Relationship of Quality of Life, Pain, and Self-Reported Arthritis With Age, Employment, Bleed Rate, and Utilization of Hemophilia Treatment Center and Healthcare Provider Services: US Results From Adult Patients With Hemophilia in the HERO Study

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Introduction

The Hemophilia Experiences, Results and Opportunities (HERO) initiative aimed to increase the understanding of people with hemophilia who have moderate–severe hemophilia and was led by an International Advisory Board that included healthcare professionals, patients, and caregivers.

Objective

To examine the potential relationships among health-related quality of life (HRQoL), pain interference, and self-reported arthritis and age, employment, activity, bleeding frequency, and hemophilia treatment center (HTC) and healthcare provider (HCP) utilization in adult patients with hemophilia (PWH) who participated in the HERO psychosocial assessment study.

Methods

- Surveys were developed specifically for either adult PWH (≥18 years) or parents of children with hemophilia (<18 years) who were either currently receiving factor replacement or had spontaneous bleeding into one or more joints within the previous 12 months.
- Ten countries participated (Argentina, Australia, Canada, France, Germany, Italy, Spain, United Kingdom, and US) between June 2011 and February 2012.
- Following Internal Review Board/Ethics Committee approvals, US patients and parents were recruited through the National Hemophilia Foundation’s website distribution and Facebook page, and informed consent was obtained.
- Adult PWH completed a 5-point Likert scale on pain interference over the prior 4 weeks, an EQ-5D VAS (mobility, usual activities, self-care, pain/discomfort, and anxiety/depression) and an EQ-5D health-related visual analog scale (VAS, 0-100), coded as an 11-point categorical response.
- This post-hoc descriptive analysis based on covariates identified in the primary analysis of HERO includes adult PWH from the US. Statistical tests to compare groups were not performed.

Results

- Data presented reflect US respondents encompassing 189 of 675 global PWH. Of the 189 US respondents, 90 (48%) reported suffering from arthritis as a concomitant medical condition related to hemophilia.
- In the US, only one patient reported EQ-5D mobility as “unable to do” and no patients reported EQ-5D usual activities as “unable” (data not shown).

HTC utilization

- PWH in the US reported a mean/median of 1.86 HTC visits in the past year.
- The median number of HTC visits in the past year was 1, regardless of EQ-5D disability or pain interference.

Figure 1 Median age was highest in adult PWH with extreme disability and pain.

Figure 2 Employment in adult PWH decreased with increasing disability and pain.

Figure 3 VAS health scores were lower in PWH with increasing disability and pain.

Figure 4 Increased annual bleed frequency was associated with worsening EQ-5D and pain interference.

Conclusions

- Increased disability and pain were associated with increased age, lower employment, higher reported bleed frequency, and lower QoL.
- Adults with hemophilia who reported experiencing more pain were more likely to report suffering both arthritis and more negative issues with mobility.
- Social worker and physiotherapist involvement was lower than expected.
- Although PWH reported pain, more were involved in PWH with better EQ-5D scores and pain less.