Breaking Barriers: Self-Reported Diagnosis Delays in Bleeding Disorder Patients by Birth Sex

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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 is conducted through NBDF community events alongside chapters and through treatment centers. Recruitment for diverse representation includes women, girls, and people with the potential to menstruate (WGPPM).
- Many studies highlight that WGPPM face healthcare disparities.
- Understanding WGPPM experiences is critical to closing these gaps, advancing health equity, and improving health outcomes.

AIM

This analysis aimed to describe the time from symptom onset to diagnosis (TTD) by birth sex and bleeding disorder (BD) type, using self-reported data from Community Voices in Research (CVR), a community-based registry supported by National Bleeding Disorders Foundation that collects data from people with bleeding disorders (PWBD).

METHODS

- Data were collected from 2019-2022.
- 442 PWBD (196 female at birth, 246 male at birth) in 4 diagnostic groups: Hemophilia A, Hemophilia B, Von Willebrand's Disease (VWD) and other (includes platelet disorders, Ehlers Danlos and other factor deficiencies).
- Self-reported TTD and age were separated into 6 time periods.
- Fisher exact tests were used to compare groups.
- Spearman's rho to evaluate the relationship between current age and TTD.
- P values <0.05 stand as statistically significant.

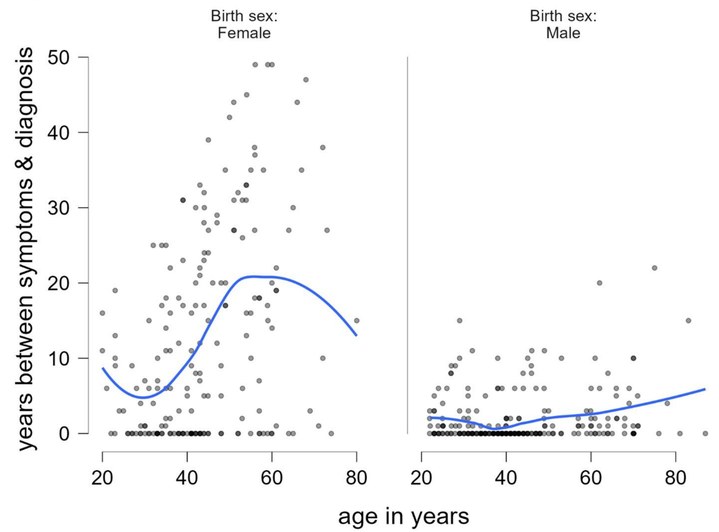
RESULTS

- TTD was significantly longer in females vs. males (p<0.001) and also varied significantly between diagnosis groups (Table 1).
- Females were significantly more likely than males to have TTD >10 years; this difference was statistically significant (p<0.05) for all diagnoses except VWD.
- Figure 1 shows the relationship between current age and TTD for males (rho=0.094, p=0.154) and females (rho=0.391, p<0.001).
- TTD is decreasing significantly in females vs. males (z=3.18, p=0.001). Within grouped age cohorts, 29.1% of females age ≥35 years had TTD within 1 year of symptom onset compared to 71.2% of males (p<0.001); in the age 18-34 cohort, 53.2% of females and 69.7% of males had TTD within 1 year (p=0.064).
- There were no differences in TTD for race, either individually (all >0.05) or when non-White races were combined and compared to White (p=0.115).
- When separated by sex, White males were more likely than non-White males to have TTD <1 year (74.4% vs. 52.5%, p=0.006) while White and non-White females did not differ (32.7% vs. 44.1%, p=0.205).
- There was a main effect of TTD for ethnicity (p<0.001); Hispanic males were more likely to have TTD <1 year than non-Hispanics (82.1% vs. 64.6%, p=0.004) but TTD <1 year did not differ between Hispanic and non-Hispanic females (38.2% vs. 34.8%, p=0.302).

Table 1. Time between onset of first bleeding symptoms and diagnosis

Time between first symptoms and diagnosis	Hemophilia A (n=224)				Hemophilia B (n=94)				VWD (n=69)				Other (n=55)			
	Female (n=67)	Male (n=157)	p (main effect)	p (time period)	Female (n=20)	Male (n=74)	p (main effect)	p (time period)	Female (n=63)	Male (n=6)	p (main effect)	p (time period)	Female (n=46)	Male (n=9)	p (main effect)	p (time period)
	n (%)	n (%)			n (%)	n (%)			n (%)	n (%)			n (%)	n (%)		
Prior	8 (11.94)	6 (3.82)		0.032	4 (20.00)	5 (6.76)		0.093	none			-	6 (13.04)	1 (11.11)		1.000
Same time	9 (13.43)	89 (56.69)		<0.001	5 (25.00)	38 (51.35)		0.044	16 (25.40)	2 (33.33)		1.000	14 (30.43)	4 (44.44)		0.454
Within 1 year	3 (45.48)	20 (12.74)	<0.001	0.090	0	7 (9.46)	<0.001	0.339	2 (3.17)	1 (16.67)	0.375	0.245	2 (4.35)	1 (11.11)	0.007	0.421
2-5 years	4 (5.97)	17 (10.83)		0.322	1 (5.00)	16 (21.62)		0.109	9 (14.29)	0		1.000	1 (2.17)	3 (33.33)		<0.001
6-10 years	6 (8.96)	22 (14.01)		0.053	2 (10.00)	6 (8.11)		0.677	8 (12.70)	1 (16.67)		1.000	6 (13.04)	0.00		0.574
>10 years	37 (55.22)	3 (1.91)		<0.001	8 (40.00)	2 (2.70)		<0.001	28 (44.44)	2 (33.33)		0.687	17 (36.96)	0.00		0.044

Figure 1. Relationship between current age and years between symptoms and diagnosis



CONCLUSIONS

- Self-reported CVR data revealed significant disparities in time to diagnosis (TTD) in WGPPMs with BDs, with race correlated to these differences for males and ethnicity for both birth sexes. Notably, a reduction in TTD for females may suggest a potential shift which needs to be further studied.
- Characterizing diagnostic delays is critical to addressing disparities which are potentially linked to limited treatment access, adverse impacts on education/work, and poor health outcomes. Further research is needed to close these gaps and promote health equity.
- Future research could use socioeconomic determinants and geographical locations of WGPPM populations to further delineate diagnostic disparities.

PLAIN LANGUAGE SUMMARY

The Community Voices in Research registry is community powered and collects information about what it is like to live with a bleeding disorder from those who know these conditions the best: lived experience experts. This research describes a sample of males and females comparing the amount of time that passed between their age at first symptoms and their age at the time of diagnosis. We have found that females tend to experience a greater time to diagnosis than males in the CVR registry, which is statistically significant for all diagnoses except VWD. The time to diagnosis appears to be decreasing for younger generations of women compared to their older counterparts. In terms of race, White males were more likely than non-White males to have a time to diagnosis of under one year, but no difference was found for females. For ethnicity, Hispanic males were more likely to have a time to diagnosis of under one year than non-Hispanics, but no difference was found for females.