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Hemophilia A Care Team: More than the Sum of its Parts

How multidisciplinary team collaboration may help improve patient outcomes



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Leading authorities in hemophilia treatment recognize the key role of the multidisciplinary team in providing patient care

The World Federation of Hemophilia (WFH) guidelines and the Centers for Disease Control and Prevention (CDC) recommend specialized care through a multidisciplinary team (MDT)—including but not limited to physicians, nurses, physical therapists, and social workers—as it is key to reduce morbidity and mortality for patients with hemophilia.^{1,2} A major cause for morbidity in patients with hemophilia includes issues with the joints as a result of recurrent hemarthrosis.¹

Through the comprehensive care model, hemophilia treatment centers (HTCs) emphasize prevention services to help reduce complications. These include preventative medicine, connecting patients with their community, and providing education and support to families.² Each member of the MDT plays an integral role in patient care, with the ability to provide unique perspectives. Collaboration and communication between the team is key in delivering effective and optimal care.^{1,3}

MDT members work together to help improve patient care and create a more complete picture of a patient.

“ Oftentimes, a patient will meet with me, the physician, the nurse, social worker, and physical therapist during their appointment. Our team then comes back together for a weekly team meeting to discuss aspects of the patient visits. We use this as an opportunity to gain additional insight from other care team members. For example, I may learn that a patient has joint swelling and pain, while the physical therapist may learn more about the patient’s limited range of motion and function, and the social worker might discover how this is affecting the patient in their everyday life. Conversations from each respective care team member may yield different puzzle pieces to obtain the full picture. ”

—Kim Schafer
MSN, FNP-C

Each member of the MDT plays a critical role in patient education, particularly around joint health. Evidence has shown that patient awareness of the negative effects of joint bleeds may result in decreased tolerance of joint bleeds, earlier initiation of preventative measures, more effective bleed control, and the increased use of physical therapy.⁴ With proper education and understanding through different members of the care team, disease management may be optimized. The profound impact that diverse HCP specialties can have through their connections with patients underlies the comprehensive care model.

Different specialties within the MDT may use their own unique tactics to make the topic of joint health more tangible, such as through storytelling, seeing below the surface through educational models, or using everyday objects that can illustrate the concept.

“ We help patients understand the importance of joints and how joint health is related to the rest of the body. It’s important for people to understand the role that their joints play. ”

—**Kim Schafer**
MSN, FNP-C

“ We know that all bleeds are important. It only takes one bleed in a joint to cause damage. With patients, it’s important to discuss their physical activity and stress treatment compliance. Sharing other patient stories can also go a long way in helping build understanding of the importance of joint health. ”

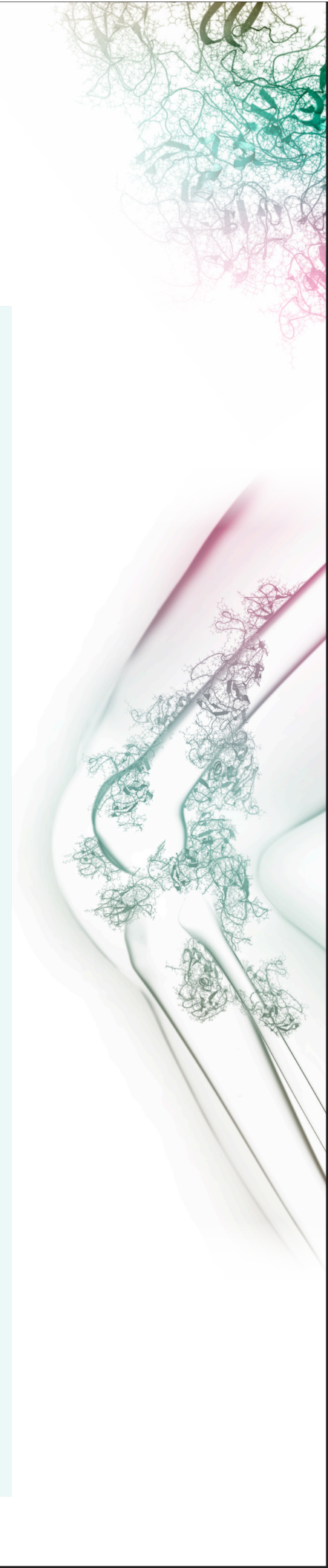
—**Nicole Reynaud**
RN, BSN

“ We have models that illustrate the synovium and inflammation to help educate our patients. We also hold educational events where we would bring younger patients and older patients, where the older patients help provide perspective on joint health to the younger patients. And we relate it to their hobbies. I recently asked one patient ‘How did your knees feel when you were out gardening?’ ”

