

Understanding Care Utilization & Perceptions of People with Hemophilia A with or without a Current Inhibitor

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BACKGROUND

- The Community Having Opportunity to Influence Care Equity (CHOICE) Project was conducted in partnership between the Centers for Disease Control and Prevention (CDC) and Hemophilia Federation of America (HFA) to survey persons with bleeding disorders (PWBD) in the US, including those who do not receive care at federally-funded hemophilia treatment centers (non-HTC PWBD).
- HFA and CDC collaborated on the development of the CHOICE survey questions with input from members of the bleeding disorders community.
- From April 2013 to July 2015, HFA recruited US PWBD ≥18 years old (adults) and caregivers of children with bleeding disorders for CHOICE through email, social media, print, and word-of-mouth to take an approximately 20-minute survey in English or Spanish, online or on paper.
- Non-HTC PWBD were solicited specifically but others were not excluded from participation.
- Survey elements included diagnosis, treatment regimen and products used, inhibitor status, joint function and disease (invasive orthopedic procedures, use of pain medication), bleeding history, HIV and hepatitis infection and other comorbidities, health services utilization (usual source of care, frequency of care, barriers to regular care, delay of care, emergency room utilization and hospitalizations within the past 12 months), demographics, and patient satisfaction (RAND PSQ-18).¹
- Participants' status as non-HTC PWBD was determined by algorithm.

OBJECTIVES

- To retrospectively explore and characterize demographics, disease severity, and care perceptions among people with hemophilia A (PwHA) with or without a current inhibitor against FVIII who took the CHOICE survey to better understand burdens of illness and how to address those burdens.

METHODS

- PWBD who took the CHOICE survey and reported single diagnosis of hemophilia A were divided into two cohorts: PwHA with or without a current inhibitor.
- CHOICE survey metrics of (1) patient characteristics, (2) symptoms and treatments, and (3) care location and physician information were reviewed to gain a better understanding of burden of illness.
- Survey elements analyzed included demographics, diagnosis, treatment regimen and treatment products used, health services utilization (usual source of care, frequency of care, barriers to regular care, delay of care, hospital emergency room [ER] utilization, and hospitalizations within the past 12 months), and patient satisfaction.
- CHOICE survey participants were only required to respond to survey questions for gender, age, and whether they took the survey for themselves or their child. Questions for other criteria included multiple response options which may not appear in the figures, including "Prefer not to respond" and providing no response. This leads to different numbers of patients (N's) for each survey question; thus, percentage calculations are unique for each question.
- Descriptive statistical analyses of PwHA were performed based on the chi-square test (P-values).
- XLSTAT version 18.07² year 2017 and Excel 10³ were used to compute frequencies for all elements, as well as the Pearson chi-square or Kruskal Wallis test to evaluate the association of inhibitor status with outcome variables.

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WEO, EC, and JC are employees of the Hemophilia Federation of America; AC is employee of AC Analytic Solutions, LLC; YX, PK, RHK, and PGS are employees of Genentech.

REFERENCES

¹ The RAND Patient Satisfaction Questionnaire Short Form (PSQ-18). https://www.rand.org/health/surveys_tools/psq.html

² Copyright (c) 2017 by Addinsoft, New York, NY, USA.

³ Copyright (c) 2016 by Microsoft Inc., Redmond, WA, USA.



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RESULTS

Patient population

- The CHOICE data set includes data from 719 participants from 48 states, with 161 (22%) being non-HTC PWBD.
- For both HTC and non-HTC PWBD, 439 (61%) indicated a diagnosis of hemophilia A only.
 - Among those 439 PwHA, 57 (13%) were deemed non-HTC PwHA; females accounted for 17%; 72% were white and 22% Hispanic; 38% reported a household income of more than \$75,000; 64% had commercial insurance; and 43% were employed full-time (Table 1).

