Quality of life and well-being of haemophilia patients and parents in China: subgroup analysis of the HERO study

Introduction
- Haemophilia A (HA) and B (HB) are serious congenital bleeding disorders whose prognosis and outcomes are improved by comprehensive care and access to treatment.
- Bleeding episodes and complications can have a negative influence on the daily life and social relationships of people with haemophilia (PWH) and parents of children with haemophilia. This may lead to psychosocial problems.
- The Haemophilia Experiences, Results and Opportunities (HERO) study is a multinational, multidisciplinary research study focusing on the psychosocial issues in PWH and parents of children with haemophilia.
- Before the quantitative survey (questionnaire-based), a literature review and a qualitative survey involving 7 countries (interview-based) were conducted to provide the foundation of knowledge.
- The primary objective of HERO was to quantify the impact of key psychosocial factors affecting PWH and parents by collecting information on demographics, social relationships, and treatment regimens of PWH and parents of children with haemophilia.

Objective
- Describe the quality of life (QoL) and well-being of Chinese PWH (≥18 years) and parents of children (<18 years) with haemophilia in the HERO study by comparing them with the participants in the other 9 countries.

Methods
- A questionnaire survey was conducted in 10 countries (Algeria, Argentina, China, Canada, France, Germany, Italy, Spain, United Kingdom, and United States).
- In 9 countries (except Algeria), including China, the survey was conducted online.
- The EuroQoL-5D (EQ-5D) Index (healthy subject score = 1.00) was used to assess the QoL of adult PWH.
- PWH completed a health-related visual analog scale (VAS, 0-100 coded as an 11-point categorical response, where 100 is the best imaginable health state and 0 the worst).
- PWH and parents responded on a 7-point scale assessing pessimistic (1) to optimistic (7) outlook on the next 5 years.
- Analysis of the quantitative research:
  - A descriptive and comparative analysis of Chinese patients and parents.

Results
- A total of 675 PWH (110 from China) and 561 parents of children with haemophilia (58 from China) completed questions on demographics, social relationships, and treatment regimens of PWH and parents of children with haemophilia.
- Parents: 52 (89.7%) vs 420 (83.5%) (P = 0.22).
- Overall, 13.6% of Chinese PWH (7.4% non-Chinese; P < 0.05) reported “extreme” pain interference with their daily life in the prior 4 weeks, while 12.7% of Chinese PWH (14.9% non-Chinese; P < 0.0001) reported pain interference as “quite a lot” (Figure 1).
- Overall, 36.4% of Chinese PWH and 28.7% of non-Chinese PWH (P = 0.11) reported their VAS health score as “poor,” with scores ≤50.
- A higher percentage of Chinese parents felt their sons disease had a negative influence on their own and their sons daily life, compared with non-Chinese parents (Table 3).
- Psychological treatment:
  - Overall, 6.9% of Chinese parents (16.7% non-Chinese; P < 0.0001) reported that their son received treatment for psychological conditions in the past 5 years.
  - In addition, 25.9% of Chinese parents (24.3% non-Chinese; P = 0.79) reported receiving treatment for psychological conditions.
- PWH and parents’ future outlook is presented in Figure 2.
  - The mean score was lower for Chinese PWH (4.22) compared to non-Chinese PWH (5.13; P < 0.0001).
  - The mean score was also lower for Chinese parents (3.96) compared to non-Chinese parents (5.64; P < 0.0001).

Table 1 Mean EQ-5D score for PWH

<table>
<thead>
<tr>
<th>Country</th>
<th>Total</th>
<th>Subgroup by disease</th>
<th>Subgroup by treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HA</td>
<td>HB</td>
<td>HWI</td>
</tr>
<tr>
<td>China, n = 565</td>
<td>0.71</td>
<td>0.72</td>
<td>0.68</td>
</tr>
<tr>
<td>Non-China, n = 565</td>
<td>0.75</td>
<td>0.75</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Table 2 Problems reported in EQ-5D questions

<table>
<thead>
<tr>
<th>Any reported problems</th>
<th>China, n = 110</th>
<th>Non-China, n = 565</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility, n (%)</td>
<td>70 (63.6)</td>
<td>319 (56.5)</td>
<td>0.0027</td>
</tr>
<tr>
<td>Self-care, n (%)</td>
<td>30 (27.3)</td>
<td>106 (18.8)</td>
<td>0.0417</td>
</tr>
<tr>
<td>Usual activities, n (%)</td>
<td>64 (58.2)</td>
<td>251 (44.4)</td>
<td>0.0081</td>
</tr>
<tr>
<td>Pain/discomfort, n (%)</td>
<td>72 (65.5)</td>
<td>431 (76.3)</td>
<td>0.0717</td>
</tr>
<tr>
<td>Anxiety/depression, n (%)</td>
<td>66 (60.0)</td>
<td>243 (43.7)</td>
<td>0.0017</td>
</tr>
</tbody>
</table>

Figure 1 How did pain interfere with the daily life of PWH?

Table 3 Parents’ perspective on how haemophilia influenced their family

Conclusions
- PWH and parents in China reported that haemophilia impacted their QoL more than those in the other 9 countries participating in HERO.
- Few Chinese PWH and parents reported receiving psychological support and treatment.
- Chinese PWH and parents were not as optimistic about their future as those in the other 9 countries.

References