



Development of a group intervention to provide education about joint assessment to adolescents and parents of children with hemophilia



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Introduction

Joint bleeding is a concern for persons with hemophilia. Inadequate treatment can give rise to chronic joint damage, pain and disability with subsequent increased use of factor and longer healing time. At BC Children's Hospital, we currently teach families how to assess joints at their review visit or when they come in with a bleed. These are suboptimal times for education due to distractions and time constraints. This prompted us to find other means of providing education and determine whether other modalities were more effective at increasing individuals' knowledge around joint bleeds, assessment and treatment.

Methods

Eligible subjects were identified from a patient list provided by the Hemophilia clinic and approached by a member of the research team. Subjects were included if they were a parent of a child aged 1 to 12 years with hemophilia A or B, or an adolescent aged 13 to 18 years with hemophilia A or B. Subjects took part in an hour-long education session, separate from their routine clinic visit. Childcare was provided to allow the parent subjects to focus on the session without additional distraction. Subjects were taught to "Look, Feel, Move, Call" when performing an assessment of the joint (figure 1). They were also taught background information about joint bleeding in hemophilia. In our clinic, we identified knees and ankles as being most prominent sites of bleeding. Therefore, education was focused on these index joints.

A questionnaire was developed using the KAP survey model (Knowledge, Attitudes, Practices) to determine parent and patient knowledge. Its purpose was to look at participant experience, knowledge and assessment regarding joint bleeds. This questionnaire was reviewed by various experts in the hemophilia field (physicians, nurses, physiotherapists) across Canada to establish face validity prior to administration to study subjects.

Subjects were given the questionnaire (figure 2) to complete before, immediately after, and at least 3 months after the education session. Subjects also conducted a joint assessment (ankle and knee) of their child or themselves at the same time points and graded using an assessment checklist (figure 3) developed by the team. This was videotaped for the team to review at a later time to confirm that the items on the checklist were completed (figure 4).

Results

36 subjects have completed the education session with the corresponding pre- and post-questionnaires and joint assessments. Of these subjects, 30 were parents of children with hemophilia, while 6 were adolescent males with hemophilia. A total of 30 subjects completed the follow-up visits 3 to 6 months after the education session. 6 subjects did not complete the final follow-up questionnaire or joint assessment (1 subject declined, 5 subjects did not respond to recall).

Initial feedback from participants was positive. Many individuals expressed better understanding of the pathophysiology of joint bleeds, and the importance of conducting an accurate joint assessment to identify a hemarthrosis. Participants voiced feeling less rushed and enjoyed having an interactive environment to ask questions and learn from others.

Conclusion

Education plays an important role in chronic disease management. Children with hemophilia can develop bleeding in their joints due to disease. In British Columbia, many families do not live in close proximity to the provincial Hemophilia Treatment Centre (HTC), and rely on phone communication with the HTC team to help with the management of bleeding episodes.

Providing additional education, separate from clinic visits, focusing on joint assessment, is likely to benefit both families and patients with hemophilia. We hope to continue these group education sessions for this population in the future.

Our next step is to score the questionnaires and assessment checklists, and analyze the data to determine the effectiveness of a group education session on joint bleeds and assessment.

Figure 1. "Look, Feel, Move, Call" for joint assessment

Joint Assessment
Ankle & Knee

LOOK

- Swollen or red?
- Look for bony prominences
- Limp? Walking on toes or foot turned out?
- Compare with good (or better) side

FEEL

- Warm to touch?
- Tender to touch?
- Tense or spongy?
- Compare with good (or better) side
- Knee:** feel front of knee, above and around knee cap
- Ankle:** feel around entire ankle joint

MOVE

- Range of motion
- Pain with movement?
- Pain with overpressure?
- Compare with good (or better) side
- Knee:** can it bend/straighten fully?
- Ankle:** can it point and flex fully? Can it lift as high as other foot (with knee bent)?

