

Changing views on the use of prophylaxis in men with severe hemophilia across the age spectrum



Jackson S^{1,3}, Poon M-C², Yang M³, Kalmar L⁴, Currie L⁵ and Oliffe J⁵

¹Division of Hematology, Department of Medicine, University of British Columbia, Vancouver, Canada, ²Division of Hematology and Hematologic Malignancies, Department of Medicine, University of Calgary, Calgary, Canada, ³British Columbia Provincial Bleeding Disorders Program – Adult Division, Vancouver, Canada, ⁴Faculty of Graduate and Postdoctoral Studies (Nursing), University of British Columbia, Vancouver, Canada, ⁵ Faculty of Nursing, University of British Columbia, Vancouver, Canada

Background

- Continuous prophylaxis is the contemporary standard of care for children and adolescents with severe hemophilia in the developed world and improves joint outcomes.
- Adults are adopting prophylaxis and across the age spectrum there are variable rates of prophylaxis use and, in particular, older adults use this less frequently.
- Hemophilia knowledge and experience between younger and older patients is expected to be different.
- The influence of masculinity at various ages upon decision making around hemophilia and prophylaxis has not been explored.

Objectives

- To explore knowledge, skills, and attitudes about prophylaxis in various age groups of men with severe hemophilia.
- To explore themes related to masculinity and behaviour with respect to prophylaxis use

Methods

- Consenting men, ≥19 years or older, with severe hemophilia A and B (factor level ≤2%) completed a 90 minute structured focus group interview with male non-clinic staff with no hemophilia experience but expertise in focus group methodology.

Methods (con't)

- Focus groups were stratified into the following age groups: 19-24, 25-39 and ≥40 years of age with minimum of 3 participants per group.
- The data collected were analyzed for emerging themes and concepts that describe the participants' experiences of hemophilia.

Results

- 11 patients, median 34 years of age (range 21- 64) took part in 1 of 3 focus groups.

	All	19-24	25-39	≥40
No.	11	3	4	4
Proph.	8 (72%)	3 (100%)	4 (100%)	1 (25%)
Daily proph.	3	1	1	1

- Diverse understandings within and across the three age cohorts about the goals of prophylaxis and what constitutes continuous prophylaxis.

- Self-infusion and prophylaxis provides a sense of freedom by allowing them to be self-sufficient and participating in more activities.

- Some older patients expressed that self-infusion and prophylaxis are difficult to adhere to because they challenge the sense of masculinity in that essentially every treatment is another reminder of having the disorder, of being vulnerable.

Results (con't)

- Some younger patients expressed instead of using alcohol, drugs, violence, or crime, that they may delay treatment, not infuse prophylactically, or participate in high risk physical activities to demonstrate their masculinity.
- Men reported taking unnecessary physical risks particularly in adolescence that resulted in injuries so that they could meet their psychosocial needs

"I feel like I fell in with the wrong crowd in high school, and it wasn't drugs or alcohol, it was, I fell in love with the basketball crowd"
"High school was probably the time when my ankles got the worst."

"if you manage it [hemophilia] properly you can do anything you want to, really."

Conclusions

- These preliminary results confirm the need to target specific education around prophylaxis and health promotion to men based on their age and investment with self-management.
- Revealed also are the potential benefits for working with men (as distinct from working to change men) through peer-support and harm reduction strategies.
- Some masculine ideals can be mobilized to garner optimal hemophilia management practices (e.g. discipline, control, rationality).

"my advice would be to find other ways to meet those needs that I know I had as a young man, you know, to challenge myself and to play, and to find ways that, other ways to get those needs met"

Acknowledgements

This project was funded through the Baxter Canadian Epidemiological Research Program (B-CHERP) and the authors would like to acknowledge the support of Baxter Canada and the Association of Hemophilia Clinic Directors of Canada (AHCDC).

"some days you don't even think that you have any disease at all,"

"No amount of product is going to make that [damaged joint] better."
... "too late now"

"every time you do [infuse, take a pill for HIV], you're in that space of 'I have these things'."

"so if you don't take that pill, or you don't use that needle, I think there's something subconsciously going on that it's like: 'I'm not this'."