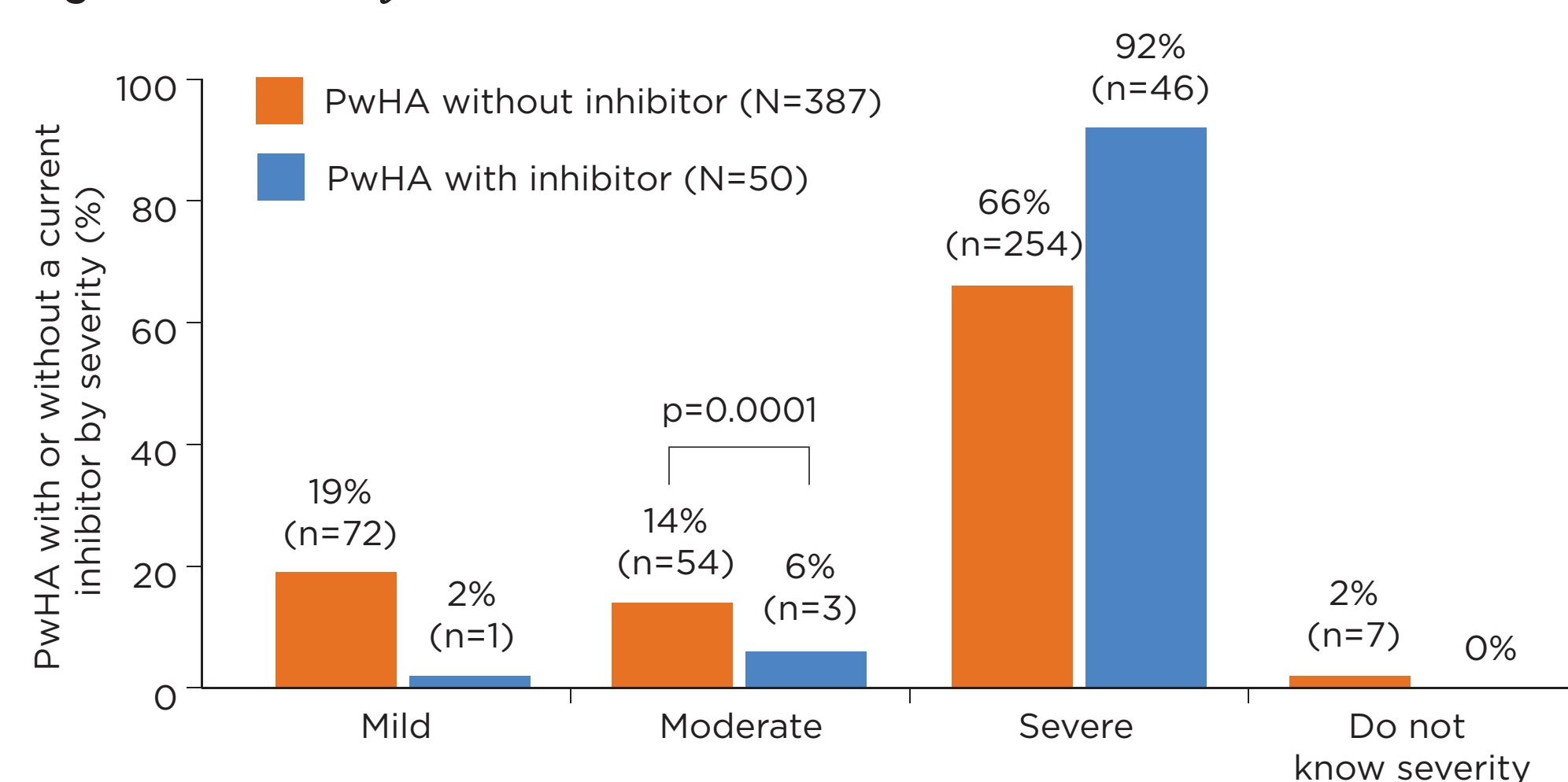
Table 1. Demographic characteristics for PwHA with or without a current inhibitor (N=439)

