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Patient Perspectives on the Impact of Severe or Moderate Hemophilia on Physical Activity: HemACTIVE Survey Findings from the US and Canada

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Abstract

Objectives: The HemACTIVE survey assesses patient perspectives on the effects of hemophilia and treatment on physical activity. It was previously shown that in the US, most survey participants wished for greater activity, believing that less pain and better protection would enable their aspirations. Whereas the majority of US participants had severe hemophilia, most Canadian participants had moderate hemophilia. The objective of this study was to evaluate findings from the US and Canada, focusing on key similarities/differences between countries and between severity levels. **Methods:** A 25-minute web-based survey was conducted on patient perception of impact of hemophilia on daily activities. Patients with moderate or severe hemophilia A (PwH), ages 2–65, from North America and EU were enrolled. Patients <18 years required caregiver involvement. Surveys were administered after screening phone interviews. No statistical analyses were included; findings are descriptive only. **Summary:** 110 participants from the US (64 PwH, 46 caregivers) and 41 from Canada (23 PwH, 18 caregivers) were analyzed. Importantly, 88% of US participants had severe hemophilia and 12% moderate, compared with 22% severe and 78% moderate in Canada. Despite these differences, prophylaxis use was similar between countries (88% US vs. 83% Canada, and 93% of participants from either country expressed the desire to be more active. The following differences were observed: 70% of US PwH considered themselves to be currently active/highly active vs. 83% in Canada. US PwH were less likely than Canadian PwH to participate in indoor/gym activities (66% US vs. 76% Canada), outdoor activities (65% vs. 80%), non-contact sports (55% vs. 71%), and contact sports (25% vs. 32%), and more likely to feel extremely/very limited in spontaneous activities (15% vs. 0 in Canada). While more US PwH adjust activities due to hemophilia (73% US vs. 66% Canada), rates of stopping activities were similar between countries (34%-35%). However, the top reason for stopping activities differed between countries: existing joint damage restrictions for US PwH vs. fear of future joint damage in Canada. More US PwH than Canadian PwH believe that greater bleed protection, less pain, and fewer bleeds would enable greater activity (85%-90% US vs. ~30%-40% Canada). Compliance to prescribed treatment regimens also differed, with 54% of US PwH occasionally or frequently missing infusions vs. 38% in Canada. US PwH were more likely than those in Canada to indicate that having hemophilia has made them into a stronger person (85% vs. 76%). **Conclusions:** Despite differences in baseline characteristics, with most US participants having severe hemophilia, and most Canadian participants having moderate hemophilia, >80% from either country were on prophylaxis, and >90% wished to be more active.