

Healthcare Utilization and Health Related Quality of Life in Persons with von Willebrand Disease

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Background

- ❑ von Willebrand disease (VWD) is the most common inherited bleeding disorder
- ❑ Questions remain regarding the impact of VWD-related bleeding phenotype on healthcare utilization, joint health, and health-related quality of life (HRQoL) in the US
- ❑ The study objective is to investigate the impact of VWD bleeding phenotype on healthcare utilization, joint health, and HRQoL in a geographically diverse cohort of individuals with VWD who obtain care at seven US Hemophilia Treatment Centers (HTCs)

Methods

- ❑ Study participants: age ≥ 12 with VWD Type 1 (VWF:Ag/RCo: $\leq 30\%$), low VWF (VWF:Ag/RCo: 30-50%), Type 2, and 3
- ❑ Survey collected sociodemographic and clinical data, self-reported healthcare utilization and bleeding in last 6 months, self-reported pain, joint health and HRQoL measured by EQ-5D-3L at enrollment
- ❑ Clinical chart reviews abstracted information about VWD type and treatment
- ❑ Association of bleeding and VWD type with healthcare utilization, joint health, and HRQoL were assessed

Results: Participants Characteristics by Bleeding Status

Variable	Total (N=100)	Bleed in last 6-month		P Value*
		Yes (N=40)	No (N=60)	
Mean (SD) age	31.7 (18.6)	34.2 (19.3)	30.0 (18.0)	0.28
Mean (SD) age diagnosed VWD	13.6 (13.0)	13.8 (12.4)	13.5 (13.4)	0.91
Mean (SD) age of VWD treatment	15.7 (14.4)	17.0 (12.6)	14.9 (15.4)	0.51
Female gender	80 (80.0)	32 (80.0)	48 (80.0)	1.00
Doctor visits	45 (45.0)	22 (55.0)	23 (38.3)	0.10
Underwent medical procedures	25 (25.0)	17 (42.5)	8 (13.3)	0.001
Hospitalizations	10 (10.0)	8 (20.0)	2 (3.3)	<0.01
Emergency room visits	17 (17.2)	10 (25.0)	7 (11.9)	0.09
Self-reported joint pain	43 (43.4)	19 (48.7)	24 (40.0)	0.39
Joint range of motion limitation	26 (26.3)	14 (35.9)	12 (20.0)	0.08
EQ-5D Mobility: reported any problem	22 (22.2)	13 (33.3)	9 (15.0)	0.03
EQ-5D Usual activities: reported any problem	32 (32.3)	16 (41.0)	16 (26.7)	0.14
Covariate adjusted EQ-VAS ⁺		71.57 (7.32)	75.62 (7.48)	0.36
Covariate adjusted EQ-5D index score ⁺		0.79 (0.06)	0.83 (0.06)	0.23

Note: *P values were calculated from Chi-square tests for categorical variables, and one way ANOVA for continuous variables.
 + Covariates included age, education, employment, race, self-reported joint pain, range of motion limitation, age of diagnosis, and age of start treatment.

Results: Participants Characteristics by VWD Type

Variable	Total (N=99)	VWD Type			p Value*
		Type 1 (N=47, 47.5%)	Low VWF (N=20, 20.2%)	Type 2&3 (N=32, 32.3%)	
Mean (SD) age	31.6 (18.6)	31.5 (19.1)	25.4 (11.5)	35.6 (20.8)	0.16
Mean (SD) age of VWD diagnosis	13.5 (12.9)	13.7 (12.7)	19.2 (11.8)	9.4 (12.9)	0.03
Mean (SD) age began VWD treatment	15.7 (14.4)	15.6 (13.7)	19.4 (11.9)	13.3 (16.6)	0.35
Hospitalizations	10 (10.0)	1 (2.1)	1 (5.0)	8 (25.0)	<0.01
Bleeding events in last 6 months	40 (40.0)	17 (36.2)	7 (35.0)	16 (50.0)	0.48
Self-reported joint pain	43 (43.4)	19 (41.3)	6 (30.0)	17 (53.1)	0.25
Joint range of motion limitation	26 (26.3)	9 (19.6)	4 (20.0)	13 (40.6)	0.16
EQ-5D item anxiety or depression					0.42
No problem	59 (59.6)	30 (65.2)	10 (50.0)	19 (59.4)	
Any problem	40 (40.4)	16 (34.8)	10 (50.0)	13 (40.6)	
Adjusted EQ-VAS ⁺		77.30 (7.59)	64.77 (8.82)	78.71 (7.40)	0.06
Adjusted EQ-5D index score ⁺		0.84 (0.06)	0.76 (0.07)	0.84 (0.06)	>0.11

Note: *P values were calculated from Chi-square tests for categorical variables, and one way ANOVA for continuous variables.
 + Covariates included age, education, employment, race, bleeding in last 6-month, self-reported joint pain, range of motion limitation, age of diagnosis, and age of start treatment.

