Factors influencing quality of life in adults with haemophilia in China: results from the HERO study

Introduction
- People with haemophilia A (HA) and B (HB) may need additional care and may encounter barriers in their daily lives and their careers due to the lifelong bleeding tendency, which may lead to psychosocial issues.
- In China, people with haemophilia (PWH) have been reported to have a significantly lower health-related quality of life (QoL) compared with the general male population.
  - Using a specially designed questionnaire that measured 4 dimensions of a person’s QoL, age, severity of disease, degree of arthropathy, hepatitis status, salary, and mean annual expenditure for replacement therapy were predictors of QoL.
  - The Haemophilia Experiences, Results and Opportunities (HERO) study aimed to identify psychosocial issues in PWH and parents of children with haemophilia.

Objectives
- To describe potential factors influencing QoL in PWH (aged ≥18 years) in China.

Methods
- HERO included a questionnaire survey that included 675 PWH from 10 countries (Algeria, Argentina, China, Canada, France, Germany, Italy, Spain, UK, and USA).
  - HERO collected information regarding demographics, relationships, disease control, treatment, and QoL.
  - QoL was estimated using the EQ-5D index (healthy subject score = 1.00) and the EQ-5D visual analog scale (VAS, 0-100, coded as an 11-point categorical response).
  - ANOVA models were used to analyse the effect on the EQ-5D index/VAS score.
    - Current age, diagnosis age, treatment regimen, usage of replacement factor concentrates, and bleed frequency were fixed factors.
    - Univariate analyses were first performed to examine the relationship of the following variables with the EQ-5D index/VAS score: employment, work industry, marital status, psychological treatment, person responsible for treatment, treatment location, adherence to prescribed dosing, and number of visits to the haemophilia treatment centre (HTC).
    - Only those variables with significant impact on QoL were incorporated into the multivariate ANOVA model.

Results

Characteristics and QoL of PWH in China
- A total of 110 PWH from China completed the questionnaire.
  - The age, diagnosis age, annual bleed frequency, and EQ-5D scores of PWH in China are summarized in Table 1.

Employment of PWH in China
- With the univariate analyses, employment was verified to significantly correlate with QoL of PWH in China.
  - Employment status of PWH in China (Figure 1)
    - Less than half of PWH were employed: 25.2% full time; 2.9% part time, 17.5% self-employed.
    - PWH on other status are counted as unemployed: 29.1% with long-term disability; 5.8% with short-term disability.

Employment of PWH in China for different age groups (Figure 2)
- The majority (68.2%) of PWH in China believed having haemophilia had a very large negative impact on their working life (Figure 2).

Potential predictors of QoL
- In the multivariate ANOVA model, age, diagnosis age, treatment regimen, replacement factor usage and bleed frequency were not identified as significant factors influencing QoL of PWH in China (Figure 3 and 4).

EQ-5D index was higher for those who were employed compared to those who were unemployed (Figure 2), but VAS did not differ significantly (Figure 3): 
  - EQ-5D index score (least square [LS] means): employed (0.75) vs unemployed (0.66) (P<0.05).
  - VAS (LS means): employed (7.47) vs unemployed (6.78) (P=0.16).

Conclusions
- In China, employment of PWH was, in general, negatively impacted by the disease.
- Employment of PWH in China was positively associated with better QoL, as assessed by EQ-5D index.

References

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