Team, Processes/Services (Fig. 1):

Overall, patients reported being 'always' or 'usually' (A/U) satisfied with HTC care, team members and care processes/services at: 97.2%, 93.1%, and 90.0% respectively.

Impact of Tele-health on Satisfaction (Fig. 1): 1875 (35.3%) reported at least one telehealth visit.

Among 'telehealth' 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 that insurance, 701 (13.2%) reported COVID-19, and 66 (1.2%) reported that language were 'always,' 'usually,' or 'sometimes' barriers to obtaining needed HTC care.

Impact of COVID-19 on Satisfaction (Fig. 3): For the 701 (13.2%) who reported that COVID was A/U or sometimes a barrier to obtaining needed HTC services, overall satisfaction with HTC care, team members and care processes/services at A/U levels was 89.8%, 80.6% and 72.3% respectively.

Table 1

Race		Gender		Bleeding Disorder	
White	80.9%	Male	67.7%	Hemophilia	61.0%
Black or African Amer.	5.1%	Female	32.2%	von Willebrand Disease	27.6%
Asian	3.3%	Other	0.1%	Other or Unknown	11.4%
Native HI or Pac Islander	0.3%				
Amer Indian or AK Native	1.1%	Age Group		Disease Severity	
Multi	3.4%	0-11 years	19.6%	Severe Hemophilia or vWD Type 3	28.7%
Other	5.7%	12-17 years	16.3%	Moderate Hemophilia or vWD Type 2	18.5%
Ethnicity		18-34 years	20.1%	Mild Hemophilia or vWD Type 1	33.8%
Hispanic/Latino	13.4%	35-99 years	44.0%	Other or Unknown	19.0%
Not Hispanic/Latino	86.6%				

