# PART-TIME EMPLOYMENT AND EARLY RETIREMENT IN PEOPLE WITH SEVERE HEMOPHILIA: INSIGHTS FROM THE PROBE STUDY

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#### BACKGROUND

Advances in haemophilia treatment have revolutionized care and management of the disease, however economic, social and educational barriers still remain for people living with severe haemophilia (PwSH). Contextual factors such as impact on employment and work life are typically not captured in cost-effectiveness analysis.

### **METHODS**

- This analysis utilized data from the PROBE (Patient Reported Outcomes, Burdens and Experiences) study.
- People with severe hemophilia A and B (550 PwSH) and controls with no bleeding disorder (458 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 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.

#### **RESULTS**

- 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)

# 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 parttime 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.

# **ACKNOWLEDGEMENTS**

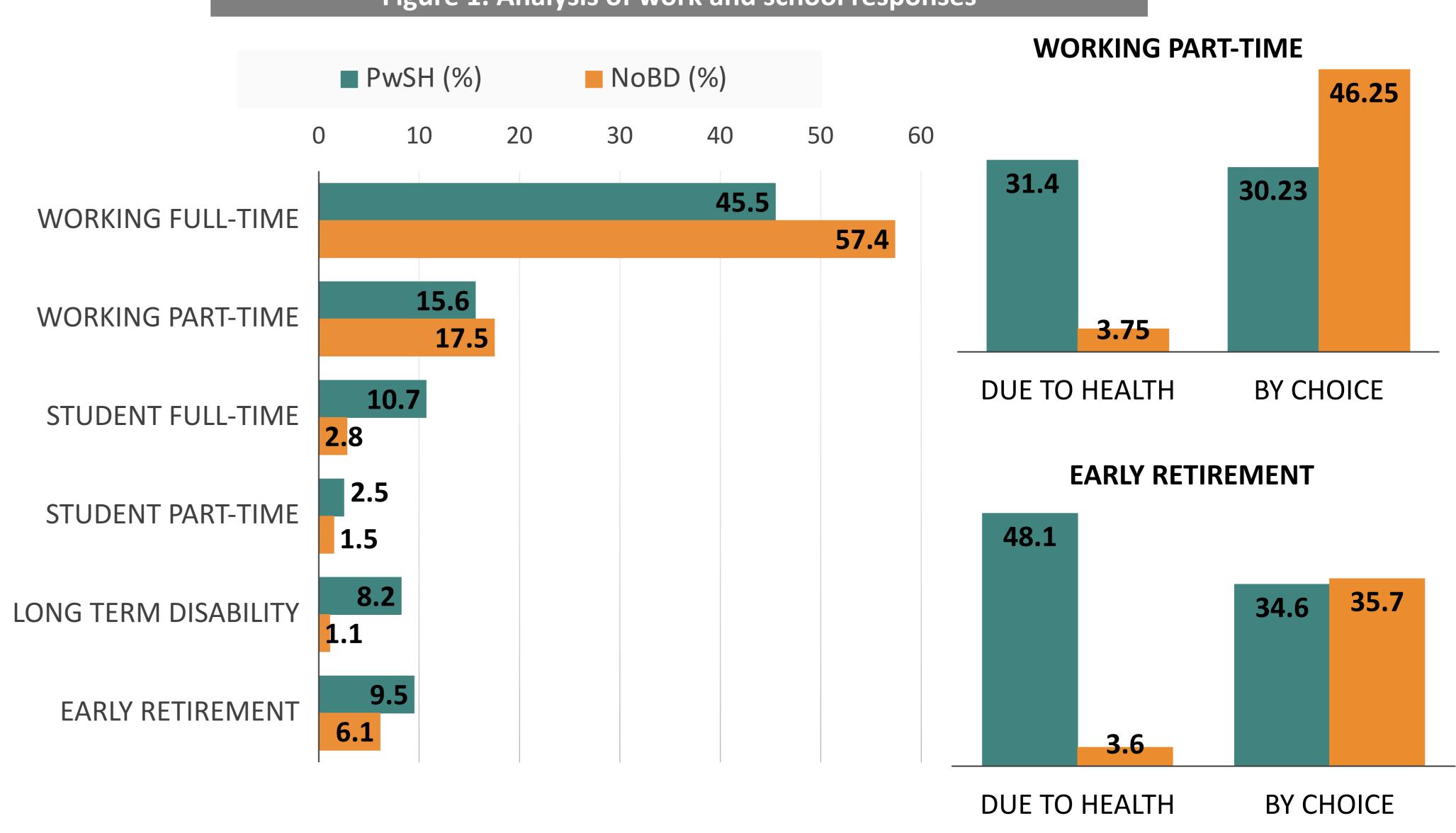
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## Table 1. Analysis of work and school responses for PwSH vs NoBD

	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
<ul> <li>Due to health</li> </ul>	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
<ul> <li>Due to health</li> </ul>	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			<b>∠</b> 0.001
• 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	02 /1 ( 7))	NI/A	NI/A
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

†P-value is calculated according to Sheskin, 2004



