Unraveling the Pain vs. Bleeding Mystery in Hemophilia

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Who am I?

- Physical therapist at The Hemophilia Center of Western Pennsylvania since April 2023
- BS in Biology and Chemistry from University of Pittsburgh at Johnstown 2012
- Doctor in Physical Therapy from Wheeling Jesuit University 2015
- Previously managed an orthopedic outpatient clinic
- Live in North Hills with wife and two children
- Family history of hemophilia and vWD
- Free Time?! Spending time with family, fly fishing, soccer, cooking, and gardening

Objectives

1. Differentiate between pain and bleeding in hemophilia
2. Understand the causes of pain
3. Learn how to monitor and describe pain accurately
4. Review Strategies for managing pain
5. Explore tools to detect bleeding vs. non-bleeding with case studies

What is Pain?

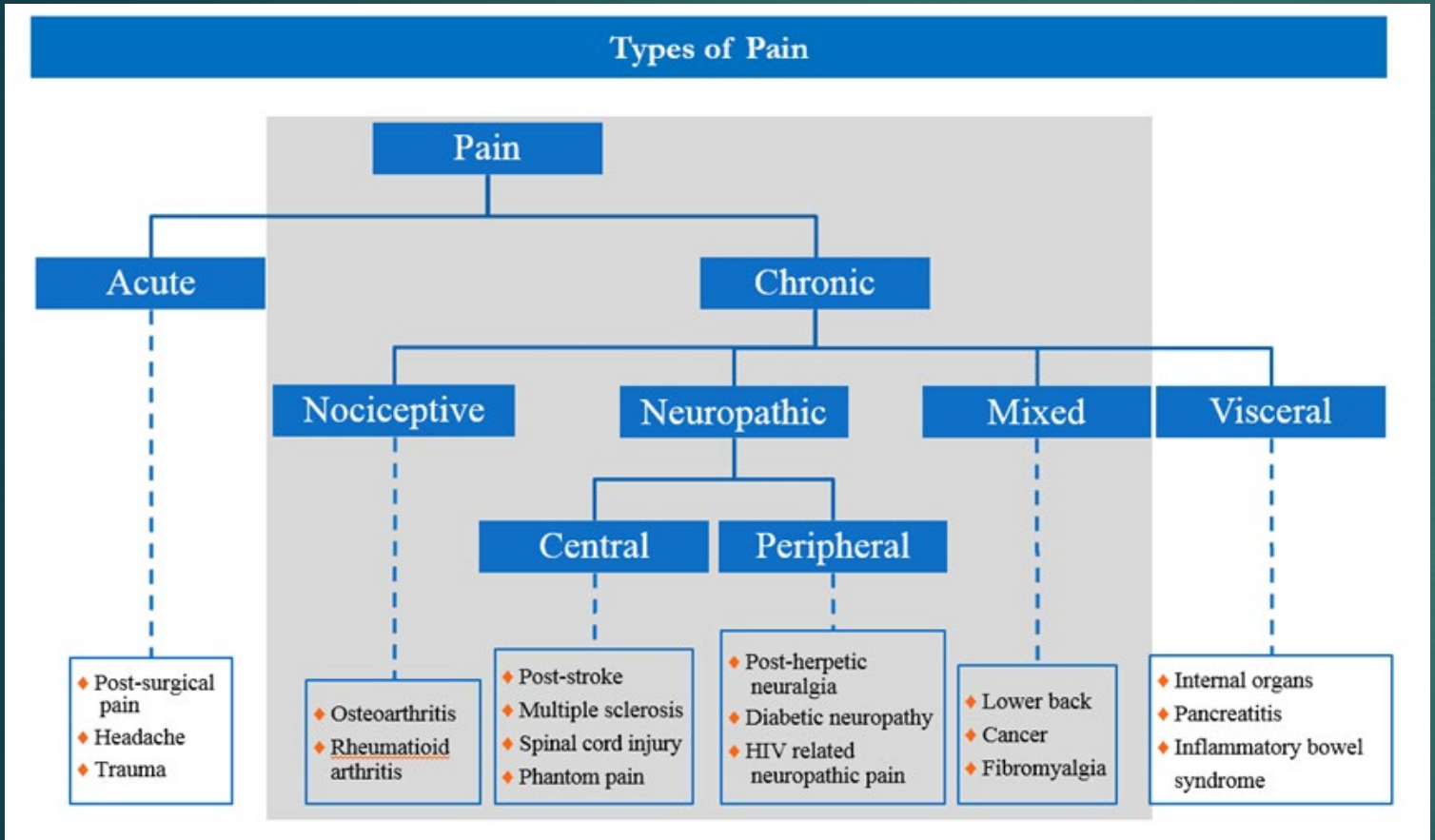
- "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" -IASP
- Personal experience influenced by various factors, including biological, psychological, and social elements

https://www.jospt.org/do/10.2519/jospt.blog.20200812?utm_source=chatgpt.com

Symptoms of Different Pain Types[1-3]

NOCICEPTIVE	NEUROPATHIC	NOCIPLASTIC
Pain Quality: sharp, stinging, dull, throbbing	**Pain Quality:** burning, stabbing, numbness or tingling, hypersensitivity	**Pain Quality:** sharp, dull, tingling or numbness; non-specific
 Stabbing	 Burning	 Electric shock-like
 Dull	 Pins & Needles	 Numbness
 Throbbing		 Sensitive to touch
Examples of conditions: osteoarthritis, bone fractures, burns, physiological pain to brain	**Examples of conditions:** diabetic neuropathy, HIV/AIDS, multiple sclerosis	**Examples of conditions:** fibromyalgia, IBS, migraine, interstitial cystitis

https://restore-painrelief.com/patient-portal/what-is-pain/



https://samarpanphysioclinic.com/types-of-pain-physiotherapy/

Pain Duration:

Acute pain: 0–4 weeks
Subacute pain: 4–12 weeks
Chronic pain: > 12 weeks

https://www.ihs.gov/opioids/painmanagement/acute/

Multiple Factors of Influence

- Pain perception influences
  - Biological
    - Genetics, Brain function, Age & Sex, Medical Condition
  - Psychological
    - Mood Disorders, Stress and Coping Mechanisms, Cognitive Factors
  - Social
    - Support Systems, Cultural and Societal Influences, and Access to Healthcare
- "Ultimately, the patient himself is the 'expert' on (and the best evaluator of) his own pain. However, objective pain assessment methods aim to give visibility to a subjective phenomenon and provide a scale for treatment evaluation."

https://journals.lww.com/bloodcoagulation/fulltext/2016/12000/Pain_and_pain_management_in_haemophilia.1.aspx
https://www.research.va.gov/topics/pain.cfm?utm_source=chatgpt.com
https://www.bu.edu/dental/ce/systemic-factors-influencing-the-experience-of-pain/?utm_source=chatgpt.com
https://obssr.od.nih.gov/sites/obssr/files/inline-files/Exec_Summ_Pain_Measurement_Mt_02_13_2020_508_0.pdf?utm_source=chatgpt.com
https://pain.ucsf.edu/topics/understanding-pain-pain-basics?utm_source=chatgpt.com

Describing pain : What does it feel like?

