Instruments designed to evaluate the economic and disease burden associated with living with severe hemophilia A (HA). Preventing HA impacts patients' lives to a certain extent regardless of disease severity.

The majority of patients with severe HA believe their daily life is compromised due to their HA (Figure 2A).

PHHA reported having to cut down or give up exercising/physical activity regardless of disease severity (Figure 2B).

Increased participation in sports and recreational activities appears to be associated with increased bleeding frequency in moderate and severe HA (Figure 1).

Table 1. Baseline demographics and clinical characteristics of people with mild, moderate, and severe HA, by activity level.

Figure 1. CHESS II study design.

Figure 2. Activity levels and mean ADR (USD) in people with mild, moderate, and severe HA.

Figure 2A. People with HA (HA) and severe HA (SH) have lower activity levels than those with mild HA (MH).

Figure 2B. People with HA (HA) and severe HA (SH) have lower activity levels than those with mild HA (MH).

Table 1. Baseline demographics and clinical characteristics of people with mild, moderate, and severe HA, by activity level.

Table 2. Demographics and characteristics did not differ according to activity levels.

Methods (continued)

Results (continued)

Conclusions

A considerable proportion of patients feel that they have to cut down or give up exercising/physical activity due to HA, and believe their life is compromised by HA.

To people with moderate and severe HA, the data suggest a trend towards increased bleeding frequency in patients with greater participation in sports and recreational activities, regardless of treatment strategy.

Limitations of the study include the variability of the endpoints, the cross-sectional study design, and potential for recall bias. Consensus regarding a preferred tool for assessing activity is lacking. Thus the categorization of activity levels used should be carefully considered when interpreting these results.

Strengths of the study include the sample size, particularly the size of the mild and moderate HA cohorts.

While these real-life data help to define the burden associated with activity and bleeding risk in PHA, it is also important to note that they are descriptive only; thus, prospective studies using validated tools are needed in the future to further quantify risks.

CONCLUSIONS

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