

The relationship between different pain measures, depression, and social support and race and ethnicity in persons with hemophilia.

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INTRODUCTION

- The Community Voices in Research (CVR) registry, supported by the National Bleeding Disorders Foundation (NBDF), is a community-powered platform designed to gather information directly from individuals with inheritable bleeding disorders (BDs) and their immediate family members.
- Its primary objective is to enhance understanding of their lived experience and identify pertinent research questions.
- Enrollment occurs through NBDF's and chapter events with a focus on diversity and representation.
- Disparities in healthcare and health outcomes within minoritized and marginalized populations have been extensively documented in the literature.
- Addressing these potential differences necessitates that they first be defined and characterized.
- Despite growing evidence that race/ethnicity may have a negative impact, few studies in BDs account for these variables when analyzing results.

AIM

This analysis aimed to describe the relationship between age, birth sex, pain intensity, impact, and interference; depression, and social support and race/ethnicity in people with hemophilia A and B participating in CVR.

METHODS

- Data were collected from 2019-2022.
- Self-reported measures used included PROMIS Pain Intensity 3a v2.0, Pain Interference 4a v1.1, and depression 8b v1.0; ASCQ-Me Pain Impact SF; and Duke-UNC Functional Support Questionnaire (FSSQ) (7 item version).
- Missing data were pairwise excluded to permit use of partial surveys.
- The 2-sample t-test with unequal variances and Pearson r (Bonferroni-adjusted) were used for analysis.
- Black/Indigenous/People of Color (BIPOC) included those with ≥ 1 race or ethnicity self-identified as Hispanic/Latino (105/30.8%), Black/African American (31/9.3%), Asian (15/4.5%), American Indian/Alaska Native (10/3.0%), South Asian (5/1.5%), Native Hawaiian/Pacific Islander (1/0.3%), or Middle Eastern (0).
- Relationship status was defined as whether or not the respondent was married or in a long-term relationship.
- P values <0.05 stand as statistically significant.

RESULTS

- Adult respondents with hemophilia A or B who disclosed race and/or ethnicity were included (n = 341).
- Social support did not differ significantly by age, race/ethnicity, or relationship status, but was higher in males vs. females (28.5 vs. 26.7, p = 0.036).
- All pain and depression measures were inversely correlated with social support (ranging from -0.30 to -0.57, p <0.001).
- Pain measures were positively correlated with depression score (correlations ranged from 0.50-0.62, p <0.001).
- Depression had a weak inverse correlation with age (r=-0.190, p=0.009); age was not significantly correlated with any of the pain measures.
- Age was lower in Black/African American respondents (35.7 vs. 41.0, p = 0.025) and those of Hispanic ethnicity (37.5 vs. 42.1, p <0.001).
- When combined and compared to White/Caucasian non-Hispanic (WCnH), BIPOC respondents had higher scores for depression scores and all pain measures (Table 1).
- Ethnicity (Hispanic/Latino compared to non-Hispanic/Latino) demonstrated a similar pattern (Table 2).
- Those with Hispanic/Latino ethnicity who were born in the US had lower social support scores as well as higher pain interference, pain impact, and depression scores compared to those born outside of the US (Table 3).

Table 1. Pain, depression, and social support scores for Black/Indigenous/People of Color (BIPOC) respondents compared to White/Caucasian/non-Hispanic or Latino (WCnH) respondents

	BIPOC (n=156)	WCnH (n=160)	p**
PROMIS pain intensity t-score (mean, sd)	59.80 (7.98)	57.33 (10.69)	0.020
PROMIS pain interference t-score (mean, sd)	57.56 (8.06)	55.16 (9.58)	0.016
ASCQ-Me pain impact t-score (mean, sd)	39.27 (9.26)	35.71 (8.98)	<0.001
FSSQ score (mean, sd)*	27.61 (6.01)	28.25 (7.10)	0.393
PROMIS depression t-score (mean, sd)	19.75 (7.95)	15.82 (7.39)	<0.001

Table 2. Pain, depression, and social support scores for Hispanic/Latino respondents compared to non-Hispanic/Latino respondents

	Hispanic/Latino (n=102)	Non-Hispanic/Latino	P
PROMIS pain intensity t-score (mean, sd)	61.29 (6.52)	57.19 (10.40)	<0.001
PROMIS pain interference t-score (mean, sd)	59.61 (6.77)	54.70 (9.43)	<0.001
ASCQ-Me pain impact t-score (mean, sd)	42.21 (7.46)	35.19 (9.27)	<0.001
FSSQ score (mean, sd)*	27.74 (4.89)	28.01 (7.24)	0.687
PROMIS depression t-score (mean, sd)	21.64 (7.58)	15.88 (7.58)	<0.001

Table 3. Pain, depression, and social support scores for Hispanic/Latino respondents born in the US compared to those born outside of the US

	born in US (n=90)	born outside US (n=12)	P
PROMIS pain intensity t-score (mean, sd)	61.71 (6.02)	58.08 (9.20)	0.208
PROMIS pain interference t-score (mean, sd)	60.42 (6.42)	53.54 (6.41)	0.004
ASCQ-Me pain impact t-score (mean, sd)	43.06 (7.12)	35.83 (7.06)	0.005
FSSQ score (mean, sd)*	27.30 (4.65)	31.00 (5.56)	0.046
PROMIS depression t-score (mean, sd)	22.36 (6.92)	16.25 (7.57)	0.019

*7 item version

**2 sample t-test with unequal variances, 2 tailed

CONCLUSIONS

- When compared to WCnH, BIPOC/Hispanic participants reported significantly higher scores on depression and all pain measures, with no difference in social support.
- Among Hispanic participants, those born in the US had the highest pain and depression scores and less social support.
- To comprehensively understand the experience of minoritized and marginalized communities, future studies in BDs should not only collect and report race and ethnicity but they should also analyze results based on these variables.

