IMPACT OF HEMOPHILIA ON EMPLOYMENT - INSIGHTS FROM THE PROBE STUDY

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OBJECTIVE

The impact of hemophilia on working life, the ability to pursue a desired career or sustain full employment have been previously reported. The aim of this analysis was to seek a better understanding of hemophilia-related health problems likely to impact employment.

METHODS

- This analysis utilized data from the PROBE (Patient Reported Outcomes, Burdens and Experiences) study.
- People with severe hemophilia A and B (PwSH) and controls with no bleeding disorder (NoBD) reporting working part-time due to their health or having retired early due to their health were compared with those working full-time.
- Descriptive statistics were used to present the results as n (%) and odds ratio (95% CI) for associations for participants with any health problems, use of mobility aids, use of pain medication, having acute or chronic pain, difficulties with activities of daily living and history of joint surgery.

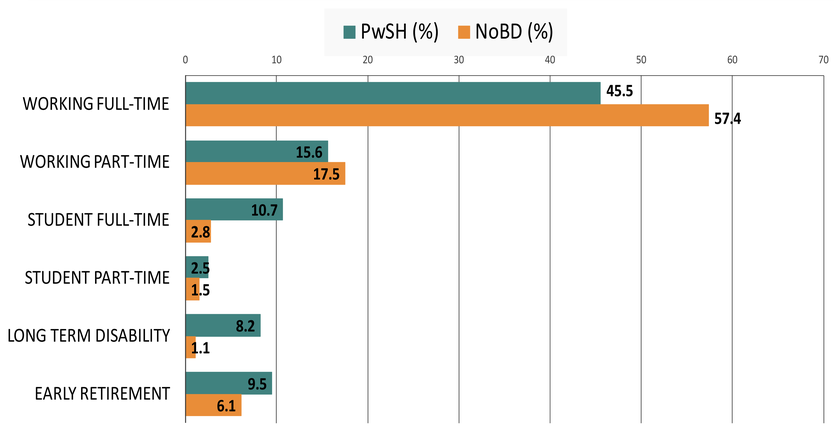
SUMMARY

- Data from 1008 participants (550 PwSH, 458 NoBD) ≥ age 18 from 21 countries were analyzed. (Table 1, Figure 1)
  - 250 PwSH (45.5%) and 263 NoBD (57.4%) reported working full time.
  - 86 PwSH (15.6%) and 80 NoBD (17.5%) reported working part-time. 27 of the 86 PwSH (31.4%) and 3 of the 80 NoBD (3.8%) reported working part-time due to health.
  - 52 PwSH (9.5%) and 28 NoBD (6.1%) reported taking early retirement. 25 of the 52 PwSH (48.1%) and 1 of the 28 NoBD (3.6%) reported taking early retirement due to health.
- Mean age of participants was 39 (14.4 SD) for PwSH and 45.3 (13.7 SD) for NoBD. (Table 2)
- Association between reporting a health-related problem and reporting to be working part-time or taking early retirement due to health: use of mobility aids 77.7 (3.8-1645), acute pain 41.2 (2-831.8), use of pain medication 23 (2.05-258.1), participants with any health problems 22.5 (2-252.6), chronic pain 16.5 (1.5-179.2), difficulties with activities of daily living 16.5 (1.5-179.2), and history of joint surgery 7.3 (0.4-148). (Table 3)