- Acute Pain
  - Usually caused by trauma or sudden injury
  - Common sources: sprains, fractures, strains, inflammation, surgery
  - Sharp, localized pain
  - Starts suddenly, often with a clear cause
  - Typically, short-term and improves with healing
  - May be accompanied by swelling, redness, or limited mobility
- Chronic Pain
  - Persists >3 months, often beyond expected healing time
  - Common causes: osteoarthritis, fibromyalgia, chronic back pain, neuropathic pain
  - Dull, aching, or burning pain, sometimes intermittent
  - Can impact sleep, mood, and quality of life
  - May not have an obvious injury or visible damage
  - Often worsens with activity or prolonged positioning

What about a Person with Hemophilia?

- Acute Pain
  - Caused by ***spontaneous bleeding*** into joints or muscles
  - Deep, throbbing, or pressure-like pain
  - Often no external trauma; pain can begin suddenly and intensely
  - Accompanied by joint swelling, warmth, and limited movement
  - Pain worsens with movement and improves slowly with factor treatment
  - May present with muscle tightness or guarding
- Chronic Pain
  - Persistent, dull, or aching pain, even at rest
  - Affects commonly used joints: ankles, knees, elbows
  - Associated with joint deformity, stiffness, and reduced mobility
  - Can significantly impact daily function and quality of life
  - Often leads to muscle imbalances and altered gait

How to differentiate pain from bleeding

- Clinical assessment
- Location
- Response with factor
- Adherence to prophylaxis
- Response to movement
- Role of Imaging
  - Musculoskeletal Ultrasound (MSKUS)
  - MRI
  - CT
- Key Question: Is it pain from an old joint bleed (arthropathy) or is it new active bleed

Acute Joint Bleeding Episode s/s

- Bubbling or tingling sensation
- Swelling in joint or surrounding tissue
- Tenderness and pain in the joint
- Stiffening of joint into position of comfort (open packed position)
- Decreased/limited ROM
- Heat/warmth
- Muscle guarding
- Spasms in muscles supporting the joint
- Discoloration may or may not occur in joint bleeds

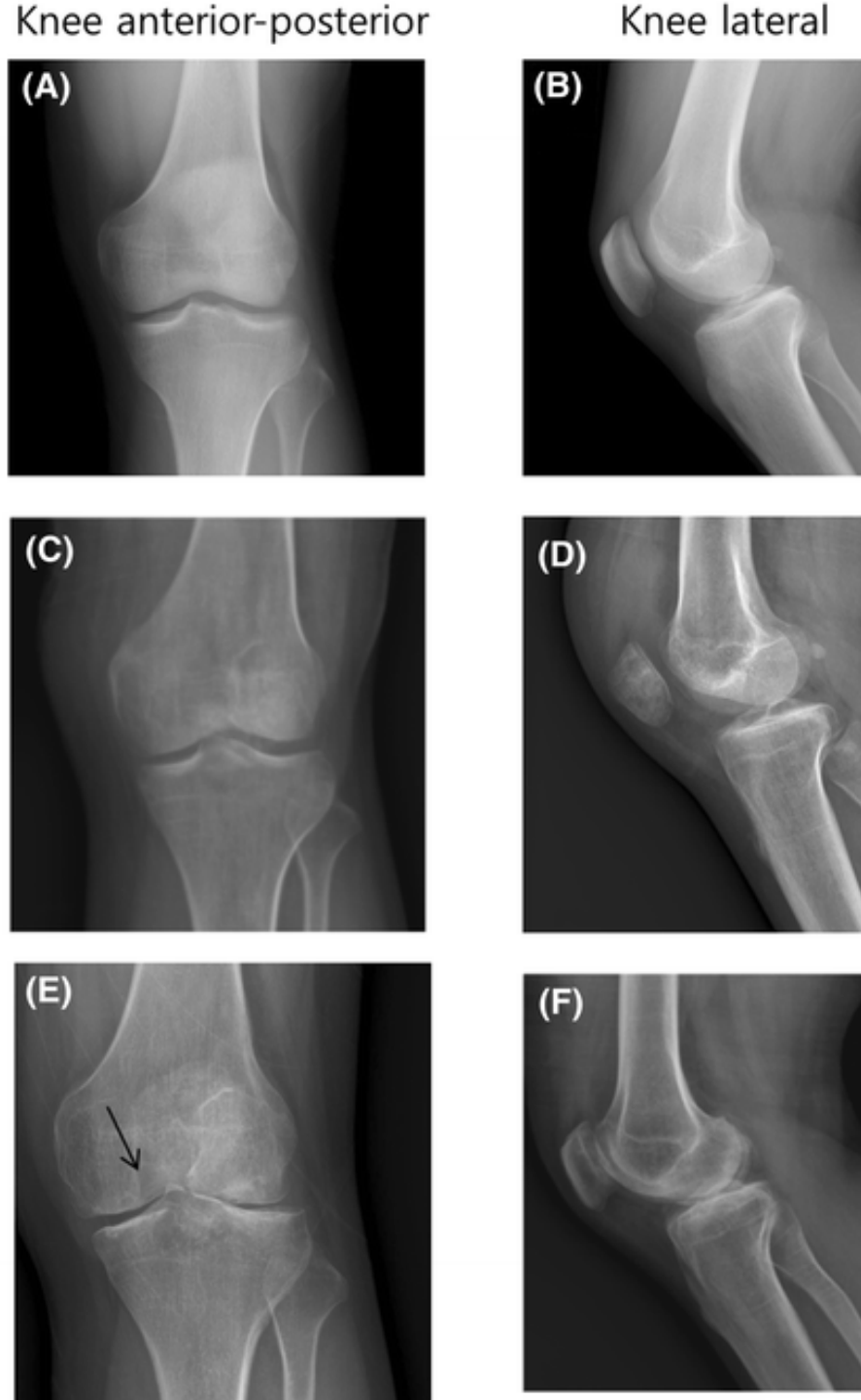
1. "Acutely Swo2. *WFH Guidelines for the Management of Hemophilia, 3rd Edition*, www1.wfh.org/publications/files/pdf-1863.pdf. Accessed 18 Apr. 2024.
llen Joint." *TeachMeSurgery*, teachmesurgery.com/orthopaedic/principles/acutely-swollen-joint/. Accessed 18 Apr. 2024.
2. *WFH Guidelines for the Management of Hemophilia, 3rd Edition*, www1.wfh.org/publications/files/pdf-1863.pdf. Accessed 18 Apr. 2024.

Acute Muscle Bleeds s/s

- Muscle pain, swelling, and warmth
- Contracture/spasm
- Increased pain with muscle movement/stretching or weight bearing
- Muscle guarding
- Area over muscle injury may appear shiny or tense
- Possible palpable hematoma
- Discoloration may or may not occur
- Possible numbness/tingling

Chronic Hemophilic Arthropathy s/s

- Decreased ROM with painful movements
- Contracted or fused joints with loss of motion
- Joint malalignment
- Visible muscle atrophy
- Pain and crepitus with movement



Chung, W. S. et al. "Figure 2." Springer Link. Retrieved 24, April, 2024, from https://link.springer.com/article/10.1007/s12288-016-0717-4.

