Introduction

Psychosocial issues affect the ability of persons with hemophilia (PWH) and their families to lead the lives that they desire. The Hemophilia Experiences, Results and Opportunities (HERO) initiative aimed to understand the psychosocial issues impacting people with moderate-to-severe hemophilia in the United States (US) and in 10 other countries that included healthcare professionals, patients, and caregivers. HERO began with a systematic survey of PWH (n = 189) and WOI respondents with parents, patients, and healthcare professionals to identify issues for this quantitative study.

Objective

To describe access to and utilization of Hemophilia Treatment Centers (HTCs) in PWH and parents responding to HERO in the United States (US).

Methods

Surveys were developed specifically for either adult PWH (≥18 years) or parents of children with hemophilia (CHW; <18 years) who were either currently receiving factor replacement or had spontaneous bleeding into one or more joints within the last 12 months. Of those reporting difficulty, the most consistent themes were around travel, although it is a long way to travel (81%), the travel is expensive (89%), and People were few in number of sources of information included: Hemophilia nurse (67%/77%), Hematologist (71%/86%), Patient associations (46%/71%), Non-pharmaceutical websites (48%/64%), Social worker (43%/9%), Complementary therapist (32%/9%), Physical therapist (32%/9%), and Complementary therapist (32%/9%).

Results

Data presented reflects US respondents encompassing 189 of 675 total PWH and 190 of 511 total parents.

Access to Hemophilia Treatment Centers

Only 22%/22% of PWH/parents reported it very/quite difficult to access the HTC. Most PWH/parents reported being very/somewhat knowledgeable about hemophilia (89%/77%), less so for PWH with inhibitors (56%/85%).

Conclusions

HERO’s US adult PWH and parents of CHW generally perceive good control of hemophilia. More than half report difficulty with access or affordability primarily due to financial factors. Follow-up will be important as healthcare reforms are implemented.

Sources and usefulness of information

- Hemophilia nurse (67%/77%)
- Patient associations (46%/71%)
- Non-pharmaceutical websites (48%/64%)
- Social worker (43%/9%)
- Complementary therapist (32%/9%)
- Physical therapist (32%/9%)

The single source considered most useful by PWH/parents was the hematologist (37%/21%) or nurse (17%/21%)


d Present at NHF’s 64th Annual Meeting; Orlando, Florida; November 8-10, 2012.

Table 1

<table>
<thead>
<tr>
<th>Type of HTC</th>
<th>% Reporting</th>
</tr>
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<tbody>
<tr>
<td>Hematologist</td>
<td>83</td>
</tr>
<tr>
<td>Hemophilia Nurse</td>
<td>81</td>
</tr>
<tr>
<td>Social Worker</td>
<td>49</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>46</td>
</tr>
<tr>
<td>General practitioner/family doctor</td>
<td>43</td>
</tr>
<tr>
<td>Complementary therapist</td>
<td>6</td>
</tr>
<tr>
<td>Physician assistant</td>
<td>3</td>
</tr>
<tr>
<td>Nurse</td>
<td>8</td>
</tr>
</tbody>
</table>

# CTs in the last 12 months were more common in children than adults (mean 3.77 ± 1.85), and patients with inhibitors (mean 3 ± 0.6) (Table 1).

# Access to factor due to availability or affordability

- Some PWH/parents (25%/21%) reported difficulty obtaining factor or concerns about availability or affordability in the last 12 months.

- In contrast to issues identified in other countries, the predominant reasons in the US were financial, including insurance and affordability (Figure 2).

# Data presented reflects US respondents encompassing 189 of 675 total PWH and 190 of 511 total parents.

- Of those reporting difficulty, the most consistent themes were around travel, although it is a long way to travel (81%), the travel is expensive (89%), and it is hard to get to the center (83%).

- Most PWH/parents reported being very or somewhat knowledgeable about hemophilia (89%/77%), less so for PWH with inhibitors (56%/85%).

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- PWH/parents reported their main source of information included: Hemophilia nurse (67%/77%), Patient associations (46%/71%), Non-pharmaceutical websites (48%/64%), Physical therapist (32%/9%), and the single source considered most useful by PWH/parents was the hematologist (37%/21%) or nurse (17%/21%).

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