CALL

- Hemophilia clinic:** 604-875-2345 x 5334 (Monday to Friday 0830-1630)
- Hematologist on call:** 604-875-2161 (after hours/weekends)

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Figure 3. Example of checklist for ankle assessment

Joint: ANKLE

<p>Swelling</p> <input type="checkbox"/> Identifies presence/absence of swelling <input type="checkbox"/> Describes location(s) <input type="checkbox"/> Describes amount	<p>Redness</p> <input type="checkbox"/> Identifies presence/absence of redness <input type="checkbox"/> Describes location(s)
<p>Pain</p> <input type="checkbox"/> Identifies presence/absence of pain <input type="checkbox"/> Describes location(s) <input type="checkbox"/> Describes if present with palpation <input type="checkbox"/> Describes if present with weight bearing <input type="checkbox"/> Describes if present with movement	<p>Bruising</p> <input type="checkbox"/> Identifies presence/absence of bruising <input type="checkbox"/> Describes location(s)
<p>Range of Motion</p> <input type="checkbox"/> Compares injured side to non-injured side <input type="checkbox"/> Identifies limitations in range of motion (i.e. decreased)	<p>Heat</p> <input type="checkbox"/> Identifies presence/absence of heat <input type="checkbox"/> Describes location(s)

Figure 2. Examples of questions from parent subject questionnaires

Section 1: Personal experience with joint bleeds

1. Has your child ever had a joint bleed?
 Yes No Unsure

2. If yes, did he get treatment for it? (i.e. factor, ice, etc.)
 Yes No Unsure

3. If he received treatment, what treatment(s) did he get? List all treatments ever given.

4. How many joint bleeds (elbows, knees, ankles) do you remember your child having? (total number of elbow/knee/ankle bleeds in his life)
 None 1-4 5-9 10 or more N/A (never had joint bleed)

5. Which joint(s) did your child have bleeds in? Please list below. N/A (never had joint bleed)

6. Do you have previous experience assessing a joint or joint bleed? (i.e. academic background, occupational experience, another child with hemophilia)
 Yes No

7. Has anyone taught or shown you how to assess a joint or joint bleed?
 Yes No Unsure

8. If yes, who taught/showed you to assess a joint or joint bleed?
 Hematologist (doctor) Nurse Physiotherapist Other: _____

Section 2: Knowledge about joint bleeds

21. The function of the synovium (joint lining) is to: (Select all that apply)
 Absorb the shock from walking and running
 Lubricate the joint by making joint fluid
 Give nutrients to the cartilage
 Make the joint stronger
 Absorb blood and waste products after a bleed
 Not sure

22. The function of the joint cartilage is to: (Select all that apply)
 Protect bone surfaces from rubbing
 Absorb the shock from walking and running
 Supply blood and nutrients to the joint
 Help the joint move smoothly
 Protect the bone against infection
 Not sure

23. What happens within the joint during a bleed? (Select all that apply)
 Damages blood vessels in cartilage (flexible connective tissue)
 Blood leaks into the joint space
 Joint capsule becomes stretched
 Factor VIII (8) and IX (9) are destroyed by antibodies
 Blood vessels in joint lining are injured
 Blood is quickly absorbed by the body, limiting damage to the joint
 Synovium (joint lining) becomes inflamed
 Not sure

Section 3: Assessment and treatment of joint bleeds

36. Your child just had an injury. What is your confidence level in your assessment skills to figure out if it is a joint bleed or not?
 Not at all confident Somewhat confident Neutral Confident Very confident

37. How confident do you feel in telling your child's health care provider(s) what your assessment was?
 Not at all confident Somewhat confident Neutral Confident Very confident

38. You call the hemophilia clinic or hematologist on call to report a joint bleed. What information do you give them? What do you say?
 I have the joint arayed
 I feel for heat
 I test strength of muscles around the joint
 I test for range of motion
 I check for pain with movement. I check for pain with walking

39. What **SHOULD** you do to **ASSESS** your child's joint when you think there is a bleed? (Select all that apply)
 Look for redness
 Check for swelling
 Test strength of muscles around the joint
 Check for pain with movement
 Check for pain with walking

40. How **SHOULD** you treat a joint bleed? (Select all that apply)
 Elevate the limb
 Rest
 Massage the area around the joint
 Put on a splint if available
 Call clinic or hematologist on call
 Do see your physiotherapist



Figure 4a. Parent conducting knee assessment (knee extension)



Figure 4b. Parent conducting knee assessment (knee flexion)

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Educational and Communication Models
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