The Relationship Between Bleeding Frequency and EQ-5D in Severe Haemophilia

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INTRODUCTION

- Joint bleeding (haemarthrosis) is a distinctive characteristic of haemophilia with physical and psychological effects. It has an immediate impact resulting in pain, swelling, inability to follow daily activities, as well as long-term severe consequences for patients’ mobility and general well-being.1 A single joint bleed may cause permanent damage. Two or three bleeds into the same joint can result in increased bodily pain, reduced physical functioning or disability.2

- Recurrent haemorrhage in the same joint may result in irreversible intra-articular damage, chronic pain, impaired mobility, and inability to do certain jobs culminating in haemophilia arthropathy. This along with the psychological consequences for the patients and their social function can negatively impact their health-related quality of life (HRQoL).2

- Haemophilia treatment depends on the severity of the condition and the patient’s preferences. There are two main approaches to treating haemophilia patients: preventative (prophylaxis) and on-demand (OD) treatment.

- Optimal HRQoL outcomes can be supported by maintaining low or zero ABR among haemophilia patients through prophylactic treatment.2

OBJECTIVE

- The purpose of this abstract is to investigate, using descriptive analysis, the association between annual bleeding rates (ABR) and HRQoL of patients with severe haemophilia A or B.

METHODS

- Data were taken from the Cost of Haemophilia across Europe: Socioeconomic Survey (CHESS) – A cross-section of 159 haemophilia patients (surveyed between January and April 2015) providing demographic and clinical information and 12-month ambulatory and secondary care activity for 1,255 patients via an online survey. In turn, 501 of these patients provided corresponding direct and indirect non-medical cost information, including work loss and out-of-pocket expenses. A cost database was developed for each country using publicly-available information. Study ethics was governed and approved by the University of Chuo’s Ethics Committee.

- The inclusion criteria for the study were that patients have a factor level of < 1%, are over 18 years old and are diagnosed with hereditary haemophilia A or B.

- The EQ-5D-3L instrument was the patient-reported outcome measure (PROM) used to assess the HRQoL of participants in CHESS.

- Physician-recorded monthly bleeding rates were annualized to generate ABRs. Patients were grouped into one of five cohorts (ABR ≥ 12, 4, 36, or 48). Standard Hists were conducted to test for between-group differences.

- Patients with inhibitors were excluded from this analysis

- Treatment strategies in this analysis have been categorized as primary prophylaxis (on prophylaxis from diagnosis), secondary prophylaxis (on prophylaxis, previously on-demand at any point), primary on-demand (always on-demand), and secondary on-demand (previously on prophylaxis and moved to on-demand regimen).

RESULTS

- Table 1: Breakdown of Treatment Strategies of Study Population

- Patients with no recorded bleeding (n = 172) reported the highest mean EQ-5D score, 0.34 (standard deviation (SD) 0.211.

- ABRs inversely correlated with EQ-5D: individuals with one recorded bleed per month (ABR = 12; n = 251) reported mean EQ-5D of 0.78 (SD 0.26); in the ABR = 24 cohort (n = 68), mean reported EQ-5D decreased to 0.48 (SD 0.31); for ABR = 36 (n = 15), mean reported EQ-5D is similar, 0.69 (SD 0.25). In the ABR = 48 cohort (n = 7), mean EQ-5D almost halves versus the ABR = 36 cohort (mean 0.37, SD 0.32). With the exception of ABR = 24 versus ABR = 36, cohort differences between groups were found to be statistically significant (P < 0.05).

- Patients with zero bleeds (n = 172) had higher EQ-5D compared to non-zero bleeds (0.84 vs 0.74), which was statistically significant (P < 0.001) and clinically meaningful.1

- The majority of patients were using secondary prophylaxis (n=239, 47%).

- Primary on demand was the second most common treatment regimen (113, 22%), secondary on demand and primary prophylaxis accounted for the remaining population (87, 17% and 74, 14%, respectively).

- Figure 1: Haemophilia Subtype of Study Population

- Figure 2: Mean EQ-5D by Haemophilia Type

- Figure 3: EQ-5D by ABR

- Figure 4: EQ-5D by Treatment Strategy and Haemophilia Type

CONCLUSION

- The analysis conducted on the chosen sample suggests an inverse relationship between patient bleeding rates and reported HRQoL, with patients with zero bleeding reporting the highest HRQoL.

- Further investigation is needed to better understand the impact of underlying confounding factors (including age, previous incidence of infection, comorbidities and country effects).

- This descriptive analysis supports care pathways and treatment strategies which are geared toward lower ABR among haemophilia patients, as this is positively related to better HRQoL.

REFERENCES


DISCLOSURES

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