Hemophilia Impacts Quality of Life (QoL) in Adult PWH at an Early Age, with Pain a Contributing Factor: US Results From the Hemophilia Experiences, Results, and Opportunities (HERO) Study

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Introduction
- Psychosocial issues affect the ability of persons with hemophilia (PHW) and their families to lead the lives that they desire.
- The Hemophilia Experiences, Results, and Opportunities (HERO) initiative aimed to increase the understanding of psychosocial issues impacting people with moderate-to-severe hemophilia and was led by an International Advisory Board that included healthcare professionals, patients, and caregivers.
- HERO began with a systematic literature review and 150 interviews with patients, parents, and healthcare professionals to identify issues for this quantitative study.

Objectives
- To describe quality of life (QoL) in PWH responding to HERO in the United States (US).
- To describe the QoL of (PHW) in PWH responding to HERO in the United States (US).
- Following Internal Review Board/Ethics Committee approvals, US PWH and their families were recruited through the National Hemophilia Foundation website and Facebook page, and informed consent was obtained.
- Surveys in the US and most other countries (except Algeria) were completed online. Ten countries participated (Algeria, Argentina, China, Canada, France, Germany, Italy, Spain, United Kingdom, and US) between June 2011 and February 2012.
- The characteristics of the pain were also different between groups. Patients with inhibitors showed more acute pain, however this group is younger on average.
- Overall, 79% reported pain interfered with daily life in the past 4 weeks. Pain interference was more noticeable in those with inhibitors, of older age, or with self-report of arthritis (Figure 4).

Table 1: EQ-5D for PWH by Age Group in the United States

<table>
<thead>
<tr>
<th>Age Group</th>
<th>No Problem</th>
<th>Some Problem</th>
<th>No Problem</th>
<th>Some Problem</th>
<th>No Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 18</td>
<td>70%</td>
<td>30%</td>
<td>60%</td>
<td>40%</td>
<td>70%</td>
</tr>
<tr>
<td>18-34</td>
<td>65%</td>
<td>35%</td>
<td>70%</td>
<td>30%</td>
<td>65%</td>
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<td>35-44</td>
<td>60%</td>
<td>40%</td>
<td>60%</td>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>45-54</td>
<td>55%</td>
<td>45%</td>
<td>55%</td>
<td>45%</td>
<td>55%</td>
</tr>
<tr>
<td>55-64</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>65-74</td>
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<td>45%</td>
</tr>
<tr>
<td>75+</td>
<td>40%</td>
<td>60%</td>
<td>40%</td>
<td>60%</td>
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</tr>
</tbody>
</table>

Overall, 92% reported pain interfered with daily life in the past 4 weeks. Pain interference was more noticeable in those with inhibitors, of older age, or with self-report of arthritis (Figure 4).

Conclusions
- Impairment of QoL was consistent with other hemophilia studies and reflects the impact of hemophilia and arthropathy, particularly in regard to physical disabilities and pain.
- EQ-5D index reflected worse QoL than the general population, with a decline in those of advanced age.
- Comparison against other arthritis disorders suggests a similar physical impact at a much younger age.
- QoL assessments with the VAS were lower for older PWH, those with inhibitors, those with joint complications, and the unemployed.
- Pain was a key factor in QoL for nearly all patients, with older patients, those with arthritis, and the unemployed having a more acute, chronic, and constant pain.
- Adult PWH, including those with inhibitors, were nonetheless generally optimistic about the future.

References