| | Total | | PwHA without inhibitor | | PwHA with inhibitor | |
|---|-------|----------|------------------------|----------|---------------------|---------|
| | N | n (%) | N | n (%) | N | n (%) |
| Age (years) | | | | | | |
| <18 | 439 | 187 (43) | 389 | 230 (59) | 50 | 28 (56) |
| ≥18 | 439 | 252 (57) | 389 | 159 (41) | 50 | 22 (44) |
| Sex | | | | | | |
| Female | 439 | 76 (17) | 389 | 73 (19) | 50 | 3 (6) |
| Male | 439 | 363 (83) | 389 | 316 (81) | 50 | 47 (94) |
| Race | | | | | | |
| White | 439 | 286 (65) | 389 | 250 (64) | 50 | 36 (72) |
| Asian | 439 | 18 (4) | 389 | 16 (4) | 50 | 2 (4) |
| Black/African American | 439 | 21 (5) | 389 | 18 (5) | 50 | 3 (6) |
| Other | 439 | 21 (5) | 389 | 19 (5) | 50 | 2 (4) |
| Prefer Not to Answer/blank | 439 | 93 (21) | 389 | 86 (22) | 50 | 7 (14) |
| Ethnicity | | | | | | |
| Hispanic | 368 | 64 (17) | 323 | 58 (18) | 45 | 6 (13) |
| Non-Hispanic | 368 | 278 (76) | 323 | 243 (75) | 45 | 35 (78) |
| Prefer Not to Answer | 368 | 26 (7) | 323 | 22 (7) | 45 | 4 (9) |
| Type of insurance | | | | | | |
| Commercial | 351 | 225 (64) | 308 | 203 (66) | 43 | 22 (51) |
| Medicaid | 351 | 61 (17) | 308 | 52 (17) | 43 | 9 (21) |
| Medicare | 351 | 35 (10) | 308 | 28 (9) | 43 | 7 (16) |
| Other | 351 | 30 (9) | 308 | 25 (8) | 43 | 5 (12) |
| Employment status, respondents ≥18 years old | | | | | | |
| Able | 439 | 15 (3) | 389 | 14 (4) | 50 | 1 (2) |
| Employed Full Time | 439 | 188 (43) | 389 | 162 (42) | 50 | 26 (52) |
| Employed Part Time | 439 | 58 (13) | 389 | 50 (13) | 50 | 8 (16) |
| Homemaker | 439 | 34 (8) | 389 | 30 (8) | 50 | 4 (8) |
| Permanently Disabled | 439 | 28 (6) | 389 | 24 (6) | 50 | 4 (8) |
| Other | 439 | 116 (26) | 389 | 109 (28) | 50 | 7 (14) |
| Household income | | | | | | |
| < \$25,000 | 368 | 52 (14) | 322 | 48 (15) | 46 | 4 (9) |
| \$25,000 - \$49,999 | 368 | 76 (21) | 322 | 63 (20) | 46 | 13 (28) |
| \$50,000 - \$74,999 | 368 | 56 (15) | 322 | 49 (15) | 46 | 7 (15) |
| \$75,000 - \$99,999 | 368 | 47 (13) | 322 | 41 (13) | 46 | 6 (13) |
| ≥\$100,000 | 368 | 92 (25) | 322 | 80 (25) | 46 | 12 (26) |
| Prefer Not to Answer | 368 | 45 (12) | 322 | 41 (13) | 46 | 4 (9) |

Hemophilia A severity

- 50 of the 439 PwHA (11%) reported a current inhibitor.
- Mild severity was reported in 2% of PwHA with inhibitor vs. 19% of PwHA without inhibitor (p=0.0001) (Figure 1).

