Sexual Health in Patients with Hemophilia
The Insights from the Patient Reported Outcomes, Burdens and Experiences (PROBE) Study

INTRODUCTION
The impact of hemophilia on psychological and social aspects of life has been investigated and demonstrated. Sexual health in people with hemophilia (PWH) is inadequately assessed in routine care. Having knowledge about sexual difficulty in PWH is important in order to inform clinicians, other healthcare providers and stakeholders involved with policy development and comprehensive hemophilia care.

OBJECTIVES
The primary objective was to determine the prevalence and variables associated with sexual difficulty in PWH. The secondary objective was to compare, within PWH, the characteristics with those with and without sexual difficulty.

METHODS
Participants were recruited through non-government hemophilia patient organizations from 21 countries. Participants were excluded if they were younger than 18 years of age during the study period, carriers of hemophilia, other bleeding disorders or missing data on the hemophilia diagnosis (Fig. 1).

RESULTS

| Gender (%) | Male | 897 (90.15) | 162 (31.44) | <0.001 |
| Age, Mean (SD) | 35.14 (10.17) | 45.05 (13.56) | <0.001 |
| Marital status or long-term relationship (%) | Single 67% (477) | 62% (362) | N/A |
| Having children (%) | 1.03 (1.02) | <0.001 |

Table 1. Participant characteristics

PWH who reported health problems were associated with greater risk of sexual difficulties as compared to those who did not (Table 2). Multivariate analysis revealed that older, recent history of bleeding, acute or chronic pain and limitation of range of motion were independent risks for sexual difficulties in PWH (Table 3).

CONCLUSIONS

<table>
<thead>
<tr>
<th>Patients with hemophilia (%)</th>
<th>P-value</th>
</tr>
</thead>
</table>

Table 2. Impact of general health problems on sexual health in PWH

<table>
<thead>
<tr>
<th>Health problem</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
</table>

Table 3. Multivariate logistic regression analysis of the association between general health- and hemophilia-related problems and sexual difficulties among PWH

ACKNOWLEDGEMENTS

The PROBE investigators thank the participating patient organizations: Fundación de la Hemofilia Argentina Concha (Argentina), Hemophilia Foundation Australia, Federacao Brasileira de Hemofilia (Brazil), Canadian Hemophilia Society, Association Française des Hémophiles (France), Deutsche Hämophiliegesellschaft (Germany), Hungarian Hemophilia Egyesület (Hungary), Irish Haemophilia Society, Federazione delle Associazioni Emofili (Italy), National Haemophilia Network of Japan, Federación de la Hemofilia de la República Mexicana (Mexico), Nederlandse Vereniging van Hemofiele-Patiënten (The Netherlands), Haemophilia Foundation of New Zealand, Haemophilia Foundation of Nigeria, Polish Haemophilia Society, Federación Española de Hemofilia (Spain), The Haemophilia Society (United Kingdom), National Hemophilia Foundation (US), Asociación Venezolana para la Hemofilia (Venezuela), and Vietnamese Hemophilia Association.

PROBE is an independent investigator led research project with grant / research support from: Bailea, now part of Shire, Bayer, Borsvert, CSL, Novo Nordisk, Rhoche and Sobi and collaboration of the US National Hemophilia Foundation.

For more information visit: www.probestudy.org or info@probtestudy.org.

ASH 2017 #2141