Chronic Pain in PwH

Prevalence	• Chronic pain affects 46% of PwH • Hemophilia Severe ~53% vs 21% in the general population
Pain Type	• 92% report joint pain as most frequent • 80% of bleeds occur in the joints: knee→ ankle → elbow → wrist
Arthropathy	• Often due to recurrent joint bleeding • 32-50% experience pain from hemophilic arthropathy
Functional Impact	• Chronic pain interferes with mobility and daily activities

	Acute Pain – PwH	Chronic Pain – PwH
Primary Cause	Bleeding into joints or muscles	Hemophilic arthropathy due to repeated joint bleeds
Onset	Sudden, often without trauma	Gradual, develops over time due to joint damage
Response to Movement	Movement worsens pain; guarding common	Limited movement due to joint damage and pain
Diagnosis Tools	Clinical exam, ultrasound, MRI, factor levels	MRI, X-rays (joint damage), physical assessment
Initial Management	Factor replacement therapy ASAP, pain meds, rest	Factor prophylaxis, analgesics, PT, orthotics
Pharmacologic Limits	Avoid non-selective NSAIDs (bleeding risk)	Same as acute: NSAIDs used cautiously
Surgical Consideration	Rare for acute pain unless due to compartment syndrome	Joint replacements, synovectomy common in severe cases
Psychological Impact	Anxiety about bleeding, fear of activity	Depression, fear of movement, social withdrawal
Prevention Focus	Prevent bleeds with prophylaxis	Prevent joint damage through early bleed control

Why Understanding Pain Matters

- Misinterpreting pain vs active bleeding can lead to under or overtreatment
- Proper pain assessment is key to improving QOL
- Types of bleeding – joint, muscle, internal, external
- Consequences of repeated bleeds
  - Hemophilic Arthropathy
  - Synovitis

If I'm not bleeding, what is the next step?

Pain Management

- Requires Individualized approach
- *Physical Therapy*
- Joint care strategies (braces, orthotics, taping, assistive devices)
- Alternative Therapies (TENS, Dry Needling, Heat/Cold Therapy…)
- Tylenol, COX-2 inhibitors per hematologist
- Orthopedic consultation?

“What brace do you recommend?”

HTTPS://ORTHOTICSPLUS.COM.AU/ORTHOTICS/ANKLE/ANKLE-STABILISING-ORTHOSIS-ASO/

HTTPS://WWW.DOCORTHO.COM/PRODUCTS/MEDI-M4S-COMFORT-KNEE-BRACE

HTTPS://WWW.FREDMEYER.COM/P/DR-SCHOLL-S-COPPER-INFUSED-ELBOW-COMPRESSION-SLEEVE/00812350261O8

Pros ✅

- Joint Stabilization
- Pain Reduction
- Improved Mobility & Balance
- Protection Post-Bleed
- Customizable

Cons ❌

- Muscle Weakness Risk
- Discomfort or Skin Issues
- Limited Range of Motion
- Cost/Access Issues
- Cosmetic Concerns