Conclusions

- ❑ Persons with VWD receiving care at US HTC experience significant illness burden regardless of severity
- ❑ Self-reported recent bleeding was associated with increased healthcare utilization and negative impact on joint health and HRQoL
- ❑ Bleeding phenotype was significantly associated with healthcare utilization
- ❑ Delayed diagnosis and treatment for persons with low VWF may impact their HRQoL, and if confirmed in a larger sample size would underscore the fact that low VWF is not necessarily a mild disorder compared to other VWD subtypes

ACKNOWLEDGEMENTS

The study is supported by Investigator-Initiated Research grant provided by Baxalta US Inc., Bannockburn, IL (a Takeda Company), CSL Behring L.L.C., and Octapharma USA, Inc. Authors thanks all study participating centers (ranked by study center ID): University of Southern California: Michael B. Nichol, PhD, Principal Investigator (PI), Joanne Wu, MS, Steven Carrasco, MPH. Emory University & Children's Healthcare of Atlanta, Atlanta, GA: Robert F. Sidonio, Jr. MD, Site PI, Veronica Masters, Kingsley Abanofor, Rachana Kanvinde, Gladys Lee; Bleeding & Clotting Disorders Institute, Peoria, IL: Jonathan C. Roberts, MD, Site PI, Sarah Gonzales; Children's Hospital Los Angeles, Los Angeles, CA: Cathliyn Buranahirun, Psy.D, Emily Krava, Sarbjit Kaur; Michigan State University Center for Bleeding and Clotting Disorders, East Lansing, MI: Roshni Kulkarni, MD, Site PI, Anna Robinson, Kathleen Anderson; Children's Mercy Hospital, Kansas City, MO: Shannon L. Carpenter, MD, Site PI, Emily McElwaine, Lois Hester; Mary M. Gooley Hemophilia Center, Inc., Rochester, NY: Peter A. Kouides, MD, Site PI, Elisabeth Ambrose, Eric Iglewski; BloodWorks Northwest, Seattle, WA: Barbara Konkle, MD, Site PI, Rachel Hervey, Sarah Galdzicka, Sarah Ruuska.

Conflict of Interest

The study is supported by Investigator-Initiated Research grant provided by Baxalta US Inc., Bannockburn, IL (a Takeda Company), CSL Behring L.L.C., and Octapharma USA, Inc.

Jonathan C. Roberts Consulting: Novo Nordisk, Octapharma, Pfizer, Sanofi, Takeda, uniQure; Research funding: Takeda; Speakers Bureau: Novo Nordisk, Octapharma, Sanofi, Takeda. Roshni Kulkarni, 1) Advisory boards: Bioverativ/Sanofi, BPL, Genentech, Kedrion, Novo Nordisk, Octapharma, Pfizer, Takeda, Catalyst Bioscience Bayer; 2) Clinical Trials: Sanofi/ Bioverativ, Bayer, Biomarin, Shire/Takeda, Novo Nordisk, Freeline; 3) Speakers bureau, stocks or shares: none. Peter A. Kouides have no significant conflicts of interest to declare. Robert F. Sidonio Jr. received consultant fees from Bayer, Bioverativ/Sanofi, Novo Nordisk, Takeda, Uniquire, Biomarin, Octapharma, Catalyst, Grifols, Sigilon, Tremeau, Genentech/Roche and has study funding from Octapharma, Grifols, Takeda and Genentech. Shannon L. Carpenter received honoraria from Novo Nordisk, Genentech, and Kedrion Pharmaceuticals. Barbara A. Konkle has received grant funding from Pfizer, Sangamo, Sanofi, Sigilon, Takeda and Uniquire and has received consulting fees from BioMarin, CSL Behring, Pfizer and Sigilon. Joanne Wu and Steven Carrasco received financial support through the project funding provided by Baxalta US Inc., Bannockburn, IL (a Takeda Company), CSL Behring L.L.C., and Octapharma USA, Inc. Randall Curtis received a consultant fee from USC through the project funding provided by Pfizer. He also received consultant fees from Bayer, and Novo Nordisk. Judith Baker, Megan Ullman have no significant conflicts of interest to declare. Duc Quang Tran Jr. received consultant fees from Bayer, Bioverativ, Novo Nordisk, and Takeda. Michael B. Nichol is the principal investigator for the HUGS research group and has received grant funding from multiple sources including Pfizer, Genentech Inc., Baxalta US Inc., Bannockburn, IL (a Takeda Company), Octapharma, CSL Behring, and Global Blood Therapeutics.