

Development and Evaluation of a Self-assessment Pathway for Young Men with Mild Hemophilia

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Purpose:

To develop and evaluate a new self-assessment tool for people with mild hemophilia to apply to the management of musculoskeletal injuries and thus potential bleeds.

Relevance:

In our previous qualitative study involving 18 young men with mild hemophilia from across Canada, we found that young men with mild hemophilia were missing key information about how to recognize serious bleeds and were resistant to conferring with their hemophilia care team about potential bleeds. Often, individuals presented for treatment several days after known trauma and onset of symptoms, which can result in the use of large amounts of clotting factor concentrates, significant impairment, and lengthy rehabilitation. Evidence and clinical experiences suggest that these consequences could be avoided if treatment was initiated sooner.

Methods:

The printed tool was mailed to participants of the original study. Additional volunteers are being recruited.

Telephone interviews are being conducted, using two clinical scenarios, to get participant feedback about the applicability of the tool and the preferred format.

Results:

Interviews are in progress. The men interviewed thus far report;

1. The tool follows what they believe they have been taught in the past, but organized in a different way than it has been presented previously.

"If I was unsure if I should seek treatment, this would be a good reinforcement to do it."
"I liked it. In different situations it goes back to the reassessing thing quite often. I like that because if it feels good for one day and you don't think about it you can aggravate it and trigger a bleed."

2. The tool applied to the kinds of bleeds that they have had.

"When you think about it, we avoid the pain. Deny the fact that we have hemophilia. The case scenarios make you think about why we avoid treatment."

3. The tool would be useful to them.

"Yeah, I think mostly the reassess next day (is useful). The reminder to do the reassessment."

4. The tool would be useful to others with mild hemophilia.

"It is for newcomers who can't use their experience to tell when something is serious or the experience is ambiguous. But it may help avoid unnecessary trips to the ER until you understand what is serious. If you always went to the ER, or had overprotective parents, in a good way, you wouldn't have the experience to draw from. It's important to wait sometimes too."

5. The tool was mostly similar to what they had previously been told to do if injured.

"In line – absolutely – with what I've been told in the past."

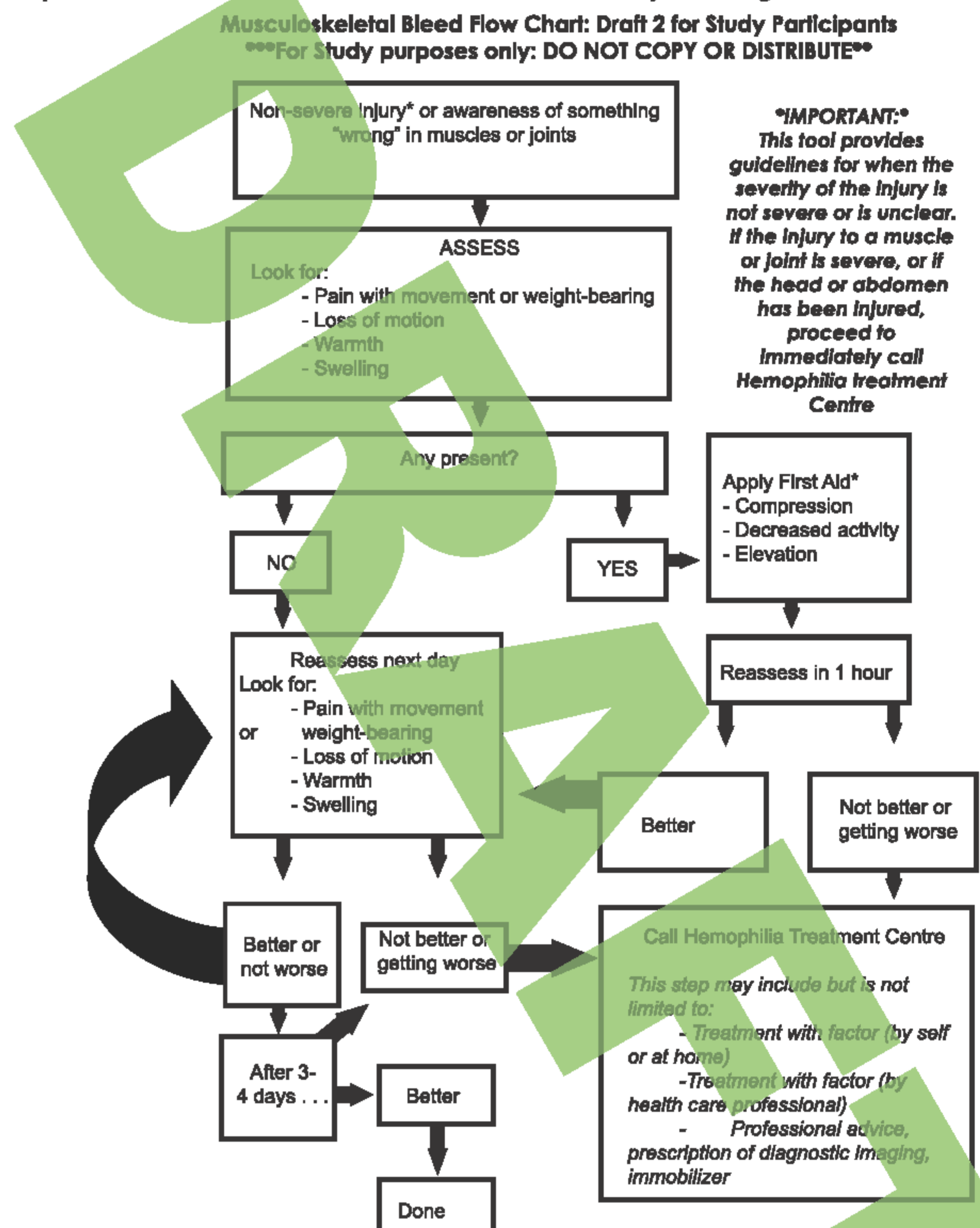
6. The tool differences included the longer duration of reassessment.

"The reassessing every day for 3-4 days, I don't think that's really taught a lot..."

7. What could make the tool better?

"Nothing. One of the biggest problems with mild hemophilia is that there is a denial, wanting to put it (treatment) off longer than I should. The tool makes the step by step process a little more clear. Rather than (thinking) it's getting worse, but maybe not that much worse...(and not knowing what to do)."

Development and Evaluation of a New Self-Assessment Pathway for Young Men With Mild Hemophilia A and B



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Suggested Format of Tool:

Participants reported that they would access the tool if available in electronic format, and appeared to prefer the idea of a smart phone application version of the tool.

"If (smart phone app) would be very convenient. You could totally make it interactive. It could start with "have you had a head or abdomen injury" (and advise immediate treatment for severe injuries)."

Conclusions:

Our overall project outcome is the creation of a user-friendly, relevant tool to assist PWMH to perform self-assessment and manage their injuries and bleeds in a timely fashion. This research is ongoing with further interviews being performed until the end of November, 2012. The final tool will be produced in the spring 2013 and future studies are planned to evaluate the long term effectiveness of this tool.

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