Blanchette, V. S., Key, N. S., Ljung, L. R., Manco-Johnson, M. J., van den Berg, H. M., & Srivastava, A. (2014). Definitions in hemophilia: Communication from the SSC of the ISTH. *Journal of Thrombosis and Haemostasis, 12*(11), 1935–1939.
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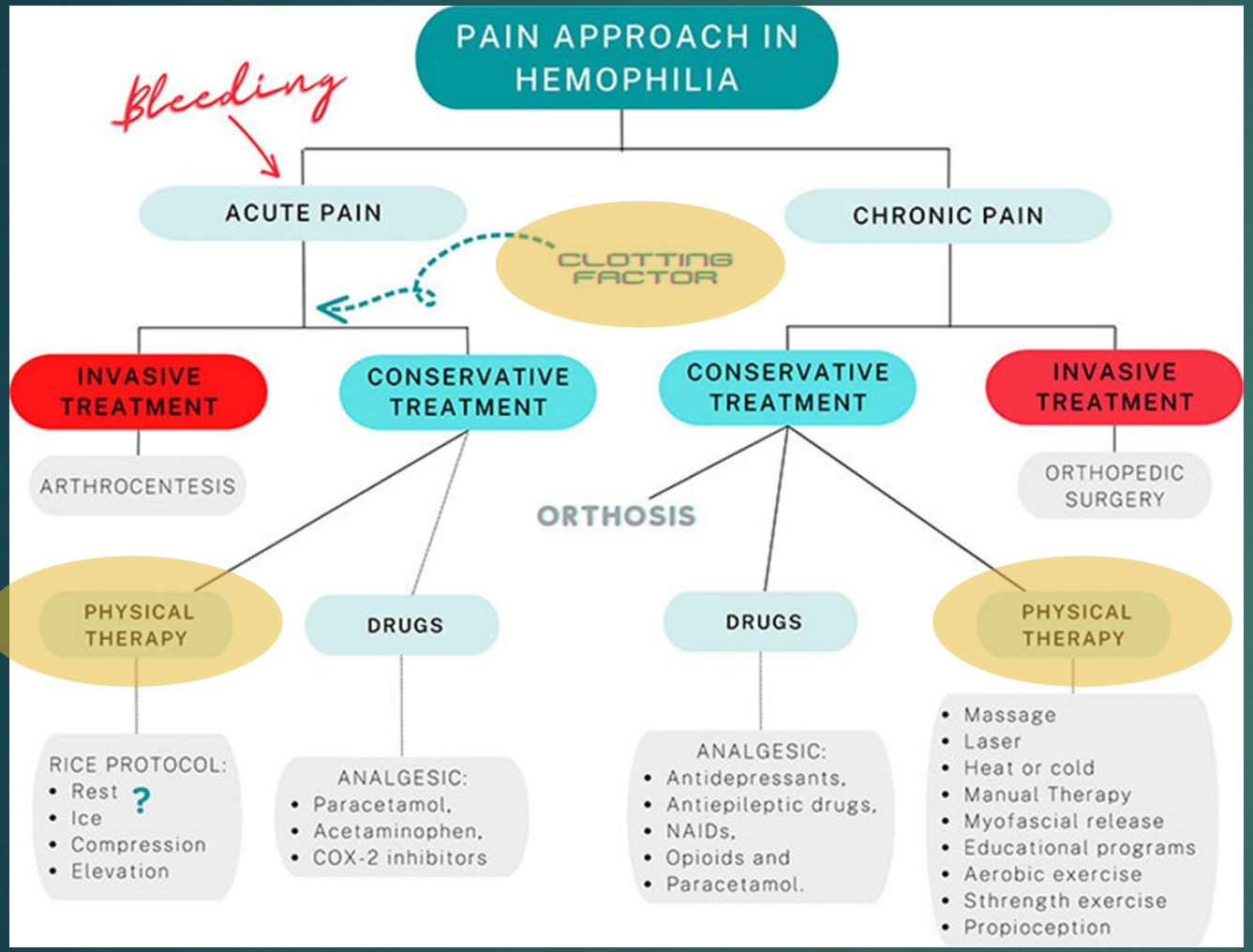
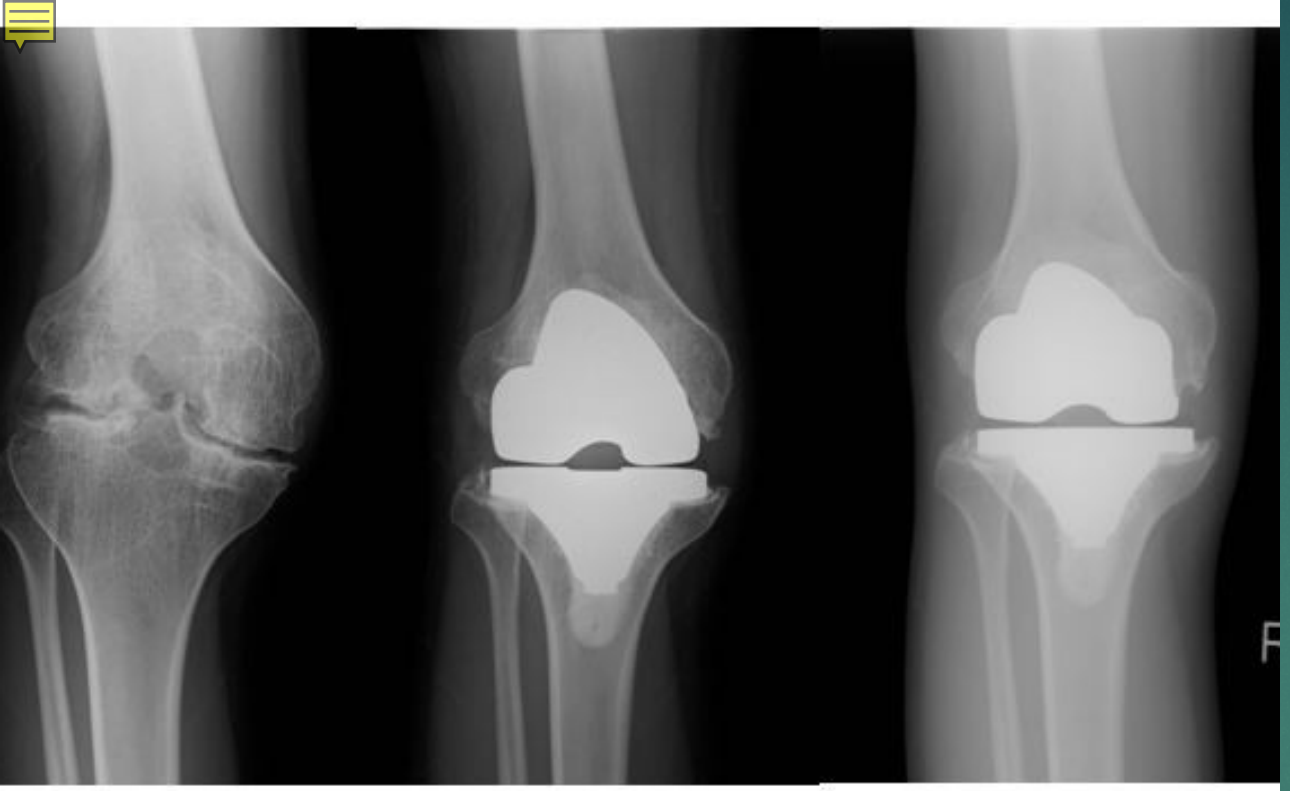
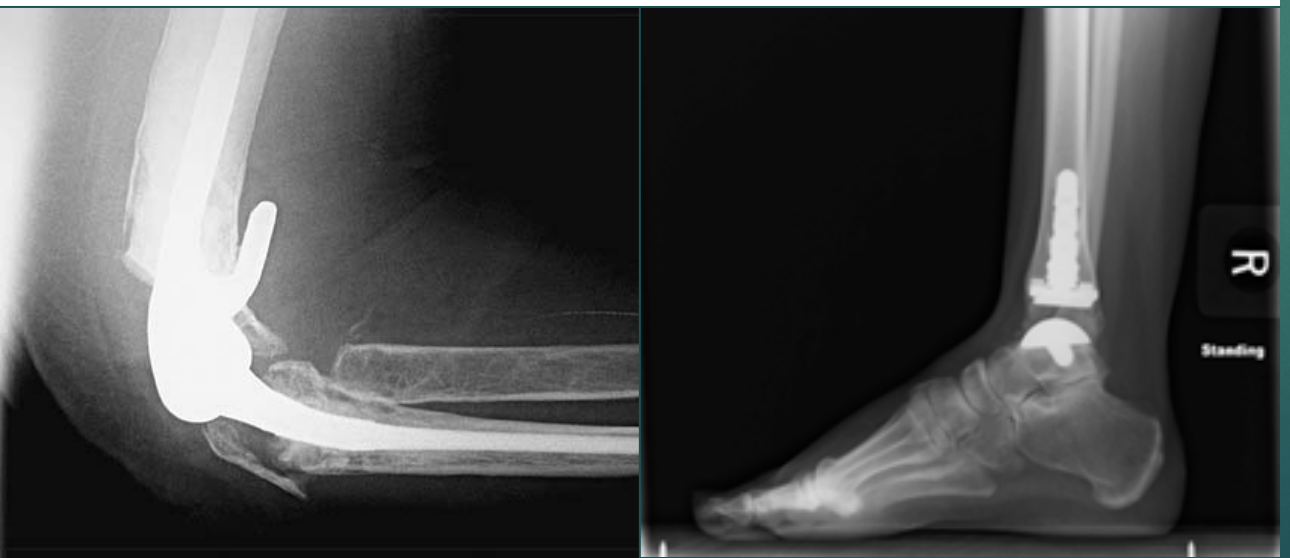


Physical Therapy?

How does PT help PwH with pain?

- Education
  - Hematomas and hemarthrosis
  - sports participation/recommendations, RTP/RTW (dependent on severity and s/s)
- Manual Therapy
  - Joint Mobilization
  - Traction
  - Passive Range of Motion
- POC-MSKUS
  - Routine joint assessment
  - DDx of articular pain
  - Lesion follow-up
- Therapeutic Exercise
- Kinesiotape
- Neuromuscular Reeducation
- **Use your resources!**





Orthopedic Consult & Treatment

- Conservative
  - Intra-articular corticotherapy
  - Aspiration
  - Hyaluronic acid injections
- Surgical
  - Synovectomy & Debridement
  - Selective Arteriole Embolization
  - Arthrodesis
  - ***Total joint replacement- When?***

