Your Inhibitor Treatment Plan and You: Is your treatment working for you?

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Introduction

•As most people need help understanding and using health information, it is important to design materials that will facilitate their learning

•As noted by Kessels (2003) 40 to 80% of the information provided by health care practitioners is forgotten immediately and half of the information patients remember is recalled incorrectly.

• Printed materials will reinforce the messages provided in verbal teaching. Well written patient education materials will enable patients/families to take a more active role in decision making and they also promote consistency in patient teaching.

•Developing patient education materials involves a series of steps beginning with establishing a planning group, identifying a purpose and patient population, writing drafts, obtaining feedback from all stakeholders, and does not end until the material has been published and evaluated.

• We partnered with Baxter Canada to produce a tool that will help patients with hemophilia who treat at home and have developed an inhibitor.

Methods

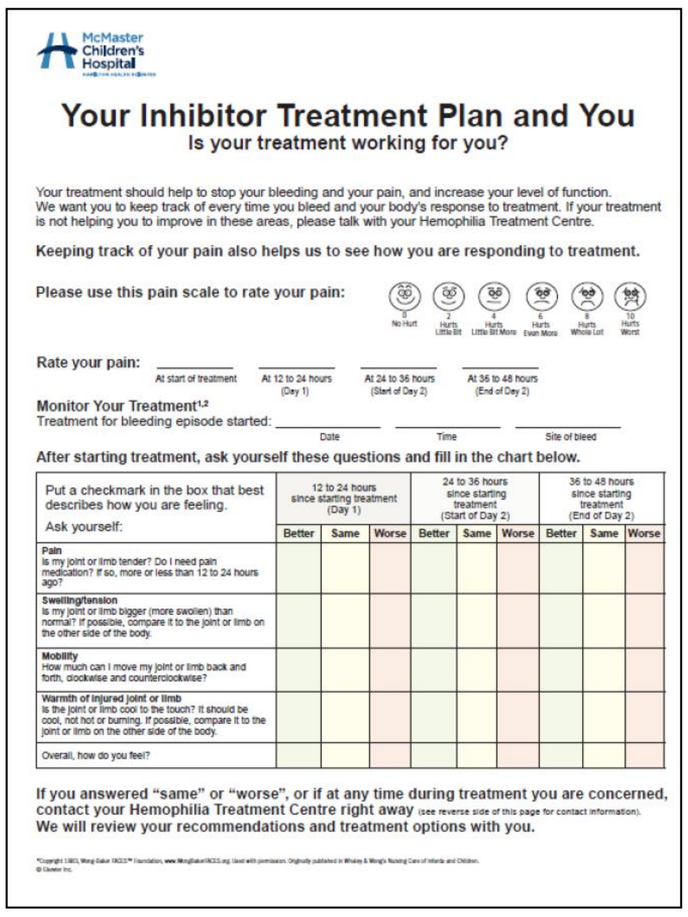
• We engaged a multi-disciplinary approach and used an interactive perspective to design the tool for patients with hemophilia and an inhibitor, treating at home.

•The criteria developed by Dr. Berntorp et al, for identifying non-responsiveness during bleeding episodes and the clinicians algorithm developed by Dr. Teitel et al. were modified for use with our patient population.

Results

•A patient self-assessment tool was developed and will be piloted with a small group of patients who receive home treatment for hemophilia and who have an inhibitor to their factor replacement therapy.

•The tool is easy to use and will assist patients treating interim bleeding episodes at home using bypassing agents such as rFVIIA or FEIBA , and making clinical care decisions. The tool may help make patients aware of the need to treat immediately and maintain communication with their health care team.



McMaster Children's Hospital

Your Inhibitor Treatment Plan and You
Is your treatment working for you?

Your treatment should help to stop your bleeding and your pain, and increase your level of function. We want you to keep track of every time you bleed and your body's response to treatment. If your treatment is not helping you to improve in these areas, please talk with your Hemophilia Treatment Centre.

Keeping track of your pain also helps us to see how you are responding to treatment.

Please use this pain scale to rate your pain: 0 No Hurt; 2 Hurts Little Bit; 4 Hurts Little Bit More; 6 Hurts Even More; 8 Hurts Whole Lot; 10 Hurts Worst

Rate your pain: _____ At start of treatment; _____ At 12 to 24 hours (Day 1); _____ At 24 to 36 hours (Start of Day 2); _____ At 36 to 48 hours (End of Day 2)

Monitor Your Treatment[1,2]
Treatment for bleeding episode started: _____ Date _____ Time _____ Site of bleed

After starting treatment, ask yourself these questions and fill in the chart below.

Put a checkmark in the box that best describes how you are feeling. Ask yourself:	12 to 24 hours since starting treatment (Day 1)			24 to 36 hours since starting treatment (Start of Day 2)			36 to 48 hours since starting treatment (End of Day 2)		
	Better	Same	Worse	Better	Same	Worse	Better	Same	Worse
Pain Is my joint or limb tender? Do I need pain medication? If so, more or less than 12 to 24 hours ago?									
Swelling/tension Is my joint or limb bigger (more swollen) than normal? If possible, compare it to the joint or limb on the other side of the body.									
Mobility How much can I move my joint or limb back and forth, clockwise and counterclockwise?									
Warmth of injured joint or limb Is the joint or limb cool to the touch? It should be cool, not hot or burning. If possible, compare it to the joint or limb on the other side of the body.									
Overall, how do you feel?									

If you answered "same" or "worse", or if at any time during treatment you are concerned, contact your Hemophilia Treatment Centre right away (see reverse side of this page for contact information).
We will review your recommendations and treatment options with you.

Your Inhibitor Treatment Plan and You

Your Healthcare Team is Here for You
Is your treatment working for you?

My weight: _____

Treatment	Prescription (to be completed by your healthcare team)
☐ Activated prothrombin complex concentrate (FEIBA® NF)	First dose: _____ Units Follow-up dose: _____ Units Frequency: _____ Notes: _____
☐ Recombinant activated factor VII (Niastase®)	First dose: _____ mg Frequency: _____ Follow-up dose: _____ mg Notes: _____
☐ Additional treatments	Notes: _____

If your treatment isn't working to improve your bleeding, your pain or your level of function, call your Hemophilia Treatment Centre right away.

Your Hemophilia Treatment Centre
Name of centre: _____
Doctor: _____ Telephone: ( )_____
Nurse: _____ Telephone: ( )_____
Physiotherapist: _____

Call your Hemophilia Treatment Centre if you need to cancel and reschedule your clinic appointment.

If at any time during treatment you are concerned, contact your Hemophilia Treatment Centre right away.

References
1. Berntorp E, Collins P, D'Oiron R, et al. Haemophilia. 2010;1-9. 2. Teitel J, Berntorp E, Collins P, et al. Haemophilia. 2007;13:256-263. 3. FEIBA NF Product Monograph, 2013. 4. NiaStase Product Monograph, 2013.

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Conclusions

•The tool will help us to reinforce treatment recommendations for patients with inhibitors at home with bleeding episodes.

•The important message to patients/families is that if your treatment isn't working to improve the bleeding, the pain, or the level of function, the health care team should be contacted.

•A further evaluation of the tool is planned with a larger group of patients/families.

References

Berntrop R, Collins P, D'Oiron R, Ewing N, Gringeri A, Negrier. Identifying non-responsive bleeding episodes in patients with haemophilia and inhibitors: a consensus definition. *Haemophilia* 2010 July;1-9.

Kessels. R. (2003). Patients' memory for medical information. Journal of the Royal Society of Medicine. 96(5), 217-222.

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