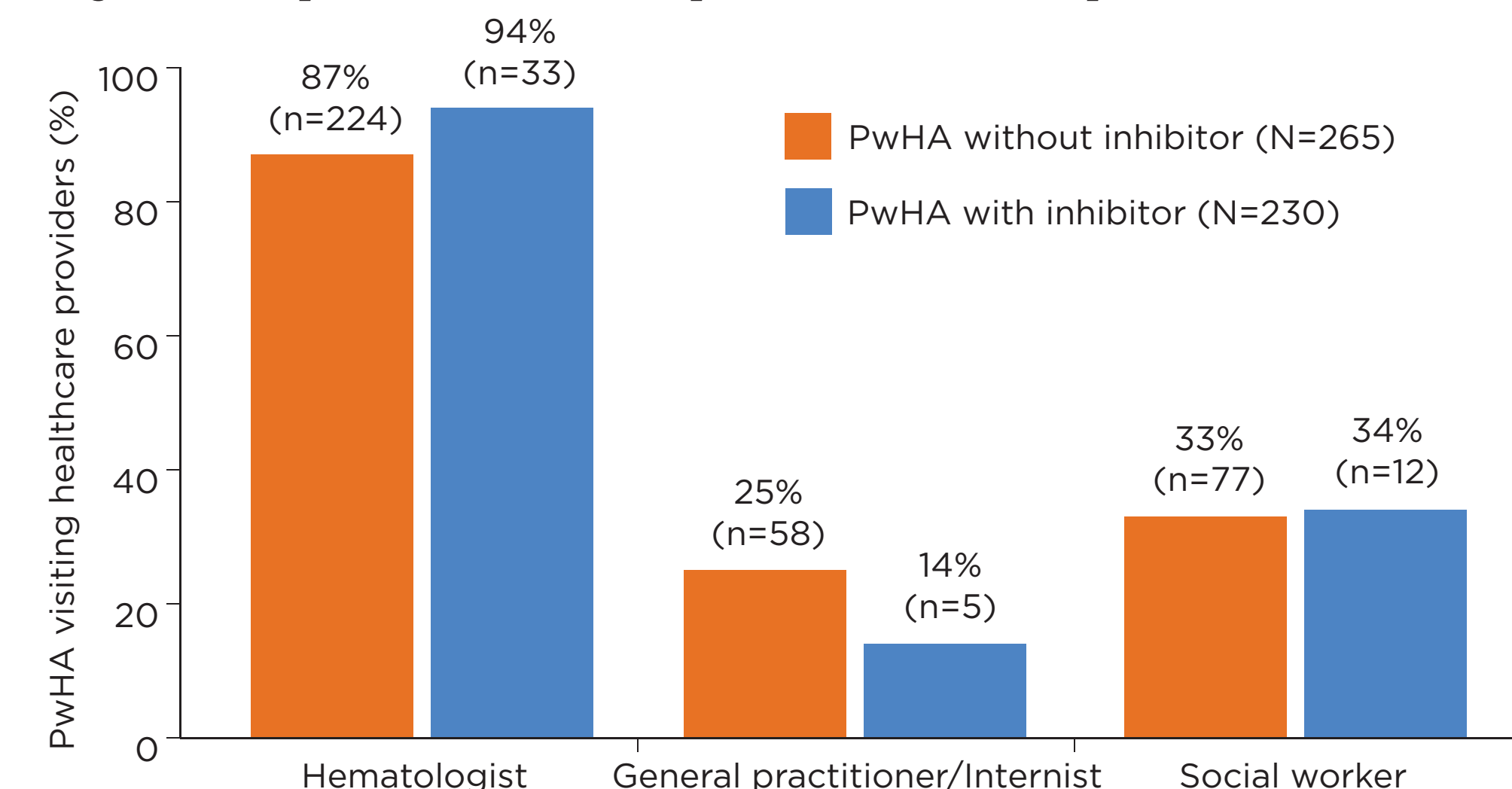
Figure 1. Severity of PwHA with or without a current inhibitor



Healthcare providers and locations for hemophilia A treatment

- Regular visits to a healthcare provider were reported by 96% PwHA with an inhibitor and 89% PwHA without an inhibitor
 - 96% PwHA with an inhibitor and 84% PwHA without an inhibitor saw a healthcare provider at least once/year
- For hemophilia treatment, 94% PwHA with an inhibitor and 87% PwHA without an inhibitor usually saw a hematologist; 14% PwHA with an inhibitor and 25% PwHA without an inhibitor saw a general practitioner/internist; 35% PwHA with an inhibitor and 33% PwHA without an inhibitor saw a social worker (Figure 2).