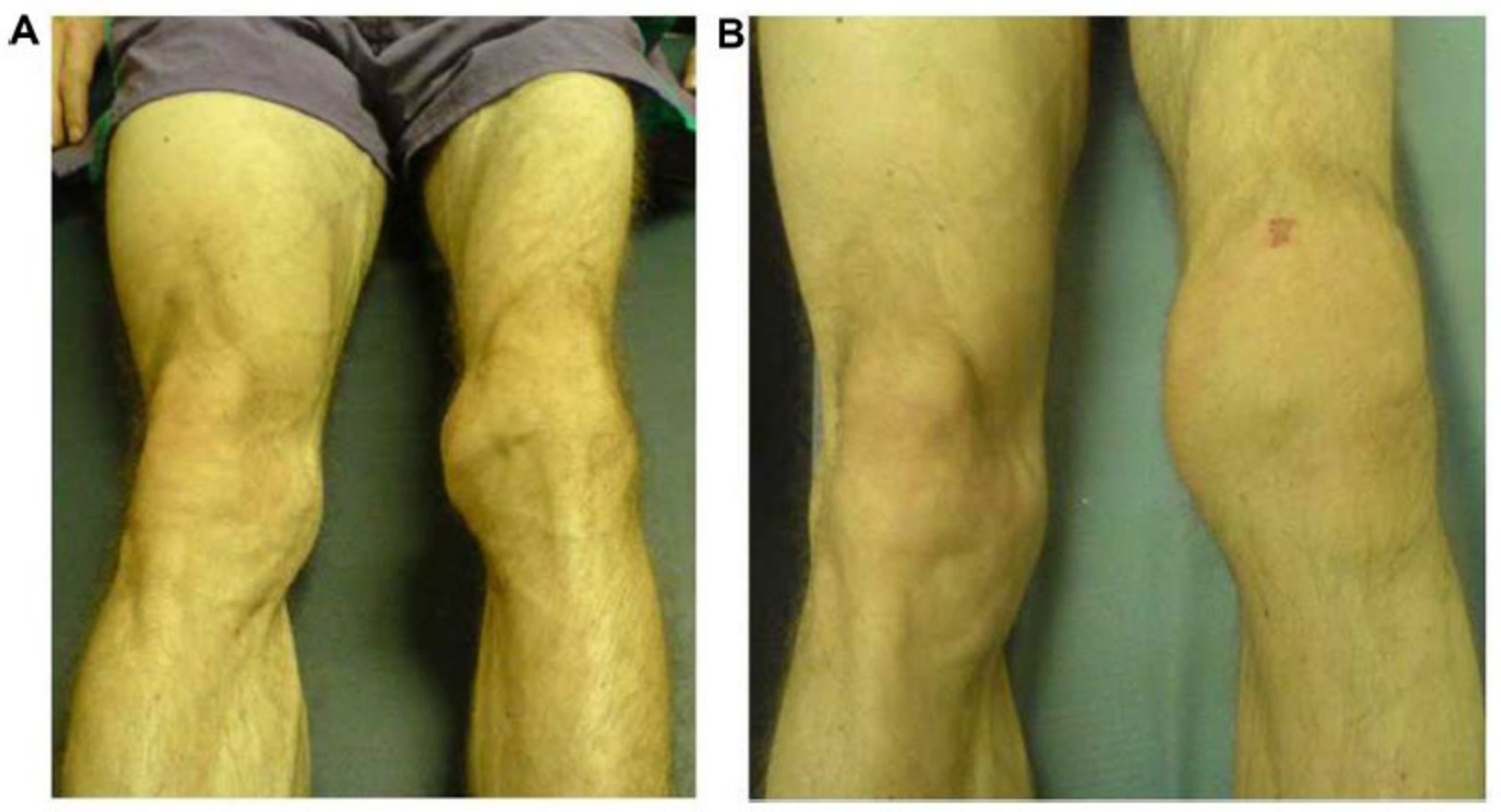
https://www.intechopen.com/chapters/41036
Takedani, H. (2013). Total joint arthroplasty for hemophilia. In Hemophilia (pp. [page numbers if known]). IntechOpen. https://doi.org/10.5772/53232
https://www.orthobullets.com/shoulder-and-elbow/3089/total-elbow-arthroplasty#popup/image/18083

I’ve tried everything & my joint is still sore and puffy… Is that a bleed?

- Not always!
- Synovial hypertrophy (thickened joint lining)
  - Impaired synovial clearance
- Hemophilic arthropathy
- Chronic joint effusion
- Muscle atrophy and joint deformity can accentuate swelling
- Chronic synovitis
- Difference between chronic hemophilic arthropathy and acute bleed

https://pubmed.ncbi.nlm.nih.gov/34197690/

Chronic Arthropathy vs. Acute Bleed



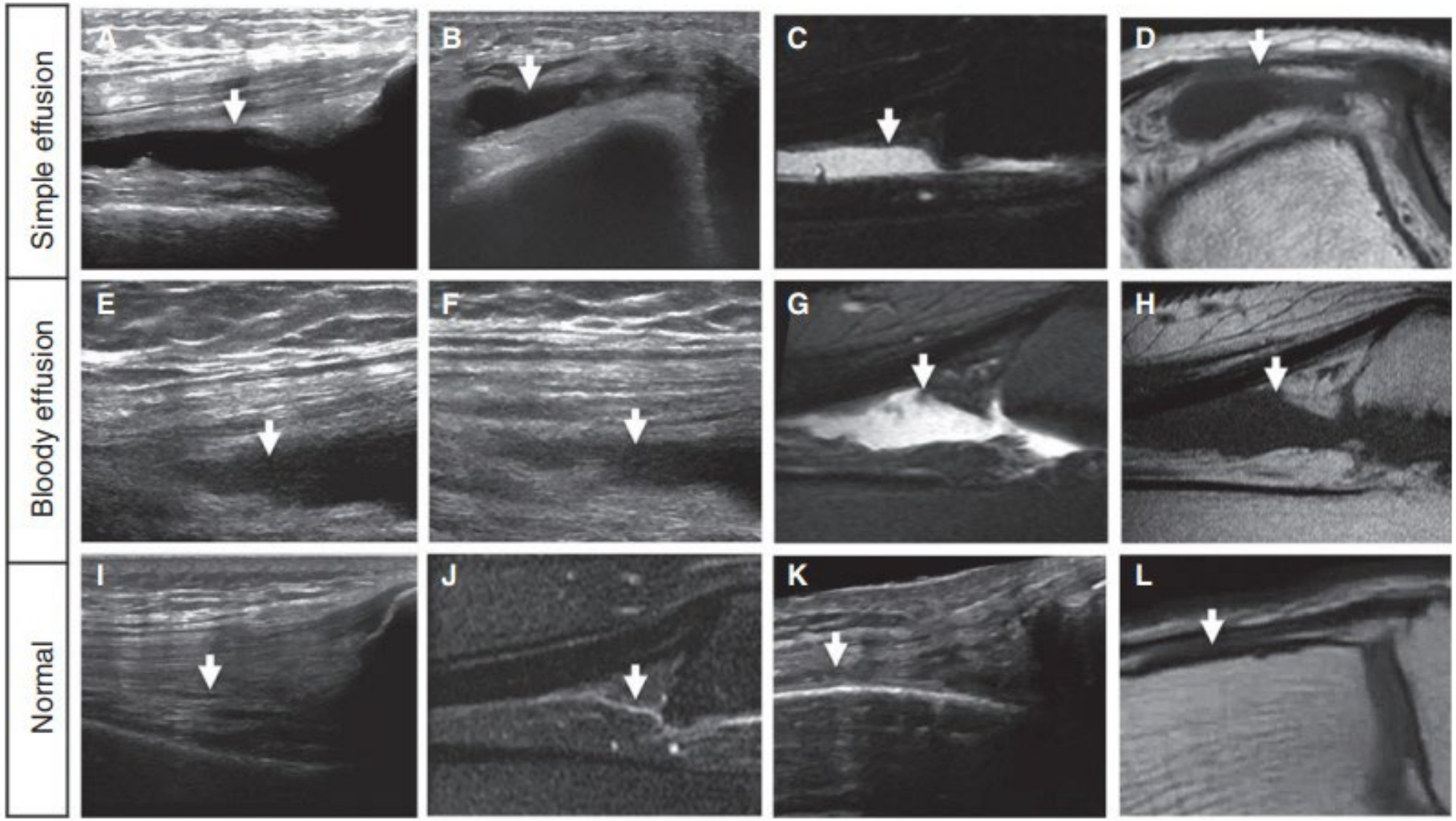
https://www.dovepress.com/optimal-management-of-hemophilic-arthropathy-and-hematomas-peer-reviewed-fulltext-article-JBM

