Caring for Mild Hemophilia: A Challenge to Comprehensive Hemophilia Treatment Centers

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Introduction:

1. Mild hemophilia A is defined by factor VIII levels between 5% and 40%[1].
2. Persons with mild hemophilia face challenges, such as difficulties recognizing bleeding symptoms and appropriate treatment, which are distinct from those experienced in severe or moderate hemophilia.
3. The optimal approach to providing care for mild hemophilia has many uncertainties, yet unanswered by the current body of research.

Objectives:

To explore attitudes and experiences of adult males living with mild hemophilia.

Methods:

42 adult males (≥18 years) with mild hemophilia registered with the Southern Alberta Rare Blood and Bleeding Disorders Program at the Foothills Medical Centre in Calgary were invited to participate in semi-structured interviews.

10 individuals provided informed consent to participation with 8 transcripts available for analysis and coding based on common themes identified from the transcripts. 2 raters reviewed and coded the data.

Results:

Common themes identified included:

- Perception that mild hemophilia does not affect daily lives but paradoxically influenced career choices and quality of life
- Regular follow up at HTC is not needed unless surgery is required
- Treatment is needed only for invasive procedures
- Uncertainty about treatments available for bleeding associated with mild hemophilia

HTCs were identified as the primary source of disease education. One participant recognized the importance of multidisciplinary approach to care.

Conclusions:

1. Themes identified in this study suggest a disconnect between patient attitudes toward living with mild hemophilia (generally positive and not impacting their lives) and actual life experiences/choices. With additional research efforts focused on the challenges experienced by the mild hemophilia population, HTCs will be better equipped to develop effective education and treatment programs to target these patients.

2. As the primary source of education for persons with mild hemophilia, HTCs must ensure that these individuals have the knowledge and tools needed to improve disease ownership and coping. With better understanding of their condition, relationship between persons with mild hemophilia and HTCs may be strengthened leading to more consistency with follow up and earlier involvement of the clinic during bleeding episodes as well as prior to invasive procedures.

3. The data obtained during this study will be further investigated through a validation of the themes through a focus group composed of the original participants, development of a questionnaire based on the identified themes to be distributed to a larger population of adult males with mild hemophilia A and a focus group of hemophilia comprehensive care personnel.

References:

[1]White GC, Rosendaal F, Aledort LM, Lusher JM, Rothschild C, Ingerslev J. Definitions in haemophilia. Recommendation of the Scientific subcommittee on factor VIII and factor IX of the scientific and standardization committee of the international Society on Thrombosis and Haemostasis. 2001; 85(3): 560

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