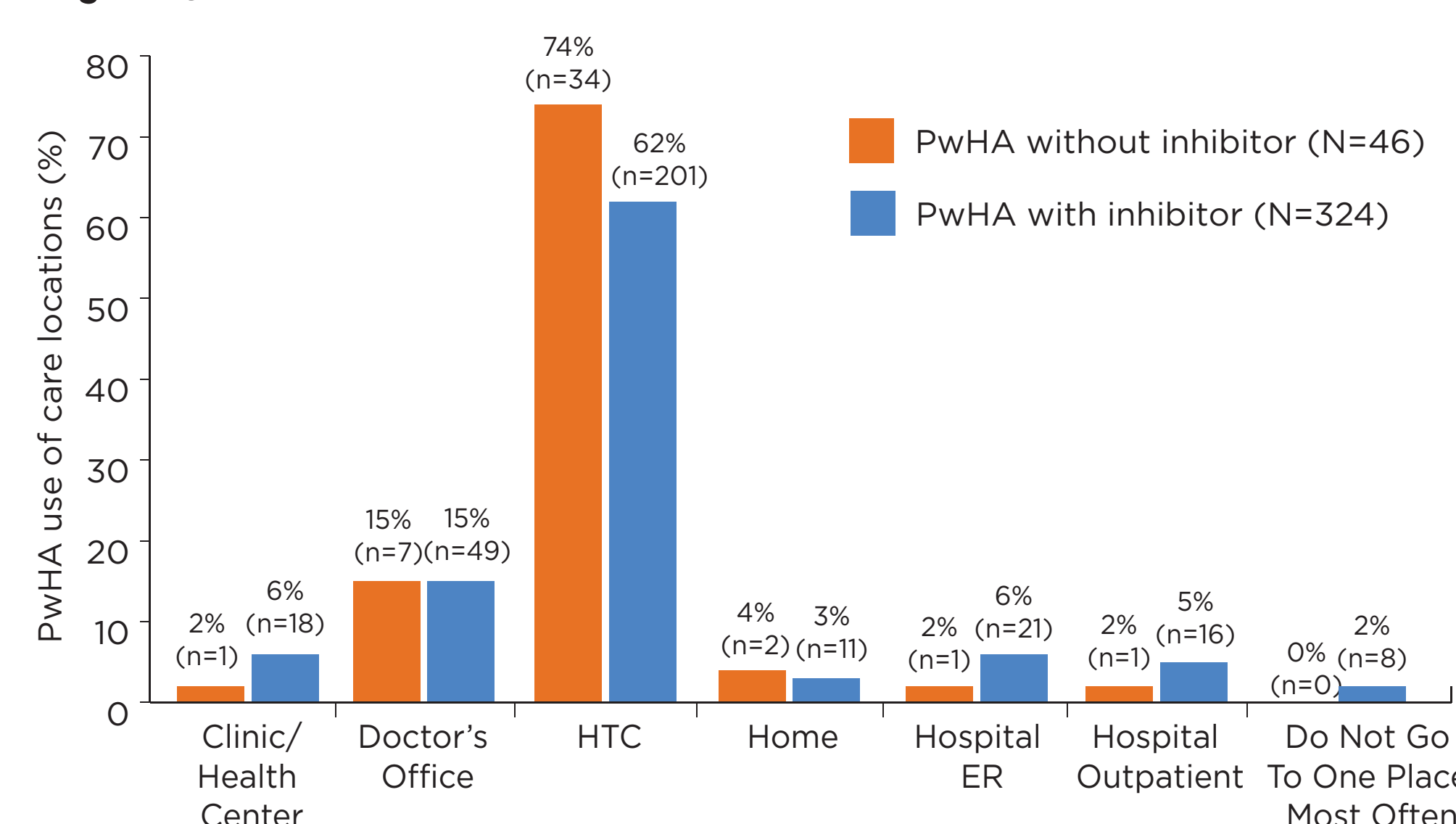
Figure 2. Reported healthcare providers for hemophilia A treatment*



*More than one response allowed.

- Usual places of care for PwHA included: HTC for 74% PwHA with inhibitor and 62% PwHA without inhibitor and doctor's office for 15% PwHA with inhibitor and 15% PwHA without inhibitor (Figure 3).