Let's take a closer look

The Role of MSKUS in Bleeding Disorders

- Acute Concern
  - Compliment clinical assessment of painful MSK episodes *to answer yes/no questions to help with dx and management*
- Chronic Concern
  - Detection of joint disease, soft tissue pathology, and monitor synovial changes
- Interventional
  - US guided joint aspiration and of corticosteroid or viscosupplement injection
- Baseline (serial) Scans
  - Early detection and serial imaging of hemophilic arthropathy

Bakeer, N. (2020, November). *Point-of-care ultrasound in persons with inherited bleeding disorders: A call for guideline development* [PowerPoint slides]. MASAC Meeting.



Nguyen, S., Lu, X., Ma, Y., Du, J., Chang, E. Y., & von Drygalski, A. (2021). Musculoskeletal ultrasound for intra-articular bleed detection: A highly sensitive imaging modality compared with conventional magnetic resonance imaging. Haemophilia, 27(2), e199–e202. https://doi.org/10.1111/hae.14222

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https://doi.org/10.1016/j.rpth.2024.102372

ORIGINAL ARTICLE

Ultrasound in addition to clinical assessment of acute musculoskeletal complaints in bleeding disorders: impact on patient management

Flora Hendrica Pieternella van Leeuwen[1] | Wouter Foppen[1] | Pim A. de Jong[1] | Wobke E. M. van Dijk[2] | Johan Blokzijl[2] | Kathelijn Fischer[2] | Merel A. Timmer[2]

Conclusion?

- Ultrasound findings ***in addition*** to clinical assessment impacted diagnosis in 36% and treatment plans in 39% of episodes
- Results show it is difficult to correctly diagnose an acute MSK episode based on clinical assessment with and without HA
- Encourage MSKUS for management of acute MSK complaints

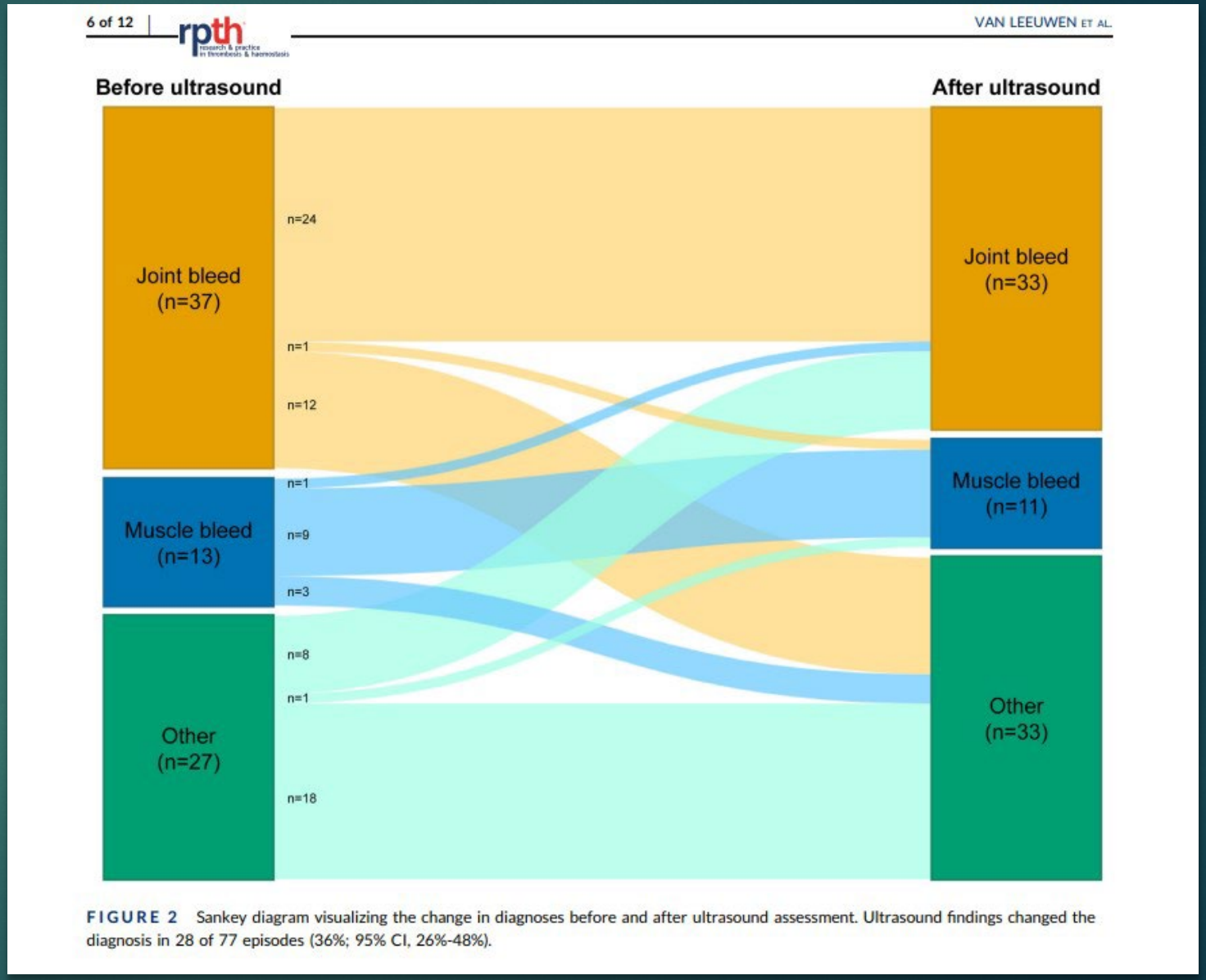


FIGURE 2 Sankey diagram visualizing the change in diagnoses before and after ultrasound assessment. Ultrasound findings changed the diagnosis in 28 of 77 episodes (36%; 95% CI, 26%-48%).

