

Impact of hemophilia on employment - Insights from the PROBE Study

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. The analysis utilized data from the Patient Reported Outcomes Burdens and Experience (PROBE) study. Participants selected from among 7 possible responses (working full-time, working part-time, student full-time, student part-time, long-term disability, early retirement and other (e.g., unemployed, parental leave, retired)) to describe their current employment or school status. People with severe hemophilia A and B (PwSH) and controls with no bleeding disorder (NoBD) were compared for the proportion (percentage) reporting either working part-time due to their health or having retired early due to their health, and the proportion reporting working full-time. Descriptive statistics were used to present the results as n (%), and odds ratio (95% CI) were calculated for the associations and assessed for their statistical significance.

Summary. Data from 1008 participants (550 PwSH, 458 NoBD) \geq age 18 from 21 countries were analyzed. Mean age of participants was 39.0 (14.4 SD) for PwSH and 45.3 (13.7 SD) for NoBD. 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. Analysis of the association between reporting a health-related problem and reporting to be working part-time or taking early retirement due to health include [odds ratio (95% CI), positive numbers indicating number of times higher chance of being part-time/retired early]: use of mobility aids 77.7 (3.8-1645), acute or chronic 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).

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.