Figure 3. Care locations of PwHA with or without a current inhibitor*

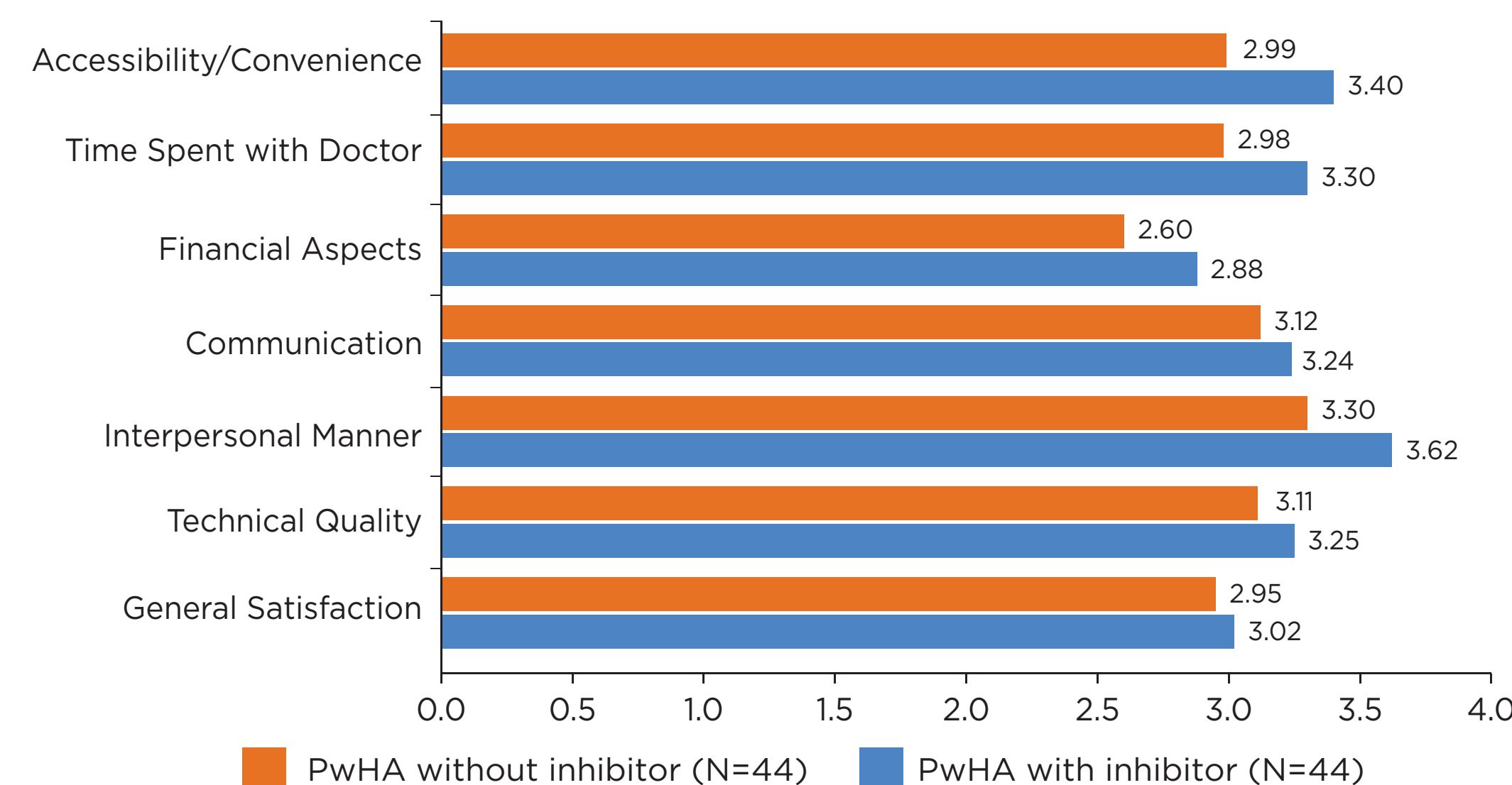


*More than one response allowed.

Patient satisfaction with care

- PwHA with inhibitor reported a slightly higher satisfaction with care than PwHA without inhibitor (3.02 vs. 2.95) (Figure 4).

Figure 4. Average patient satisfaction scores of PwHA with or without a current inhibitor*



*RAND-18. Higher scores reflect satisfaction with medical care.

- PwHA with a current inhibitor were more satisfied with accessibility and convenience of their medical care, the time they spent with their doctor, and interpersonal manner of their doctor.

CONCLUSIONS

- General care satisfaction reported in the CHOICE survey was nearly equal despite differences in inhibitor status, demographics, disease severity levels, care utilization, and where and who PwHA usually see for care of their bleeding disorder.

- Additional analyses are needed to investigate care utilization by age and severity to support improvements in care.

- This sample may not necessarily represent all PwHA, as targeted outreach in some regions may have led to over-representation of some participant characteristics.