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Hemophilia: Joint Health in Action

Real patient cases illustrating a multidisciplinary hemophilia management approach to joint health



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It's always the right time to emphasize joint health in hemophilia management

Joint health is an important part of hemophilia management, whether or not a patient has previously experienced joint complications.¹ Though some patients may feel discouraged over long-term complications of hemophilia, continued support through a multidisciplinary team (MDT) is key for patient management and joint health.^{1,3} Support may include physical therapy, psychosocial care, and monitoring disease management through both subjective reports and objective evaluations, such as through clinical evaluation and imaging.¹

Each member of the MDT has the opportunity to uncover different elements of joint health that may help encourage patients to be more engaged in their management

Each patient is unique and has different challenges, desires, and goals. Understanding this and ensuring proper education can help patients take a more active role in their hemophilia management. Members of the MDT often leverage their unique patient- and colleague-collaborative approaches to uncover the struggles and motivators that can inform a patient-specific management plan.

“ I think that every member of the MDT brings their own breadth of experience to the table, and we all work so closely together. Our combined experiences can help guide our patients and help us learn what motivates them in different ways. ”

— Kim Schafer, MSN, FNP-C

Patient cases: All patients can benefit from an enhanced focus on joint health

Patient Case #1: MSKUS motivation

Background:

An adolescent patient with severe hemophilia A struggled with his weight since childhood until he began playing a recreational sport, which enabled him to achieve a healthier weight.

The challenge:

Though he was prescribed prophylactic treatment, he was nonadherent and followed an on-demand regimen. At some point while participating in his sport, the patient twisted his ankle and then experienced bleeding.

MDT action:

- With the advice of the MDT, he performed 3 factor VIII infusions for treatment of his bleed and then reported to his hemophilia treatment center (HTC) for evaluation
- Despite the patient reporting that he was “feeling fine,” point-of-care MSKUS was ordered
- MSKUS revealed evidence that there was still blood in his ankle, much to everyone’s surprise. The physical therapist advised the patient to suspend physical activity until his joint improved
- The nurse understood how important his sport was to him, but helped him understand that the active bleed was evidence that “feeling fine” isn’t the same as the joint being healthy
- He rested as directed, resumed a prophylactic regimen, and came back to the HTC every month for follow-up

Resolution:

- After about 3 months, this course of action allowed the joint to recover enough for the patient to be cleared to play again and prevented him from exacerbating his injury through continued physical activity
- By understanding the patient’s goals, the MDT was also able to utilize the evidence provided by MSKUS to educate the patient and help increase engagement with his joint health

Patient Case #2: Knowledge is power

Background:

An older patient in his mid-60s had never received a diagnosis of hemophilia in spite of suggestive family history. With the urging of a family member, he sought support of an HTC prior to seeking treatment of a hernia.

The challenge:

He came into the clinic in a wheelchair. Significant joint damage and mobility problems were explained with a formal diagnosis of hemophilia.

MDT action:

- After thorough evaluations from the physician, nurse, and physical therapist, it was discovered that the patient had trouble getting out of the house and was no longer able to do the little things he enjoyed, such as going to the store with his wife or going to work
- In addition to supporting his search for a hernia assessment and eventual treatment, an official diagnosis of hemophilia led to a recommendation of prophylaxis with factor. He was also prescribed physical therapy to improve his mobility
- The social worker facilitated home infusion through an agency to make the patient’s management plan easier

Resolution:

- After 6 months of adhering to a prophylactic regimen in an effort to prevent bleeds and joint bleeds, combined with supportive care, the patient came back to the clinic with his wife, presenting with improved mobility
- Because of the comprehensive care he received, he returned to the clinic with a happier demeanor, increased self-care, and the ability to return to work

“ This particular case was when we first started implementing MSKUS. What it taught us was that we were unknowingly allowing kids to go back to their normal activities because we weren’t able to see inside those joints. And in the end, they just weren’t getting better. Now, whenever a patient has a bleed, the physical therapist performs an ultrasound, and it has made a world of difference with my patient education because when the patient sees the bleed, it becomes real for them. ”

— Dezarae Tate, RN

“ It was one of those cases where nobody realized the patient was suffering because he was a quiet sufferer and did not complain. He thought his pain was normal. This case was significant because with proper care and management, his life was really able to turn around. And it’s not just my effort, or a physician effort, social worker effort, or physical therapy that helped this patient improve. It’s the entire collaboration. Most people don’t understand that it’s an entire team effort—with follow-ups and calling the patient and making sure they are taken care of. ”

— Dezarae Tate, RN

Patient Case #3: It's never too late

Background:

An older patient with hemophilia presented to the HTC with significant joint damage due to bleeds from primary on-demand treatment in his younger years.