Figure 1

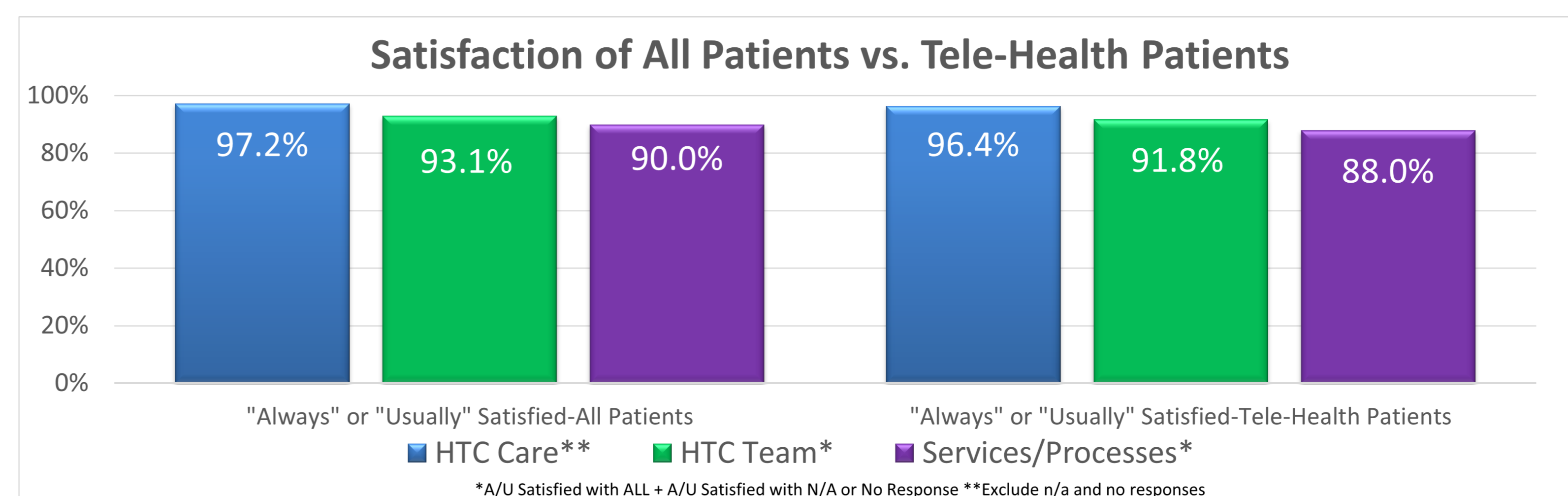


Figure 2

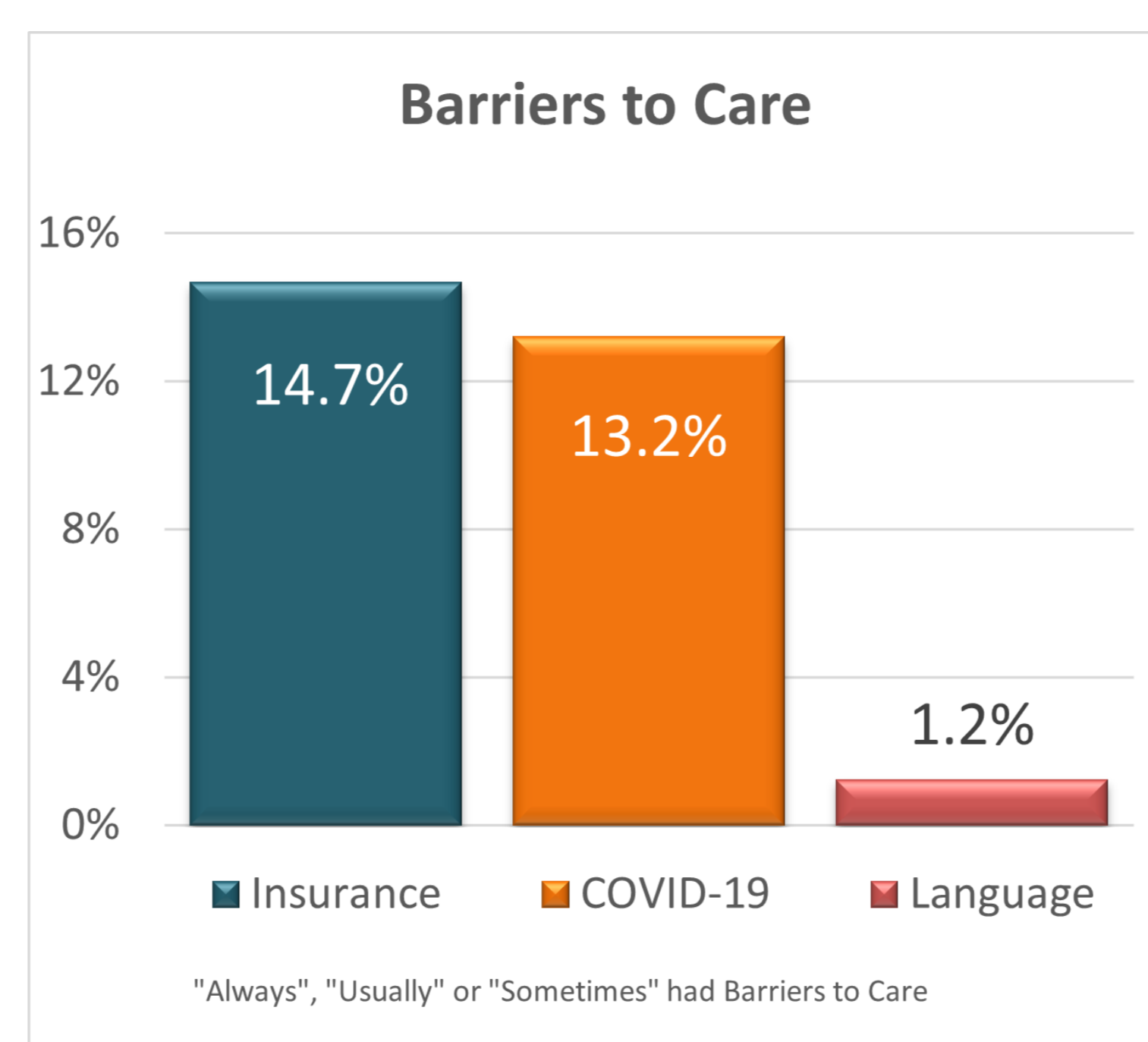
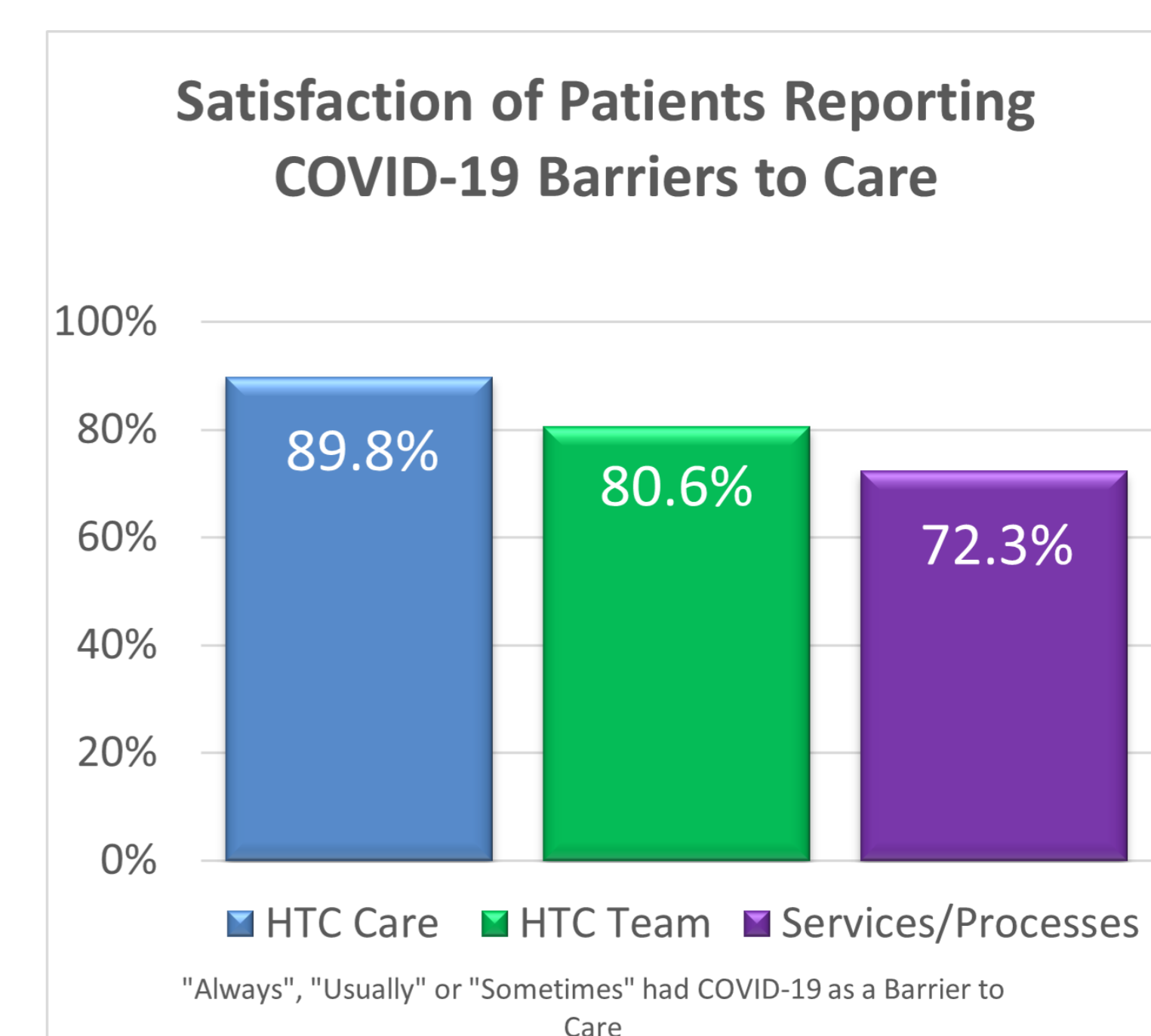


Figure 3



CONCLUSIONS

Conclusions: Patient-reported satisfaction with US HTCs remained high in 2020, despite implementing telehealth and modifying operations due to COVID. Telehealth did not substantively reduce satisfaction with HTC care, services, or processes. But where COVID posed barriers to HTC services, patients reported lower satisfaction levels. A National Patient Satisfaction Survey administered throughout the US HTC Network remains feasible, is supported by HTCs nationally, and provides valuable information.