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Women and girls with inherited bleeding disorders: Focus on haemophilia carriers and heavy menstrual bleeding
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Abstract
Raising awareness and improving recognition, accurate classification, and enhanced access to new treatments represent current key challenges for carriers of haemophilia. Women and girls carrying genes for haemophilia often experience significant bleeding and/or low factor levels. The bleeding associated with female haemophilia is frequently overlooked, has a weak correlation with factor levels, and manifests differently than in males, with heavy menstrual bleeding being a predominant symptom. Recent changes in terminology now allow the diagnosis of haemophilia in females with low factor levels and differentiate between symptomatic and asymptomatic carriers of the gene. Observations from real-world experiences and limited clinical trial data have highlighted the positive impact of various new haemophilia treatments for women and girls with clotting factor deficiencies. There is an urgent need for initiatives that increase their access to these treatments and encourage well-designed clinical trials focusing on female-specific outcomes. In women with inherited bleeding disorders, early recognition and optimal management of heavy menstrual bleeding are crucial. However, treatment options and guidance from high-quality clinical trials are currently insufficient. Menstrual health assessment should be a regular part of monitoring women and girls with inherited bleeding disorders throughout their lives, emphasizing the importance of gathering data to improve future management. © 2024 John Wiley & Sons Ltd.

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