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) ≥ 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.