—**Denise Lowery**
LCSW

“ It is essential to educate the patient on how a normal joint is constructed and functions. After the patient understands the normal joint, they can then be educated on the damaging process of blood getting into a joint and the lifelong impact that will have. Not all patients learn best from PowerPoint presentations or informational handouts. MDTs use multiple educational tools. These range from everyday items—like a kitchen sponge to demonstrate how hyaline cartilage inside of a joint gets its nutrition—to anatomy models, the patient’s own imaging, or the patient’s functional test results, etc. This helps ensure that each patient can be supported and educated in the way they learn and comprehend information the best. ”

—**Cindy Bailey**
PT, DPT, OCS, SCS, ATC



Along with patient education for preventative measures, identifying bleeds and existing joint damage is also important. Though patients may not always understand why their joints are important, they can speak to how their joints are feeling. Having multiple conversations and talking to different members of the care team may help to uncover any new changes pertaining to a patient's joint health.

Asking the right questions can reveal this information when a patient may not reveal changes themselves.

“ We evaluate range of motion and pain through functional assessment. And usually, the first part of the functional assessment is asking questions such as, ‘Are you the same this year as you were last year?’ If they say no, then we may actually go through some functional activities with them to see what they, or we, think has changed and in what way. ”

—Cindy Bailey
PT, DPT, OCS, SCS , ATC

“ If a patient says, ‘I haven't had any bleeds,’ I'll go into more detail and ask, ‘When you wake up in the morning, do you feel stiff?’ I'll also ask, ‘Do you feel sore?’ I'll then go into even more detail with questions and ask ‘Well, do you notice issues in one joint? Is it your elbow? Is it your ankle? Does one bother you more than the other?’ This way, I am able to learn more. ”

—Nicole Reynaud
RN, BSN

“ We ask psychosocial questions to understand the patient's joint health. What are they doing? Do they have children they are chasing around? Are they resting adequately? ”

—Denise Lowery
LCSW

In addition to subjective reports, identifying bleeds and joint damage through objective measures, such as imaging, may be important to inform their hemophilia management plan. The value of musculoskeletal ultrasound (MSKUS) is recognized by the WFH guidelines during the clinical assessment and management of hemophilic arthropathy.¹

Imaging can also serve as a valuable educational and monitoring tool to help patients visualize their joints.

“ Our physical therapist can show them images from 6 months or a year before compared to what it looks like today. When you show patients the imaging, the images speak a lot more than what we are able to convey with words. I think when patients are able to physically see it, it makes sense. ”

—Nicole Reynaud
RN, BSN

“ Now with the availability of ultrasound, the patients have a way to see their own joint, which really reinforces treatment compliance and education. ”

—Cindy Bailey
PT, DPT, OCS, SCS , ATC

Care is critical for patients in between appointments.

“ We’ve had patients send us pictures of swelling. They can take a picture, if they’re having joint swelling or a bleed, so then our whole team can see it. Then the physical therapist or the nurse will call and get the rest of the details, such as when the bleed happened and how their range of motion is. ”

—Nicole Reynaud
RN, BSN

Different platforms—such as phone calls, apps, and virtual assessments—may provide valuable opportunities to extend comprehensive care beyond the appointment. These tools can also be used to connect with patients who are unable to come to the clinic in person.

Each member of the MDT is uniquely positioned to support patients and optimize joint health

Hemophilic arthropathy may cause psychosocial limitations compounded by chronic pain, gait changes, and multiple joints being affected.¹ The ultimate goal of psychosocial care is to empower people affected by hemophilia to manage their circumstances and challenges autonomously.⁵

In psychosocial care, asking the right questions and learning from patients are just as important as providing guidance and counseling.⁵ Another tactic to make the importance of joint health more tangible is to engage in conversation about what is important to the patient outside of hemophilia management.

Asking questions about their goals now and in the future is a critical component of psychosocial care.

“ I ask patients ‘What is it that you would like to achieve? Let’s look at how we can get you from point A to point B and what you would need to do for that.’ And so, essentially, I sit down with them and help them outline what a comfortable life would be for them. What would make them happy? ”

—Denise Lowery
LCSW

“ We’re all tied into whatever the patient’s goal is. We’re all speaking the same language. ”

—Denise Lowery
LCSW

Ultimately, patients may be happier and more engaged with their treatment when they are more engaged with their full care team. Evidence has shown that from a clinical perspective, patients reported more beneficial health behaviors, reduced symptom severity, fewer or lower frequency of symptoms, higher quality of life, and more satisfaction with treatment when they had higher trust in their health care professional.⁶

Comprehensive care through an MDT who works closely together, along with the use of educational programs and tools to facilitate discussions, may be helpful for maximizing outcomes in hemophilia and helping patients understand the importance of maintaining their joint health.

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