Characteristics Associated with Annual Bleeding Frequency Among Hemophilia Patients in the United States

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OBJECTIVES

- To identify socio-demographic and clinical characteristics associated with ABR in persons with hemophilia A (HA) or hemophilia B (HB).
- To examine characteristics associated with ABR between adult and pediatric patients with hemophilia.

METHODS

- Participants or parents of pediatric patients completed an initial survey with information regarding socio-demographics, clinical characteristics, inhibitor status and treatment patterns.
- Follow-up surveys were administered regularly for two years to collect data on bleeding episodes and development of inhibitors.

RESULTS

- Differences were significantly associated with ABR among children vs. adults, including being 10-17 vs. 2-9 years old, HB vs. HA, having moderate or mild hemophilia and annual factor usage per body weight.

CONCLUSIONS

- Further significant differences in ABR and in characteristics associated with ABR existed between adults and children. Notably, in adults, the effect of annual factor usage per unit of body weight on ABR was significantly different among those taking prophylactically vs. on-demand. These preliminary findings suggest potential for treatment optimization in individuals of varying ages and reinforce the importance of adopting a precision medicine approach.

Future studies should investigate how variations in bleeding outcomes, patient characteristics and treatment vary in other subgroups of hemophilia and other coagulopathies with healthcare utilization resources available.

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REFERENCES