https://pmc.ncbi.nlm.nih.gov/articles/PMC10999475/pdf/main.pdf

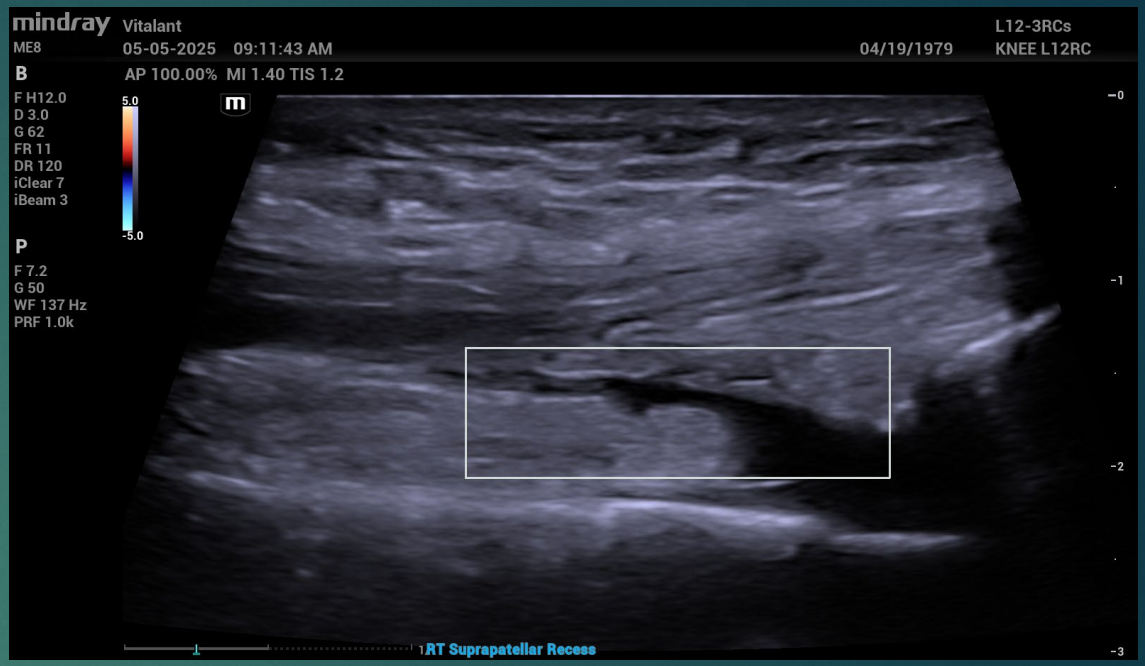
Case Study 1: 46 yoM Hemophilia B <1%

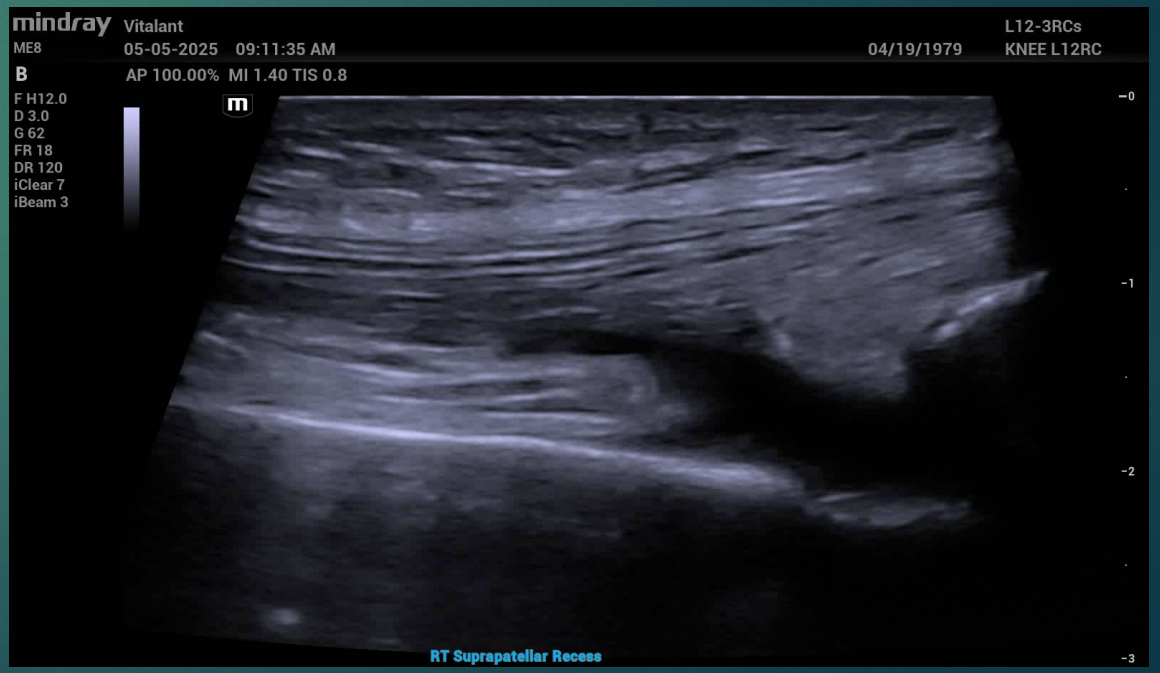
- Chief complaint: pain distal quad after being kicked by a horse
- **Treats on-demand only**
- Historically, over-treats with injuries until resolution of pain
- Called HCWP for musculoskeletal ultrasound

- Clinical Presentation:
  - Swelling, pain with movement, decrease in range of motion, arrived with antalgic gait pattern

What were the recommendations per hematologist?