The challenge:

Because of the extent of his joint damage, he thought it was too late for him to make improvements.

MDT action:

- By posing only the simple question, “What is one thing that would make your day better?”, the physical therapist was able to discern that the patient could no longer participate in ice fishing, something he enjoyed for many years but could no longer do because of joint discomfort
- Further probing on challenges revealed the patient was unable to lift the heavy fishing equipment onto the ice and was worried about slipping and falling
- With this information, and after regrouping with the physician and nurse, the MDT was able to work together with the patient and come up with a plan. The physical therapist made lifestyle recommendations to help the patient resume his hobby, and the physician and nurse helped tweak his treatment plan moving forward with this new activity in mind

Resolution:

Through MDT collaboration with the patient and recommending only minor lifestyle adjustments—such as wearing different shoes and finding alternative ways to transport heavy fishing equipment safely—the patient was able to return to ice fishing.

“ If a patient feels that nothing else can be done to improve the circumstances of their lifestyle, we talk some more and ask, ‘What is one little thing that would make a difference in your day?’, and then we collaborate and work with the patient to see what little things we can do to get them back to what they want to do. ”

— Kim Baumann, MPT

Patient Case #4: Maintain adherence to maintain what matters

Background:

A young patient in his early 20s with moderate hemophilia was physically active and enjoyed participating in a recreational sport.

The challenge:

- Despite advice from the MDT, the patient was nonadherent to a prophylactic regimen
- Communications with the nurse practitioner revealed that as a result, over the course of a year, the patient bled multiple times into different joints
- This bleeding affected his ability to participate in sports, causing the patient frustration, as hemophilia was affecting his life

MDT action:

- At the HTC, the physical therapist performed imaging to evaluate the patient's joints, which confirmed joint damage, and then pivoted to focus on instilling the benefit of maintaining healthy joints in order to participate in sports
- The social worker evaluated potential psychosocial barriers to prophylaxis, which led to understanding that the dosing schedule was particularly difficult for this patient to adhere to
- The nurse practitioner, understanding the patient's clear motivator of being able to play again, discussed the importance of adhering to a prophylactic regimen, and educated the patient on different treatment options
- Through their multidisciplinary efforts, the team was able to find a prophylactic dosing regimen that accommodated the patient's lifestyle
- Frequent MDT monitoring through regular follow-ups were necessary to maintain patient adherence and motivation throughout the healing process

Resolution:

- After many conversations over the course of a year to keep the patient on track, his bleeding frequency decreased dramatically, and he was cleared to play again, reinforcing the benefits of infusing regularly and focusing on joint health
- Even as his passions evolved, from recreational sports to hiking, this learning experience, along with consistent check-ins with the MDT, allowed him to continue prophylactic treatment and benefit from the value of taking care of his joints

“ Sometimes it's just a matter of reminding the patient that preventing bleeds will benefit them by allowing them to participate in different activities they enjoy. This way, the patient learns globally that their treatment regimen is important to maintain. ”

— Kim Schafer, MSN, FNP-C

Patient Case #1: MSKUS motivation

Objective measures, such as imaging, may aid the MDT, serving as both a monitoring tool and a patient education tool for joint bleeds, helping to inform management.

Patient Case #2: Knowledge is power

Even patients who have accepted a greatly diminished quality of life may benefit from more comprehensive disease management and supportive care through a multidisciplinary approach.

Patient Case #3: It's never too late

Even with existing joint damage, asking the right questions and making even the smallest of adjustments may help a patient reach their goals.

Patient Case #4: Maintain adherence to maintain what matters

Continuous check-ins with patients by the MDT about lifestyle changes may help keep patients engaged and help to maintain treatment adherence.

Though each patient may be in a different point along their journey, the MDT has the opportunity to work closely together to identify what is important to each patient as a way to encourage a greater emphasis on joint health.

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