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Health status of people living with non-severe hemophilia

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PROBE
Patient Reported Outcomes Burdens and Experiences Study

BACKGROUD

- Mild haemophilia and moderate haemophilia are defined as a reduced coagulation factor of 5 to <40 IU/dL and >1 to 5 IU/dL1, respectively.
- There are limited data on the health status of people living with mild/moderate haemophilia.

OBJECTIVES

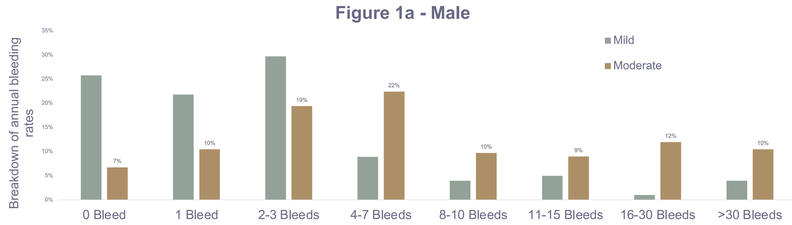
- This study aimed to investigate the overall health status of people living with non-severe haemophilia, compared to people without bleeding disorders.

METHODS

- Respondents were enrolled through non-government organizations (NGO) working in haemophilia and bleeding disorders.
- Among these, 862 people self-reported as having no bleeding disorder (NoBD), or mild or moderate haemophilia, and without history of an inhibitor were included in the analysis.
- Respondents were asked to complete the PROBE questionnaire, which comprise general health domain, hemophilic specific domain and health-related quality of life (HQRoL) domain.
- The primary outcome of the study was to compare the health status and HRQoL of people with NoBD and people living with non-severe (mild and moderate) haemophilia.

RESULTS

Figure 1. Breakdown of bleeding rates in the past 12 months in people with mild and moderate hemophilia (Figure 1a. Male, Figure 1b. Female)



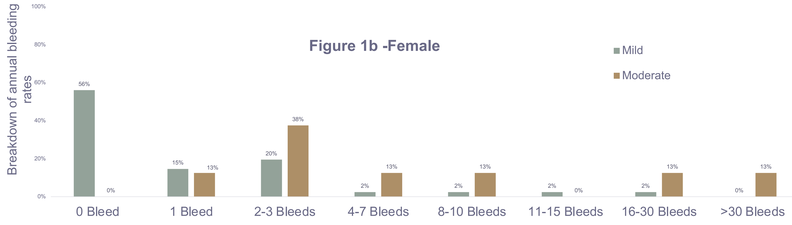
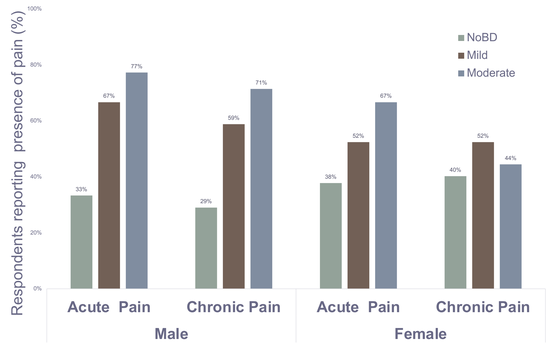


Figure 2. Reported acute and chronic pain by gender



RESULTS

Table 1. Model fit statistics for multivariable regression of categorical variables, analysed separately for VAS, EQ-5D and PROBE Score

	VAS n = 740		EQ-5D n = 725		PROBE n = 578	
	Coeff (95% C.I)	P-value	Coeff (95% C.I)	P-value	Coeff (95% C.I)	P-value
Age	-0.002 ([-0.002] - [-0.001])	<0.001	-0.001 ([-0.002] - [-0.001])	<0.001	-0.002 ([-0.003] - [-0.001])	<0.001
World Bank Income (GNI) categorisation						
Low-middle	Base Case					
Upper-middle	0.047 ([-0.016] - [0.111])	0.148	0.049 (0.016 - 0.084)	0.004	-0.017 ([-0.077] - [0.043])	0.583
High	0.034 ([-0.029] - [0.099])	0.283	0.017 (0.029 - 0.096)	<0.001	-0.031 ([-0.090] - [0.027])	0.301
Gender						
Female	Base Case					
Male	0.024 ([-0.011] - [0.060])	0.174	0.014 ([-0.004] - [0.033])	0.126	0.040 ([0.009] - [0.070])	0.011
Comorbidities	-0.042 ([-0.053] - [-0.031])	<0.001	-0.021 ([-0.028] - [-0.014])	<0.001	-0.041 ([-0.050] - [-0.031])	<0.001
Bleeding disorder						
NoBD	Base Case					
Mild	-0.073 ([-0.114] - [-0.033])	<0.001	-0.058 ([-0.080] - [-0.037)	<0.001	-0.120 ([-0.155] - [-0.084])	<0.001
Moderate	-0.161 ([-0.207] - [-0.114])	<0.001	-0.118 ([-0.143] - [-0.094])	<0.001	-0.235 ([-0.276] - [-0.196])	<0.001
Constant	0.134 ([-0.206] - [-0.063])	<0.001	0.442 ([0.384] - [0.460])	<0.001	-0.025 ([-0.915] - [0.041])	0.451

CONCLUSIONS

- Majority of respondent with mild and moderate hemophilia did not receive prophylaxis. They reported varied amount of annualized bleeding episodes.
- They reported significant negative impact on pain and HRQoL compared to respondents without bleeding disorders.
- Future research is needed to identify the optimal care management of patients with mild and moderate haemophilia.