HEMOPHILIA A/ HEMOPHILIA B

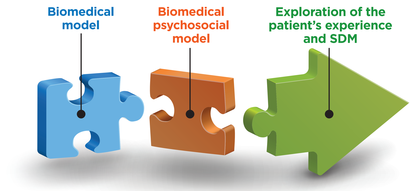
MANAGEMENT IN SPECIAL POPULATIONS

With advances in hemophilia treatment options, medical decision-making also must progress, from acute care to chronic care...

Acute Care
- Clinical evidence

Chronic Care
- Patient interpretation
- Feelings
- Preference
- Values
- Social context

...and from a strictly biomedical model to a more complex model, including a psychosocial consideration of the patient's experience and SDM.



Diverse populations may face difficulties in fully participating in SDM due to several reasons beyond strictly language barriers and/or health literacy.

SDM in special populations also requires other considerations:

- Gender and culture
- Health disparities
- Insurance and financial barriers
- Psychosocial considerations

Gender and Cultural Sensitivity

- Women with hemophilia may face **underdiagnosis and limited access to care** due to gender bias.
- **Cultural norms and values** influence the decision-making process, potentially leading to miscommunication or misunderstanding

Health Disparities

- Minorities may experience **unequal access to healthcare resources** or face **systemic barriers** that impact the quality of care
- **Socioeconomic factors**, including **lack of insurance**, often exacerbate disparities in hemophilia treatment and care

Insurance and Financial Barriers

- Patients with **limited or no insurance** may struggle to access necessary treatments, leading to suboptimal care
- **High costs of factor replacement therapy** and other treatments can create challenges in treatment adherence and long-term care management

Psychosocial Considerations

- **Stigma and misconceptions** surrounding hemophilia, especially in marginalized communities, can affect patient willingness to seek care
- Addressing **emotional and psychological needs** of patients from diverse backgrounds is crucial for effective SDM

Strategies for Improved Care in Special Populations

- Use of interpreters and culturally competent care models
- Flexible treatment options and financial assistance programs
- Empowering patients with knowledge and support to make informed decisions

Healthcare providers must be trained to address the unique needs of different populations to ensure all patients with hemophilia are actively involved in their care decisions.

The Haemo-QoL, Haem-A-QoL, and Hemo-Sat instruments have been culturally adapted and linguistically validated into multiple languages to accurately assess health-related quality of life and treatment satisfaction among diverse patient populations.

Importantly, incorporating SDM and consideration of special populations does not require compromising evidence-based medical decision-making.

All images shown are for educational purposes only.

Abbreviations

Haem-A-QoL: Haemophilia Quality of Life Questionnaire for Adults
Haemo-QoL: Quality of Life of Children with Haemophilia in Europe
Hemo-Sat: Hemophilia Patient Satisfaction Scale
SDM: shared decision-making

Additional Resources

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