Table 1. Analysis of work and school responses for PwSH vs NoBD

	PwSH (n=550) (n, %)	NoBD (n=458) (n, %)	Odds Ratio (95% CI)*	Z Statistic	Chi-square	P-Value†
Working full-time	250 (45.5)	263 (57.4)	0.74 (0.54-1.01)	1.88	3.56	0.059
Working part-time	86 (15.6)	80 (17.5)	1.01 (0.7-1.5)	0.04	0.001	0.972
•Due to health	27 (31.4)	3 (3.75)	22.9 (5.75-91.2)	4.44	26.17	<0.0001
•By choice	26 (30.23)	37 (46.25)	0.4 (0.16-1.05)	1.87	3.56	0.06
Student full-time	59 (10.7)	13 (2.8)	4.8 (2.6-9.2)	4.9	27.8	<0.0001
Student part-time	14 (2.5)	7 (1.5)	1.9 (0.8-4.9)	1.4	2.04	0.16
Long term disability	45 (8.2)	5 (1.1)	8.9 (3.5-22.8)	4.53	28.3	<0.0001
Early retirement	52 (9.5)	28 (6.1)	1.7 (1.1-3.05)	2.4	5.89	0.015
•Due to health	25 (48.1)	1 (3.6)	83.3 (7.7-899)	3.6	22.86	0.0003
•By choice	18 (34.6)	10 (35.7)	1.8 (0.5-6.3)	0.9	0.86	0.35

Figure 1. Analysis of work and school responses



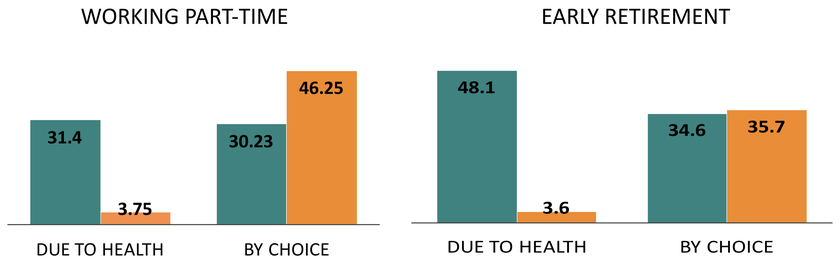


Table 2. Participant Characteristics

	PwSH (n=550) (n, %)	NoBD (n=458) (n, %)	P-Value†
Gender			
•Male	534 (98.7)	147 (32.1)	<0.001
Age, Mean (SD)	39 (14.4)	45.3 (13.7)	<0.001
Married or in a long relationship	349 (63.5)	393 (85.8)	<0.001
Having children	239 (43.5)	346 (75.5)	<0.001
Diagnosis			
•Hemophilia A	474 (86.2)	N/A	N/A
•Hemophilia B	76 (13.8)		
Have been diagnosed with clinically significant inhibitor	92 (16.7)	N/A	N/A
Currently having a clinically significant inhibitor	34 (6.2)	N/A	N/A

Table 3. Association of the primary health related problems and working part-time or early retirement due to health

	PwSH (n=550) (n, %)	NoBD (n=458) (n, %)	Odds Ratio (95% CI)*	Z Statistic	Chi-square	P-Value†
Using mobility aids	47 (8.05)	0	77.7 (3.8-1645)	2.8	N/A	0.005
Having acute pain	43 (7.36)	0	41.2 (2-831.8)	2.4	N/A	0.01
Using pain medication	46 (7.88)	1 (0.19)	23 (2.05-258.1)	2.5	11.1	0.01
Experiencing any health problems	45 (7.71)	1 (0.19)	22.5 (2-252.6)	2.5	10.84	0.01
Having chronic pain	44 (7.53)	1 (0.19)	16.5 (1.5-179.2)	2.3	8.36	0.02
Difficulties with daily living	44 (7.53)	1 (0.19)	16.5 (1.5-179.2)	2.3	8.36	0.02
Underwent joint surgery	26 (4.45)	0	7.3 (0.4-148)	1.3	N/A	0.197

*The odd ratio (OR) and 95% confidence interval is univariate analysis.
†P-value is calculated according to Sheskin, 2004

CONCLUSION

- PwSH are more likely to report working part-time or having taken early retirement due to health-related problems than people with NoBD.
- Among the study population, we find a significant negative impact of hemophilia on employment status.
- PwSH are associated with a higher rate of working part-time or retiring early due to health than age-matched controls.
- Use of mobility aids, acute and chronic pain, difficulties with activities of daily living and history of joint surgery are associated with working part-time or retiring early.

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PROBE
Patient Reported Outcomes Burdens and Experiences Study

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For more information or to contact the investigarots
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