No infusion





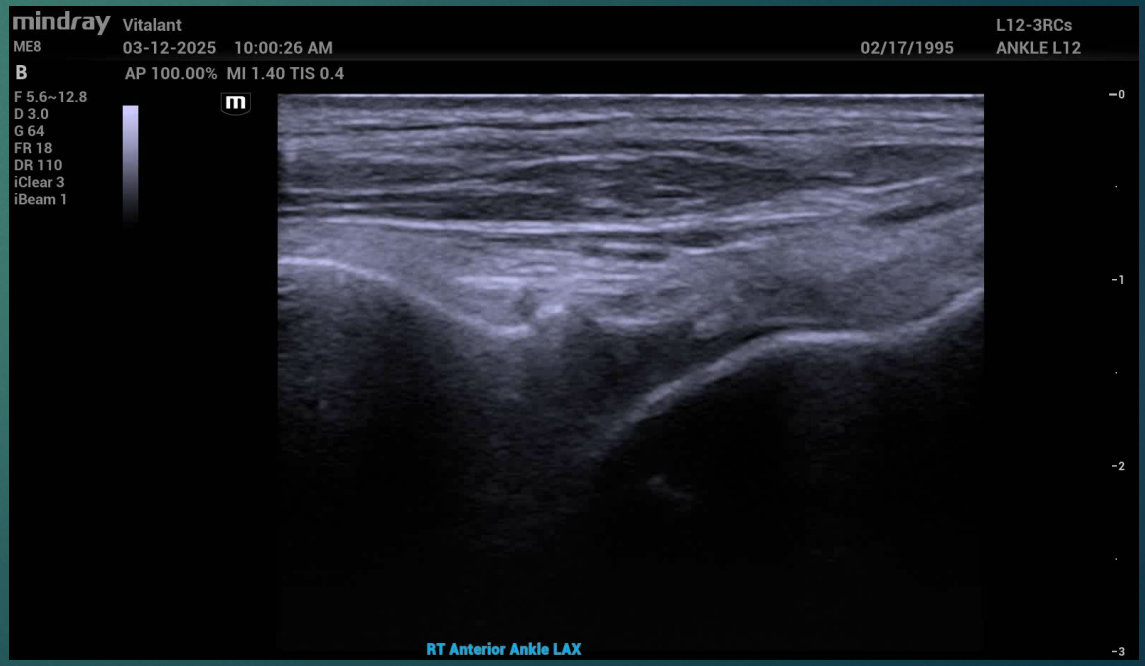
Case Study 2: 30 yoM Hemophilia A 3%

- Chief complaint: pain in right ankle after running 1-2 miles
- **Treats on-demand only**
- Historically, does not treat for this type of issue
- Called HCWP for musculoskeletal ultrasound to rule out joint hemarthrosis.

- Clinical Presentation: mild swelling, tenderness to palpation, decreased ROM, normal gait pattern

What were the recommendations per hematologist?

Yes, infuse

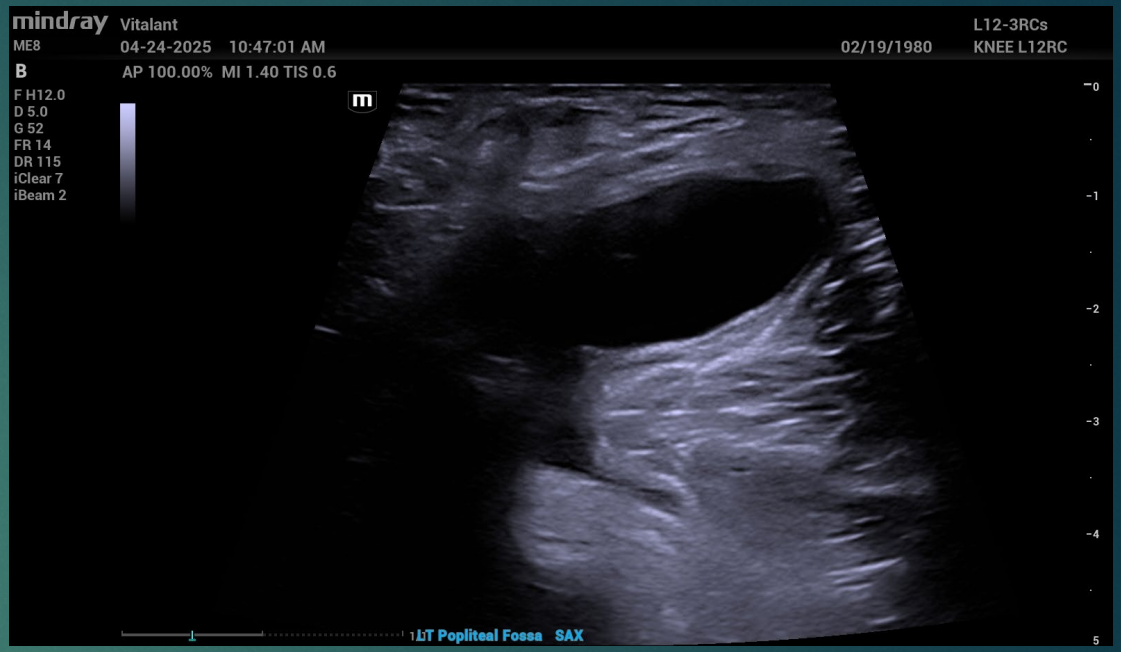


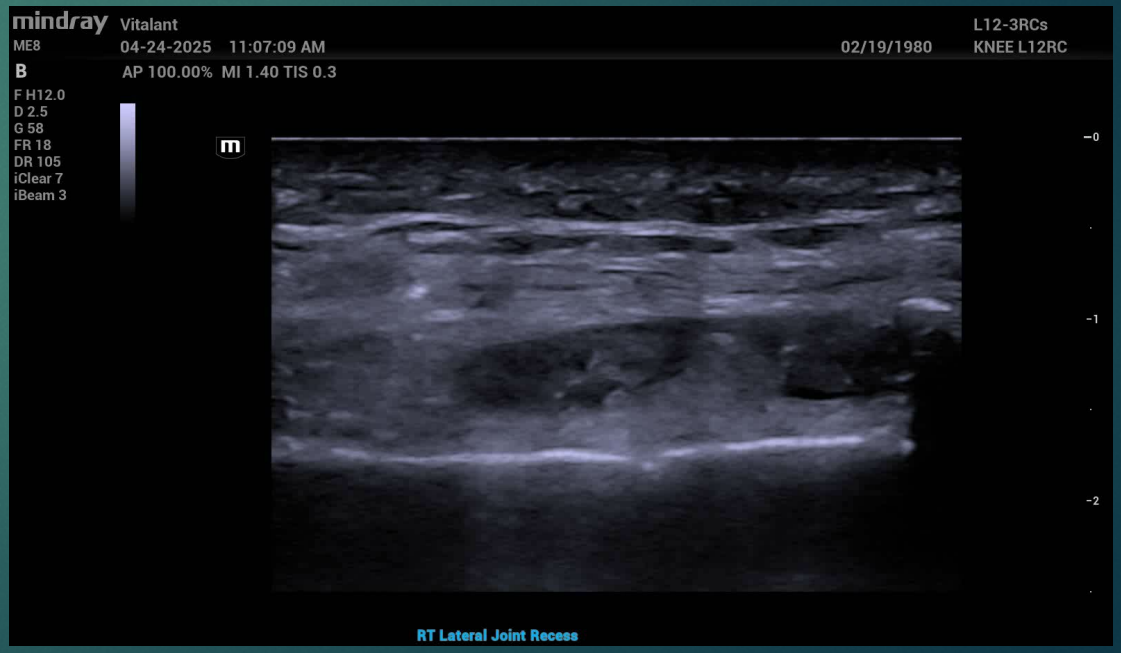
Case Study 3: 45 yoM Von Willebrand Disease Type 3

- Chief complaint: pain in left knee after walking around a Pittsburgh Pirates game
- **Treats on-demand only**
- Historically, treats with "abnormal" pain
  - Unable to self-fuse
- Called HCWP for PT exam and MSKUS to r/o joint bleed

- Clinical Presentation: decreased ROM, tenderness to palpation, swelling, antalgic gait pattern

- What were the recommendations per hematologist?
- No infusion & ortho referral





Key Takeaways

- Pain does not equal bleeding, but they are closely linked
- Proper diagnosis is crucial for effective management
- Advances in hemophilia care are improving quality of life
- Every patient and treatment plan is different
- Always check with your HTC team when you are experiencing a bleeding event

Questions?

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